A Mixed Methods Study of Outcomes, Experiences, and Perceptions of Through-Knee and Above-Knee Amputation

By

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Publications and Conferences

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Abstract

Through-knee amputation (TKA) has several theoretical physical advantages over above-knee amputation (AKA), yet AKA remains the preferred level of amputation by UK vascular surgeons when below-knee amputation (BKA) is not feasible. How clinician’s perceptions of TKA influence current UK clinical practice, and how people living with TKA experience life post amputation is not currently understood.

This thesis aimed to explore the outcomes, experiences, and perceptions of TKA compared to AKA. The current qualitative evidence regarding lived experience post TKA and AKA was synthesised, and a quantitative retrospective analysis completed to compare surgical and rehabilitation outcomes. These studies showed promising outcomes for TKA from a small number of participants with TKA in the qualitative literature and dataset. Current UK practice was further explored in two studies: a descriptive, cross-sectional online survey, and a qualitative cross-sectional comparative interview study involving specialist healthcare clinicians. The similarities and differences of people living with TKA, and AKA were further explored using a qualitative cross-sectional comparative interview study.

Evidence from this thesis suggests that people with TKA have potential advantages that can improve quality of life after amputation compared to people with AKA, however barriers to communication between healthcare clinicians including a compartmentalised approach to rehabilitation and surgery threaten the quality of patient care. More evidence and training, and better collaborative working along the amputation pathway is needed to ensure that TKA is being performed for patients who would benefit from it.

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List of Abbreviations

The following abbreviations are used in this thesis:

AHP	Allied Health Professional
AKA	Above-Knee Amputation
BACPAR	British Association of Chartered Physiotherapists in limb Absence Rehabilitation
BKA	Below-Knee Amputation
EWA	Early Walking Aid
HUTH	Hull University Teaching Hospitals NHS Trust
KDA	Knee Disarticulation Amputation
MDT	Multi-Disciplinary Team
MPK	Micro-Processor Knee
NHS	National Health Service
PAD	Peripheral Arterial Disease
PIS	Participant Information Sheet
PPAM aid	Pneumatic Post Amputation Mobility Aid
PTH	Portsmouth Trust Hospitals
QoL	Quality of Life
SIGAM	Special Interest Group of Amputee Medicine
SPARG	Scottish Physiotherapy Amputee Research Group
TA	Thematic Analysis
TES	Total Elastic Suspension

TKA	Through-Knee Amputation
WHO	World Health Organisation

Chapter 1 Introduction

1.1 Introduction

How we care for people with limb loss is evolving thanks to innovative surgical techniques and advancements in prosthetic technology. The experiences of people living with amputation and the specialist clinicians involved in their care, must be understood to guide the development of this work.

This thesis explores the outcomes, perceptions and experiences of through-knee amputation (TKA) and above-knee amputation (AKA). How outcomes compare between TKA, and AKA is a question at the forefront of leading amputation research (Conte et al., 2019; Bosanquet et al., 2021b; Rangarajan & Bhaskara, 2022). TKA is currently a rarely used surgery in the UK and relatively little is known about TKA to inform clinical practice. While prospective trials comparing surgical and rehabilitation outcomes between TKA and AKA are clearly needed, there are several important issues regarding TKA that have been identified from clinical experience and gaps in the literature, that first need to be addressed. There are several theoretical advantages and disadvantages of TKA compared to AKA, but it is not known how these impact on the surgeon's ability to perform the surgery, the physiotherapists' ability to rehabilitate this patient group, the prosthetists' ability to make a prosthesis and the persons' experiences of living with TKA and how it compares to living with AKA.

This chapter will provide the background to TKA and AKA including the surgical, rehabilitation and prosthetic differences, structures of NHS amputation care, and the literature comparing quality of life of the two groups.

1.2 Major Lower Limb Amputation

Major lower limb amputation is defined as the surgical removal of the lower limb above the level of the ankle (VSGBI, 2016). In high income countries as many as 14 out of every 100,000 people will have a major amputation every year (Behrendt et al., 2018). There are approximately 5,000 major lower limb amputations performed each year in the UK (NHS Digital, 2020) and inpatient amputation care costs the National Health Service (NHS) approximately GBP 40 million (Kerr et al., 2019) each year.

Major lower limb amputation can have a devastating life changing effect on an individual and their family. Living with limb loss leads to serious restrictions in mobility, as people must learn to move around using a wheelchair or artificial leg (prosthesis). Even the most active people with the best prosthesis can encounter daily struggles with fatigue, residual limb pain, and problems with prosthetic fit; however recent advancements in socket and prosthetic technology is improving care for these patients (Bartlett et al., 2019; Marable et al., 2020; Jayaraman et al., 2021). A significant proportion of people post major lower limb amputation, especially those who have proximal levels of amputation, do not get referred for a prosthesis (Chopra et al., 2018; Waton, 2021) and must adapt to living in a wheelchair. Becoming a full-time wheelchair user is a significant life change often requiring home adaptations and extra care from family or carers.

The ability to mobilise with a prosthesis, instead of relying on a wheelchair, has been shown to be the most important factor that can improve quality of life (QoL) post amputation (Davie-Smith et al., 2017). The ability to mobilise also prevents joint contractures, pressure sores, and improves cardiopulmonary health (Paxton et al., 2016; Kaptein et al., 2018). It is therefore crucial to make every effort to regain the patient's mobility after amputation. One of the most important clinical decisions that influences the persons potential to mobilise is the level at which the amputation is performed. A below-knee amputation (BKA) provides the best chance of mobilising with a prosthesis (Davies & Datta, 2003; Kahle et al., 2016), but when injury or disease has progressed such that a BKA is not viable, an AKA is routinely performed (Moxey et al., 2010; Waton, 2019; Davie-Smith et al., 2020). The removal of the knee joint, loss of the majority of the muscular insertions of the thigh, loss of power, and control, means that people with AKA face considerable challenges to achieve mobility with a prosthesis (Aulivola et al., 2004; Göktepe et al., 2010). Through-knee amputation (TKA) is an infrequently used alternative to AKA which has the potential to offer some functional advantages. There is a lack of consensus regarding the best way to choose amputation level (Conte et al., 2019; Catella et al., 2021); a major lower limb amputation impacts the remainder of the patient's life and therefore decisions made at time of amputation should be done so with the consideration of how it will affect the lifelong experience of the patient.

When referring to people with a major lower limb amputation the phrases such as "people with limb loss" or "people living with amputation" will be used in this thesis. There is some current debate regarding the labelling of amputation or limb loss and "amputation" is considered by some not to be inclusive as some people are born without a limb and never undergo amputation surgery (Armitage, 2019; limbs4kids, 2022). For the purpose of this PhD and its focus on amputation surgery therefore the term amputation seems appropriate. There is an important move away from describing a person as their condition or disability (GOV.UK, 2021; Silverman, 2021) which is why the phrase amputee is not used by the author of this thesis. However, it is important to recognise that many people after having an amputation embrace the label "amputee" and comfortably, and proudly, refer to themselves as an amputee. Therefore, the term amputee will be present in this thesis when it is used by the participants in the qualitative study to describe themselves. When the terms amputation, or lower limb amputation, are used in this thesis they are referring only to major lower limb amputations.

1.2.1 Causes of Major Lower Limb Amputation

The leading cause of lower limb amputation in the UK is vascular disease (Moxey et al., 2010; Davie-Smith et al., 2020). There are approximately 202 million people living with peripheral vascular disease worldwide (Behrendt et al., 2018). Vascular conditions affect the veins and arteries in the body and blood flow to the lower limbs can become compromised due to a gradual build-up of plaque and calcification of the blood vessels (peripheral arterial disease). Complications from vascular conditions that lead to major lower limb amputation include chronic or acute limb ischaemia, infection, tissue loss, and pain. The presence of diabetes as well as vascular disease increases chances of amputation as people with diabetes are more likely to experience these complications and the disease can intensify severity of symptoms (Kurowski et al., 2015; Lopez-de-Andres et al., 2015; Ólafsdóttir et al., 2019). There are estimated to be 463 million adults living with diabetes worldwide (IDF, 2017).

The second most common cause of amputation worldwide, and the leading cause in low-income countries is severe traumatic injury (Ajibade et al., 2013; Nwosu et al., 2017). The population of people with limb loss due to trauma is large because they tend to be young, and previously healthy individuals with longer life expectancy compared to people with vascular and diabetic related limb loss, where the 5-year mortality rate is between 52% and 80% (Perkins et al., 2012; Thorud et al., 2016). Traumatic amputation can be immediate, where the accident causes the removal of the limb, or the trauma can lead to an eventual amputation due to the severity of injury to the limb, potentially following several surgical attempts to salvage the limb (Jorge, 2020). Other orthopaedic reasons for amputation include non-union and in less than 0.4% of cases, a complication following a joint arthroplasty (Ryan et al., 2019).

Less than 2% of the amputations performed yearly in the UK are due to cancer (Moxey et al., 2010; Davie-Smith et al., 2020)**.** For cases of bone cancer (osteosarcoma, Ewing sarcoma, chondrosarcoma) amputation can be the only possible treatment if the tumour has grown into major nerves or blood vessels, or if limb sparing surgery won't fully remove the tumour (CancerResearchUK, 2021). Current research around amputations for cancer focus on limb salvage versus amputation, with better patient outcomes in term of survival and functional scores found in limb salvage groups, therefore amputation remains the last resort treatment option for these patients (Aksnes et al., 2008; Yin et al., 2012; Han et al., 2016).

Other, less common, causes of major lower limb amputation include sepsis and other infections, necrotising fasciitis, congenital limb defects, complex regional pain syndrome, and intravenous drug use (Davie-Smith et al., 2020).

1.3 Levels of Major Lower Limb Amputation

1.3.1 Terminology

The terms below-knee amputation (BKA), above-knee amputation (AKA), and through-knee amputation (TKA) will be used for this thesis. This is to allow for all types of through-knee amputation to be included using one term. While the terms transtibial, transfemoral, and knee disarticulation are normally preferred in publications, they do not allow for the inclusion of all types of amputation around the knee, which is what is meant in this thesis by though-knee amputation.

1.3.2 Determining the Level of Amputation

In emergency situations there is often no choice of level, and the amputation is performed at the level of injury while saving as much tissue as possible. However, in non-emergency scenarios the level of amputation should be decided by the multidisciplinary team (MDT) to ensure the best post-surgical outcomes for the patient. The surgical team will decide where the amputation needs to be to remove damaged tissue and allow for wound healing, the therapy team (physiotherapists, occupational therapists, rehabilitation consultant, and prosthetists) provide advice regarding the optimal level to allow for best chance of rehabilitation. Levels are specified at certain points along the limb which have been proven to be optimum for prosthetic limb wearing (Chakrabarty, 1998; Hanspal & Calder, 2011). A residual limb that is too long can cause discomfort within the prosthetic socket (the rigid interface between the prosthesis and the residual limb). A residual limb that is too short will not have the capabilities of holding a prosthesis in place, and in these instances, if the patient is expected to be a limb wearer, it would be of greater benefit to them to opt for a higher amputation level. The details of the different levels will be described below.

The decision of amputation level is extremely important and has lifelong implications for the patient. It therefore should be patient-centred and appropriately considered. There is currently no single method, or gold standard recommendation, to decide amputation level and with a lack of good enough tools it remains a clinical decision (Gough et al., 2014; Conte et al., 2019). UK service reports (Gough et al., 2014; Horrocks, 2018) have found that MDT assessments are not always used to decide amputation level, and that different centres sometimes make different decisions based on similar information. There is currently little understanding on how this important life-changing decision is made by surgical and rehabilitation teams in the UK.

1.3.3 Different Levels of Lower Limb Amputation

This thesis will focus on AKA and TKA and these will be explained in detail in the following sections, along with BKA as it is one of the most common amputation levels. Other levels of major lower limb amputation, as shown in the illustration below, include Syme's amputation (at the level of the ankle), hip disarticulation (the removal of the leg including the whole femur, through the hip level), and hemipelvectomy (the removal of the whole leg including part of the pelvis).

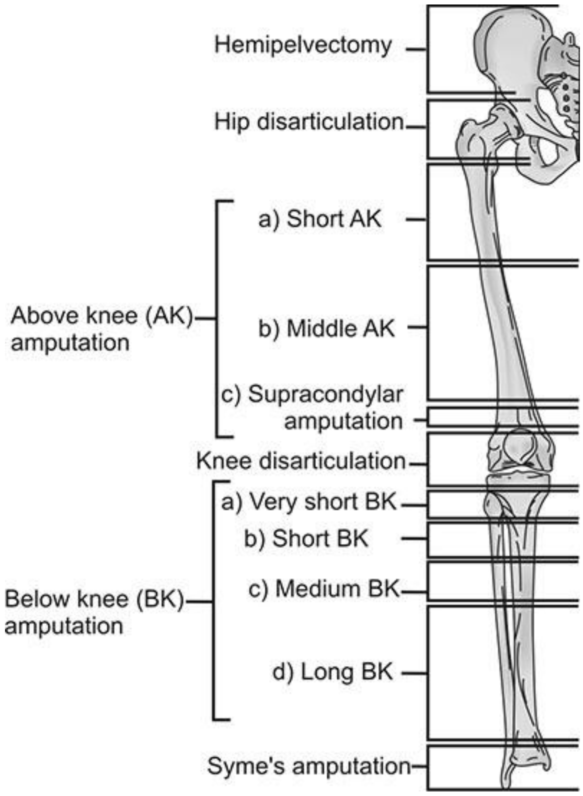


Figure 1.1 - illustration to show levels of major lower limb amputation (Khanna, 2010)

1.3.4 Below-knee amputation

Below-knee amputation (BKA), or transtibial amputation, is the transection of the tibia and fibula approximately 10-15cm below the tibial plateau (Robinson, 1991). The skin can be closed using skew flaps, sagittal flaps, or a long posterior flap (Tisi & Than, 2014). For prosthetic limb use post BKA the weight needs to be off-loaded from the end of the residuum to protect its soft tissue, so weight is taken through the patella tendon. The preservation of the patient’s knee joint makes the prosthetic limb lighter and easier to control. A BKA prosthesis is also comfortable to wear in sitting, so gives the appearance of a limb, and can be used to assist in transfers between bed and wheelchair. The Vascular Society advise that BKA should always be performed instead of a proximal amputation wherever possible and vascular units should maintain a below-knee to above-knee ratio above one (VSGBI, 2016); currently BKA make up 49% of UK amputations (Waton, 2021).

Figure 1.2 - below-knee amputation and prosthesis (Camargo et al., 2020)

1.4 Above-Knee Amputation

Above-knee amputation (AKA), or transfemoral amputation, involves transecting the femur at approximately 25cm below the greater trochanter and fashioning skin flaps (sagittal or fish mouth) to cover the sharp cut edges of bone. As the muscle attachments are lost, the muscles atrophy over time, but techniques can be used to stabilise the muscle. A myodesis involves securing the muscle to the bone, and myoplasty comprises the joining of the opposing muscle groups over the bone. These techniques are designed to retain muscle function and cover the sharp end of the femur (Konduru & Jain, 2007). The residual limb must be long enough to create a comfortable sitting platform and allow for adequate attachment of prosthesis, but short enough to allow the space for the prosthetic knee joint and prevent unnecessary extra length in the socket which can cause discomfort (Marshall & Stansby, 2008). As the sharp end of the bone is not suitable for distal end bearing, the ischium (a bone in the pelvis sometimes called “the sitting bone”) is used as the weight bearing surface for mobilising with a prosthesis. The removal of the patient’s knee joint means greater energy expenditure to mobilise with a prosthesis due to mechanical knee and shorter lever, which is why only 25% of people with AKA mobilise with a prosthesis (Davies & Datta, 2003). Forty-eight per-cent of major limb amputations performed yearly in the UK are AKA (Waton, 2021).

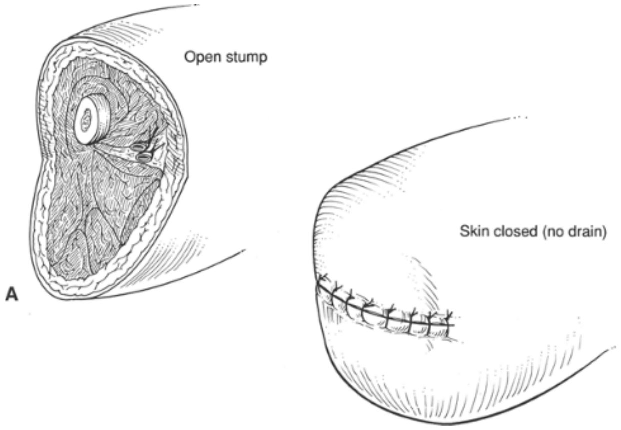


Figure 1.3 – above-knee amputation (basicmedicalkey.com, 2016)

1.5 Through-Knee Amputation

Through-knee amputation (TKA) is the surgical removal of the lower half of the leg at the level of the knee. It is seen in less than 4% of cases in the UK (Moxey et al., 2010; Davie-Smith et al., 2020; Waton, 2021). There are variations of the TKA including the knee disarticulation, a modified through-knee, and the Gritti-Stokes amputation, which will be described in this section. Despite the different surgical techniques all types of TKA share some unique key characteristics.

TKA offers the potential for distal end-weight bearing either through the intact femur in cases of the knee disarticulation or attached patella with the Gritti-Stokes. This is theoretically advantageous to the patient for several reasons. End-weight bearing is a more comfortable way of transferring body weight to the prosthesis, rather than through the ischium like with an AKA. As the socket does not need to sit under the ischium, the top of the socket can be lower down the residuum (sub-ischial) which should provide a more comfortable socket for mobilising. A sub-ischial socket also means the prosthesis should be more comfortable for sitting in and means the patient can use the toilet without the need to remove their prosthesis. How these socket differences between TKA and AKA impact on ability to mobilise, walking distance, and patient experience has not yet been researched sufficiently. An early study comparing a small sample of people with TKA and AKA (Hagberg, 1992) found the TKA group wore their prosthesis for more hours a day than the AKA group suggesting that greater socket comfort from end-weight bearing leads to greater prosthetic tolerance and increased mobility. It has also been claimed that end-weight bearing should improve gait quality, due to greater proprioception through the prosthesis, and a more normal weight transfer mechanism (Hughes, 1983). However, good quality biomechanical studies comparing people with unilateral TKA, and AKA are lacking. Another advantage for prosthetic limb users with TKA is the residuum is less vulnerable to skin breakdown from unwanted pressure; if BKA or AKA residuums shrink, a routine post amputation occurrence, then the residuum sinks in to the socket and weight is taken through the distal end causing pressure damage and skin breakdown, often this can lead to the patient not being able to wear their prosthesis until it has healed and a trip to the limb centre to line the socket. Considering the fact that half of people with amputations have diabetes (Davie-Smith et al., 2020), and up to 50% of people with diabetes have peripheral neuropathy (Hicks & Selvin, 2019) being able to end-weight bear in this high-risk group is a practical advantage. A weight bearing residual end also theoretically allows the individual to kneel or stand without a prosthesis on. This ability could potentially make some activities of daily living easier as the individual could rest their residuum on a stool or chair to wash and dress for example. While these differences may seem minor, they potentially make a huge difference to the lived experience of the individual, but this has not been previously studied. There is currently no documented evidence proving that people with TKA utilise their residual limb in these ways, we also do not know the success rates of achieving end-weight bearing and if there are any differences between the surgical variations.

As well as the residuum allowing for end-weight bearing, the greater length of the TKA residuum, compared to an AKA residuum, offers several other potential advantages. The long residuum increases surface area allowing for proficient sitting balance and the long, strong lever assists with transferring from bed to chair. The superior muscle strength is because no muscle insertions need to be excised during the surgical procedure (Baumgartner, 2011). The muscles on the anterior and posterior aspects of the residuum are balanced and therefore reduce the chance of hip flexion contractures. The surgery itself has been described as less traumatic than an AKA because no bone is transected and no muscle is divided, this could minimise blood loss, speed up operation times and assist with patient recovery (Bowker et al., 2000). The cartilage barrier around the knee remains intact which has been reported to reduce the risk of infection post-operatively (Pinzur, 2004). Leaving the femur intact also reduces the risk of developing painful bone spurs; transected bone can grow bone spurs (osteophytes) which can be painful, especially when under pressure from a prosthesis (Bowker et al., 2000; Pinzur, 2004). In addition, TKA has been reported to be a suitable option for paediatric patients, as the growth plate on the femur remains intact, allowing for the bone to grow therefore benefiting the adult life of patients undergoing amputation as a child (Smith, 2004). The femoral condyles on the distal end of the intact femur can also be used as a method of prosthetic suspension, without the condyles a suction socket often with a waist belt is needed to secure the prosthesis in place. How these difference impact on the lived experience of the patient have not been explored.

Disadvantages of TKA compared to AKA have also been reported in the literature and may be contributing factors to the small numbers of TKA performed. TKA has a bad reputation for wound healing in dysvascular patients (Murakami & Murray, 2016). The traditional knee disarticulation first described in 1825 used minimal amounts of soft tissue to fashion the closing flap meaning the dysvascular patient may be at risk of delayed post-operative wound healing (Smith, 1825). Some early papers even advised against the use of TKA due to poor wound healing outcomes (Chilvers et al., 1971; Campbell & Morris, 1987). However, more recent studies have demonstrated improved healing rates for TKA (Ten Duis et al., 2009; Albino et al., 2014; Nijmeijer et al., 2017) and techniques have been developed to improve the soft tissue coverage (1.5.2). Studies investigating healing rates of TKA describe rates of primary wound healing between 40-80% (Ten Duis et al., 2009; Murakami & Murray, 2016), but these studies are limited by their small sample sizes of TKA which range between 10 and 251 (Cull et al., 2001; Lim et al., 2018). More research using large contemporary datasets are required to compare healing rates of TKA and AKA. Another documented criticism of TKA is around issues with prosthetic fit caused by the bulbous shape of the residual limb (Early, 1968; Smith, 2004; Albino et al., 2014). Historically it was argued that the bulbous end was technically challenging for prosthetists to make the socket comfortable and results in a wide socket which can be displeasing to patients (Early, 1968). However, more recent literature has disputed these early conclusions. Penn-Barwell (2011) hypothesised that the reason for prosthetic socket problems is potentially due to lack of experience prosthetists have in creating sockets for TKA, and that if the numbers of TKA increased prosthetists would no longer find creating sockets for TKA challenging. Modified versions of TKA and Gritti-Stokes amputation can also be used which result in a cylindrical residual limb. The bulbous shape has even been described as an advantage in the prosthetic literature as it can be used for suspension (Baumgartner, 1979; Steeper, 2011). Whether this bulbous shape is considered an advantage or disadvantage by the patient has not yet been studied. As well as the bulbous shape of a TKA, the long residual limb has been criticised for causing disproportionate knee centres between the prosthetic side and remaining side (Figure 1.4). This becomes more pronounced in sitting potentially causing issues with simple activities such as sitting on public transport. The disproportionate knee centres have also been described as "uncosmetic" (Smith, 2004; de Laat et al., 2014). However, these reported concerns appear to belong to clinicians; the opinions of people living with TKA and how they experience the cosmetic appearance of their prosthesis has not been explored.

Figure 1.4 – position of prosthetic knee of TKA (Antonini, 2018)

1.5.1 Guidelines

TKA is recommended in the Global Vascular Guidelines on the Management of Chronic Limb-Threatening Ischemia (Conte 2019) due to its functional and biomechanical advantages over AKA, and they state healing rates are comparable to AKA if the surgery is performed well, but recommends a research priority of determining healing rates, mobility, and quality of life outcomes compared to AKA. The British Society of Rehabilitation Medicine recommend TKA instead of AKA as it is a quicker surgery, and claim the longer lever is beneficial to the limb wearer and non-limb wearer, and preserves the patients lap which assists with the carrying of items when using a wheelchair (2018).

1.5.2 Types of TKA

The first documented record of TKA was by Smith (1825), since then the methods of several variations of TKA have been published (e.g.,(Mazet, 1966; Weale, 1969; Burgess, 1977; Klaes & Eigler, 1985; Albers et al., 1994; Nellis & Van De Water, 2002; Eid-Arimoku & Brooks, 2020)). Types of TKA have previously been classified as knee disarticulation, modified/adapted knee disarticulation, and Gritt-Stokes (Steeper, 2011; Crane et al., 2021). A systematic review of quantitative studies (Murakami & Murray, 2016) compared outcomes of the different types of TKA and concluded further research is needed to understand the different qualities of the techniques in order to recommend how to choose between them. There is no available literature that suggests which techniques are used in the UK, why clinicians choose the method they choose, and how the differences between techniques are perceived by clinicians or patients.

1.5.3 Knee Disarticulation

A knee disarticulation first described by Smith (1825) is an amputation through the middle of the knee joint (Figure 1.5). No bone is transected and the patella tendon is attached to the cruciate ligaments to secure the patella (Jansen & Jensen, 1983). Traditionally a larger anterior flap was fashioned but this method has been replaced in favour of sagittal flaps (Jansen & Jensen, 1983) or a posterior flap (Murakami & Murray, 2016). Knee disarticulation allows a large end-weight bearing surface and the intact femoral condyles can be used for prosthetic suspension (Murakami & Murray, 2016).

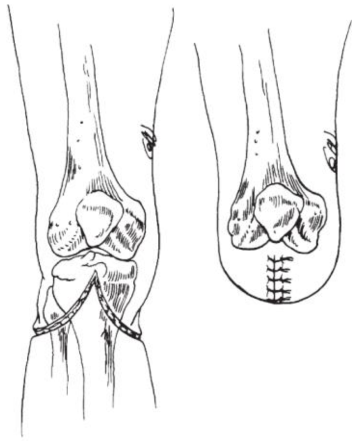


Figure 1.5 - knee disarticulation (Smith & Skinner, 2013)

1.5.4 Modified Knee Disarticulation

Several modifications have been suggested to the knee disarticulation technique (e.g.,(Mazet, 1966; Burgess, 1977; Cull et al., 2001; Albino et al., 2014; Eid-Arimoku & Brooks, 2020)). Some are minor modifications introducing a soft tissue musculocutaneous layer over the end of the femur (Albers et al., 1994; Eid-Arimoku & Brooks, 2020), others advise to trim the femoral condyles and either remove the patella (Mazet, 1966; Burgess, 1977) or secure it with a patellofemoral arthrodesis (Duerksen et al., 1990; Albino et al., 2014), and Cull (Figure 1.6) advises trimming of the condyles with removal of the patella and the end of the femur.

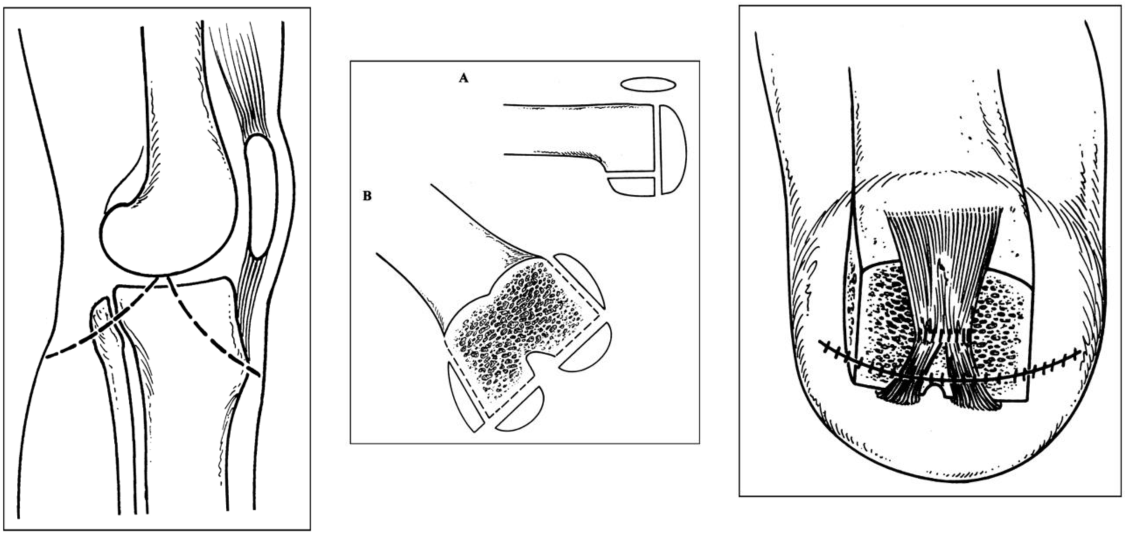


Figure 1.6 - example of a modified knee disarticulation (Cull et al., 2001)

1.5.5 Gritti-Stokes

It has been disputed if Gritti-Stokes is a type of through-knee or above-knee amputation because it transects through the femur, not the knee joint (Joseph et al., 2017; Theriot et al., 2019). For the purpose of this thesis, it is classified as a through-knee because it is considered an alternative to knee disarticulation, it is not routinely used as a type of AKA, it is considered a type of TKA in terms of prosthetic rehabilitation (Stark, 2004; Steeper, 2011; Panhelleux et al., 2021) and has been grouped with knee disarticulations in previous research papers (e.g.,(Faber & Fielding, 2001; Murakami & Murray, 2016)).

The Gritti-Stokes method was created to improve wound healing for the vascular population whilst maintaining end-weight bearing potential (Campbell & Morris, 1987). This technique involves removal of the end of the femur and attachment of the patella to the end of the transacted femur (Figure 1.7). Gritti-Stokes has received both praise and criticism in the literature. Healing rates have been reported to be superior to other methods of TKA (Campbell & Morris, 1987; Murakami & Murray, 2016) but concerns have been reported regarding the removal of the condyles as this removes the suspension options and rotational stability (Steeper, 2011). An early small study has shown inferior mobility outcomes with Gritti-Stokes compared to knee disarticulation (Houghton et al., 1989).

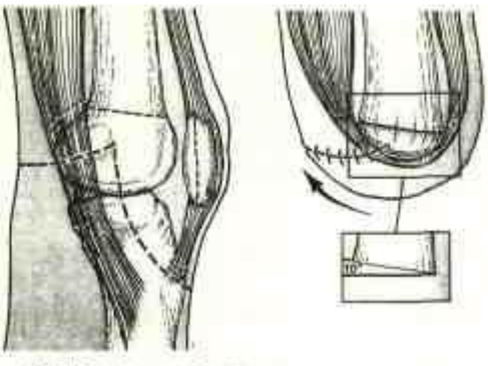


FIGURE 1. Technique for Gritti-Stokes (through-knee) amputation

Figure 1.7 - Gritt-Stokes amputation (Faber & Fielding, 2001)

1.6 Rehabilitation

This section describes the rehabilitation journey for the patient undergoing amputation.

1.6.1 Pre-operative

In non-emergency procedures, rehabilitation should start pre-operatively whenever possible (Smith, 2016; BSRM, 2018). The patient should be reviewed by a rehabilitation consultant, occupational therapist, and physiotherapist, to discuss rehabilitation goals and prosthetic options, make early assessments for wheelchair provision and home adaptations, and commence an exercise programme (Gough et al., 2014; Smith, 2016; BSRM, 2018).

1.6.2 Inpatient

Rehabilitation as an inpatient starts on the first day post operatively (Smith, 2016). Patients are taught how to sit by themselves (regain sitting balance), get from bed to chair (transfer) and complete tasks independently, like getting washed and dressed, and making a cup of tea (activities of daily living (ADLs)) and how to mobilise safely in a wheelchair (Smith, 2016).

1.6.3 Ongoing Rehabilitation

Those patients who are referred for prosthetic limb assessment commence compression therapy within ten days post-operatively to reduce limb volume in preparation for prosthetic limb casting (Smith, 2016). Early walking aids (EWA) should be used both as an assessment tool and treatment tool for patients in the early stages of prosthetic rehabilitation (Smith, 2016). Once the prosthesis has been made rehabilitation continues including learning how to look after the prosthesis, put it on (donn) and off (doff), perform ADLs with their prosthesis and work to achieve the highest level of mobility they can along with any personal realistic goals. Details of compression therapy and EWA are discussed further in Chapter 4.

Quantity, type, and location of rehabilitation varies greatly across the UK due to a lack of guidelines specifying a model of care for rehabilitation post amputation. Daily physiotherapy sessions have been shown to support good mobility outcomes (Turney et al., 2001; Hebenton et al., 2019) and clinicians reportedly prefer an inpatient care model over an outpatient model (Spyrou & Minns Lowe, 2021).

1.6.4 Lifelong

Following the initial rehabilitation stage prosthetic limb users must be educated to recognise when they need to be reviewed by their prosthetic limb centre and must be able to refer themselves for a review at any time (BSRM, 2018). Regular prosthetic reviews are important to monitor residual limb changes and make changes to prosthetic prescription as necessary.

1.7 The Multidisciplinary Team

The MDT involved in post amputation rehabilitation includes the following professional groups briefly described below.

1.7.1 Surgeon

Surgeons must be suitably experienced and trained in amputation surgery (Gough et al., 2014; VSGBI, 2016). The more experience the surgeon has in amputation surgery the better chance the patient has for primary healing and limb fitting (Cosgrove et al., 2002). The majority of amputations in the UK are performed by vascular surgeons, but orthopaedic surgeons and plastic surgeons can also perform amputation surgery when appropriate (White et al., 1997).

1.7.2 Occupational Therapist

The occupational therapist (OT) is essential to get the patient home safely after amputation. Post amputation and pre-prosthetic rehabilitation the patient will be fully dependent on a wheelchair. The OT assesses the patient for the correct wheelchair, teaches the patient how to use it safely, and makes adaptations to the home, such as installing ramps, so it can be used (Atwal et al., 2011). They also teach the patient how to complete their ADLs and make further home adaptions or provide equipment so these can be achieved.

1.7.3 Physiotherapist

Physiotherapists are involved in amputation rehabilitation at each stage (pre-operatively, post-operatively, prosthetic rehabilitation and community rehabilitation). The NCEPOD states that specialist physiotherapists must be involved in amputation rehabilitation for inpatient and outpatient care (Gough et al., 2014). Physiotherapists are directed by the guidelines for pre- and post-amputation rehabilitation and prosthetic rehabilitation published by BACPAR (Smith, 2016). The physiotherapist designs and delivers an exercise programme to target the muscles needed for prosthetic limb use, and to prevent contractures, as early as possible. They also deliver the EWA assessment and treatment and help with gait re-education with the prosthesis and educate the patient how to negotiate obstacle such as slopes, steps, stairs, and different surfaces.

1.7.4 Rehabilitation Consultant

The rehabilitation consultant assesses the patient for their rehabilitation needs, co-ordinates the rehabilitation team, gives advice on pain management, and assesses the suitability of a prosthetic limb (BSRM, 2018). The British Society for Rehabilitation Medicine Amputee and Prosthetic Rehabilitation Standards and Guidelines (BSRM, 2018) state that all patients who have an amputation should be referred to a rehabilitation consultant, however in year of NCEPOD, rehabilitation consultants were only available in 58% of UK hospitals (Gough et al., 2014).

1.7.5 Prosthetist

Prosthetists design and create bespoke prosthetic limbs for people post amputation. They work closely with the physiotherapists to provide gait analysis and engineering solutions to improve the patients function and mobility (BAPO, 2022). Prosthetists maintain and repair the prosthesis throughout its lifetime and suggest upgrade and replacement parts to improve the patient’s mobility as their needs change.

1.7.6 Psychologist

Despite the enormous psychological impact from having an amputation (NHS.UK, 2019) only 15% of patients receive input from a clinical psychologist after amputation in the UK (Gough et al., 2014). Psychologists support people to adapt after amputation and adjust to the loss of sensation and function of their limb, and accept their altered body image (NHS.UK, 2019).

Other professionals involved in pre- and post-operative care include specialist nurses, diabetologists and podiatrists.

1.8 Prosthetic Limbs

There are four basic elements comprising a prosthesis for TKA or AKA: the foot/ankle unit, the knee unit, the socket, and the method of suspension. Effective suspension and a comfortable socket have been argued to be the most important element of a prosthesis, as without a good fitting socket that stays in position the prosthesis is unusable (Schaffalitzky et al., 2012). The method of suspension is how the prosthesis remains attached to its wearer. The most common suspension method for the AKA prosthesis is a Total Elastic Suspension (TES) belt (Figure 1.8). The socket of a TKA prosthesis can be moulded to hook on to the condyles as a method of suspension without a belt (self-suspension).

Figure 1.8 – Total elastic suspension belt (ortho-europe, 2022)

The socket is made by the prosthetist by taking a plaster cast of the persons residuum, it is then made into a socket out of mouldable plastic, carbon fibre or similar and designed to take weight at the appropriate point and relieve pressure at any at risk areas. Most commonly, the socket for an AKA is designed to use the ischium as the weight bearing point (Figure 1.9). The socket for a TKA can be designed to use the end of the residuum to take weight and therefore the rim of the socket can be positioned lower down the thigh than an AKA socket (Figure 1.10).

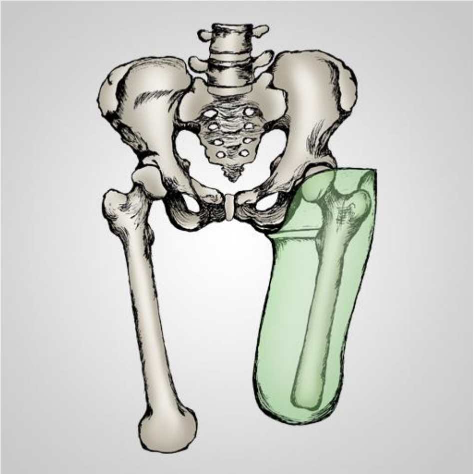


Figure 1.9 – AKA socket (Orthopedics, 2022)

Figure 1.10 - TKA end-weight bearing sub-ischial socket (Antonini, 2021)

There are a wide range of prosthetic knees available privately and on the NHS to suit the abilities of the individual. Some prosthetic knees lock in fixed extension for mobilising (mechanical locked knee), the knee lock operates either automatically on standing or is patient operated. This feature increases safety and makes walking easier for the user at the cost of an altered looking gait pattern, suitable for low to medium activity users. Knees without this locking mechanism are known as mechanical free knees. Free knees can flex on a single axis, for low to medium activity users, or on multiple axes (polycentric) for low to high activity users. Some knees can have pneumatic, hydraulic or microprocessor controls for resisted flexion on stance phase (yielding) and to prevent stumbles (stumble recovery). The foot and ankle unit are attached to the knee unit with a pylon (Figure 1.11). Similarly, to the prosthetic knees, many foot and ankle units are available with different properties to suit the abilities of the individual. If the limb user chooses to, they can have a foam cover (cosmesis) on the prosthesis to give the shape and colour of a sound limb (Figure 1.12).

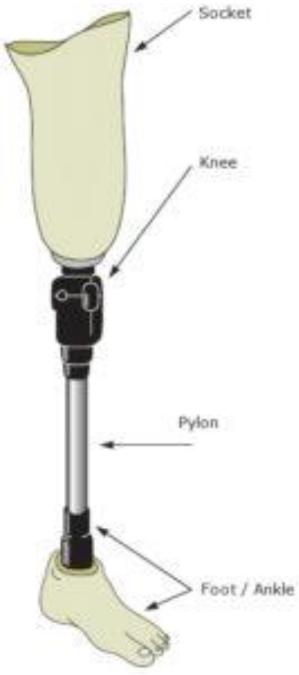


Figure 1.11 – basic composition of an AKA prosthesis (Blatchford, 2022)

Figure 1.12 – AKA prosthesis with cosmesis (Rossouw, 2022)

1.8.1 NHS Prosthetic Services

There are 35 NHS prosthetic limb centres in England (NHS England, 2018). NHS prosthetic services are currently under review partly due to lack of consistency between services offered across sites. Even the name of this type of centre is not standardised with terms such as Prosthetic and Amputee Rehabilitation Service (PARCS), Disablement Centres, Artificial Limb Centres, as well as other names, used. For consistency within this thesis prosthetic limb centre will be used to describe any outpatient prosthetic service, unless it is within a direct quote from a participant, and they use another term. NHS England spends roughly £60 million per year on prosthetic services (NHS England, 2018). Additional rehabilitation services exist away from the prosthetic limb centre in the form of satellite therapy clinics.

1.9 Quality of Life

The World Health Organisation (WHO) defines quality of life (QoL) as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” (WHOQOL Group, 1998:551). The growing demand to study QoL in health research is due to the recognition that simply investigating mortality rates and clinical outcomes is not sufficient to direct health research and improve patient centred care (Carr et al., 2001; Ferrans, 2005).

1.9.1 How Quality of Life is Measured

QoL is commonly measured using patient reported outcome measures. There are no validated measures specifically for the population of people with limb absence and therefore tools such as the Short Form-36 (SF-36), the Euro Quality of Life (EQ-5D), and World Health Organisation QoL scale (WHOQOLBREF) are commonly used in limb absence research (Davie-Smith et al., 2017). The Prosthetic Evaluation Questionnaire (PEQ) and the Trinity Amputation and Prosthetic Experience Scale (TAPES) have been developed to measure change in prosthetic related QoL (Cole et al., 2014). QoL was identified as a core outcome that must be measured in research for people post amputation (Ambler et al., 2020). QoL outcome measures are designed to measure the persons perceived QoL from their point of view but QoL is subjective, and differs between cultures and values which brings into question the usefulness of standardised outcome measures (Carr & Higginson, 2001).

1.9.2 Quality of life post TKA and AKA

There is a lack of evidence comparing the QoL of people with TKA and people with AKA, especially within the vascular population. One problem with the current literature base is that some authors in QoL after amputation research do not specify amputation level in their study samples (e.g., (Suckow et al., 2015; Puranik et al., 2021; Rosca et al., 2021)). These papers include people with any type of lower limb amputation and there is no indication if their sample is entirely people with BKA, AKA, any other level, or consists of people with different levels of amputation. As previously discussed, people with BKA have key functional and prosthetic advantages which makes their day-to-day life easier than for people with AKA or TKA. BKA has been shown to provide better outcomes than AKA in terms of gait, energy expenditure and mobility, thus making returning to work and hobbies easier, which has been shown to correlate with greater QoL scores (Horgan & Maclachlan, 2004; Sinha et al., 2011; Davie-Smith et al., 2017). Therefore, there is clear reason why QoL would be significantly different between AKA and BKA, and interpreting these results becomes difficult when amputation level is not described in the sample. Another problem with current published evidence is that when levels in the sample are described, or group comparisons performed, TKA are often grouped in with AKA due to their small numbers and both having a prosthetic knee joint (e.g. (van der Schans et al., 2002; Fortington et al., 2013; Barr & Howe, 2018) though these two groups have important differences that impact their daily lives which are worth exploring.

Murakami and Murray's (2016) systemic review found no studies investigating QoL outcomes for people with TKA for vascular aetiologies. Following this review Gökşenoğlu and Yildirim (2019) compared body image and depression scores of people with AKA, TKA, BKA, and foot amputation for all aetiologies but found no difference between groups. Studies using outcome measures to compare QoL post TKA and AKA have mainly been conducted in the trauma population (MacKenzie et al., 2004; Hammarlund et al., 2011; Penn-Barwell, 2011; Bennett et al., 2013; Tennent et al., 2018; McQuerry et al., 2019; Polfer et al., 2019). Bennett, McQuery, Polfer, and Hammarlund found no difference between AKA and TKA for QoL outcomes but would still recommend TKA over AKA due to the theoretical functional advantages. In each of these papers the numbers of people with TKA in the sample were much smaller than in the other groups making comparisons difficult. A meta-analysis by Penn-Barwell (2011) included 104 people with TKA, 48 with SF-36 data, out of a total of 3105 people with limb loss. Penn-Barwell reported greater QoL outcomes for TKA than AKA in the SF-36 but the majority of participants were from one study (Taghipour et al., 2009) which recruited veterans in Iran, therefore these results may not be transferable to the majority of people with limb loss in the UK. Many people with traumatic amputations were fit and well before their sudden amputation resulting in a significant reduction in QoL scores post-amputation compared to someone with a long history of vascular disease pre-operatively. MacKenzie et al. (2004) suggested that people who have traumatic TKA might have worse outcomes than someone undergoing elective TKA due to the potential loss of soft tissue to create a soft tissue overlay, or if the TKA was performed in an emergency there may not be the time to create a nice-looking residuum. Comparative studies are needed for people with all aetiologies including vascular disease to represent the general population of people with TKA and AKA.

Factors that influence QoL for people post amputation have been identified as prosthetic limb use, need for a mobility aid, employment status, other health problems, phantom-limb pain and residual limb pain (Sinha et al., 2011). More recently, Davie-Smith et al. (2017) concluded the biggest influencing factor on QoL post amputation is the ability to mobilise with a prosthesis and live independently. These outcomes have previously been compared between AKA and TKA. Two early studies (Houghton et al., 1989; Hagberg, 1992) found that TKA had superior outcomes to AKA for ability to donn the prosthesis independently and daily prosthetic limb use. However, Met (2008) compared SIGAM (Special Interest Group of Amputee Medicine) grades (Table 7.3) and found no functional difference between TKA and AKA, and recommended the use of AKA due to better primary healing rates. More recently Polfer et al. (2019) used surveys to compare function of TKA and AKA and also found no significant difference between scores but this time recommended TKA over AKA due to theoretical advantages of a longer residual limb. A study by Gökşenoğlu and Yildirim (2019) compared patient reported function scores for TKA and AKA and found worse outcomes for TKA, but this study only had six participants with TKA and 20 with AKA. Further studies are needed to compare the functional differences of TKA and AKA and the perspective of the person living with the amputation is also needed to give meaningful insights into the similarities and differences.

While function has been demonstrated to effect QoL scores, Desrochers et al. (2019) tried to assess if function had an impact on feeling towards prosthesis or body image for people with limb absence. Desrochers concluded that function did not influence the participants feelings towards their prosthesis of their body image. The cosmetic appearance of the TKA prosthesis has been previously criticised (Murakami & Murray, 2016) due to the asymmetrical knees as described in section 1.5. Houghton et al. (1989) did find worse satisfaction of cosmesis scores with TKA than AKA, but used bespoke, unvalidated measures and this study is now over thirty years old. MacKenzie et al. (2004) also found poor satisfaction with cosmesis scores reported by specialist clinicians. However, more recently (Toes & Kyd, 2018), reported good satisfaction with cosmesis from TKA, potentially due to advancements in prosthetic technology. The perceptions of cosmetic outcomes for TKA compared to AKA from the point of view of specialist clinicians and people living with these types of amputation requires further investigation.

One of the biggest problems with recruiting people with TKA to compare to people with AKA is the small population of people with TKA to recruit from, in addition the current QoL and experience outcome measures do not appear to be sensitive enough to identity differences between TKA and AKA, and most prior work has focused on people with traumatic causes of amputation, which may not be transferable to the wider population whose amputations are mostly due to vascular causes. Therefore, to address these important knowledge gaps qualitative studies exploring the similarities and differences of TKA and AKA for all aetiologies would be of great benefit. Research so far using outcome measures have provided outcome scores for these groups but do not inform us as to why people feel the way they do. This thesis aims to go beyond what is quantifiable and explore the difference in the lived experience of the people living with TKA or AKA.

1.10 Overview of thesis

This chapter provided a background to the topic of TKA, the current problems, and introduced some of the available literature. The following chapter, chapter two will provide the methods and results of a qualitative evidence synthesis of the qualitative literature of TKA and AKA. At the start of chapter three the research questions and overall thesis aim will be stated, and the methodology used to address the thesis aim will be discussed. Chapters four to seven will provide the methods and results of the four separate studies conducted to answer the research questions. The final chapter integrates the findings of all four studies in the discussion.

Chapter 2 A qualitative evidence synthesis of the lived experience following through-knee or above-knee amputation

2.1 Introduction

The previous chapter discussed the literature which quantifies and statistically compares QoL scores of people with TKA and AKA. A Cochrane review was also conducted (Crane et al., 2021) which found no randomised trials comparing QoL, or any other outcomes, for TKA and AKA. Quantitative systematic reviews of QoL post amputation (Sinha et al., 2014; Davie-Smith et al., 2017) found factors that influence QoL include the ability to walk, the use of assistive devices, and pain. Level of amputation, when comparing AKA to BKA, has also been to shown to have an effect on QoL, with people with AKA scoring lower on QoL questionnaires than people with BKA (Davie-Smith et al., 2017; Kizilkurt, 2020; Cruz Silva et al., 2021). Davie-Smith et al. (2017) reported that people with BKA tend to be more mobile with greater social functioning thus improving their QoL. A low quality study by Gökşenoğlu and Yildirim (2019) found that people with TKA had significantly lower locomotor capabilities than people with BKA or AKA. A robust study by MacKenzie et al. (2004) also found worse scores for physical and psychosocial function post TKA than other levels of major lower limb amputation, though these differences were not statistically significant and only patients with traumatic aetiology were included. A review of quantitative data (Murakami & Murray, 2016) compared the surgical techniques of TKA. They found no studies measuring QoL for people with TKA and recommended comparison with AKA. The Global Vascular Guidelines (Conte et al., 2019) recommended that more research is needed to compare QoL data of TKA and AKA to inform clinical decision making about the most appropriate level of amputation surgeons should perform.

QoL outcome measures only tell us part of the story, qualitative data is needed to provide insight into what the different levels of amputation are like to live with from the perspective of the person living with the amputation. As service users are now empowered to make more decisions about their own health care within the NHS, it is essential that health care professionals understand the perspective of the person living with different amputations before offering advice to a person about level of amputation. To truly assess the impact of the differences of TKA and AKA the point of view of the person with the amputation must be sought. A qualitative evidence synthesis is the most appropriate way to interpret lived experiences and feelings of the person living with the condition and the impact it has on their lives (Flemming et al., 2019). Furthermore, by combining findings of multiple qualitative studies we can generate a greater understanding of the issue, especially in regard to any subtle differences that may exist between TKA and AKA (Flemming et al., 2019).

A recent qualitative meta-aggregative review (Behera & Dash, 2021) found eight qualitative studies with a total of 149 participants exploring the broad concept of life after amputation. They included papers exploring the journey from amputation to prosthetic use and compared their findings to the five stages of grief whereby people had to accept their new limited abilities immediately after amputation and develop coping strategies in order to adjust to their changed body. They found that once the person was ambulating with a prosthesis that the lived experience improved and described the prosthetic limb as a “life-line” which is essential to recovery. However, no sub-group analysis between levels of amputation was conducted in this review.

The physiological differences between TKA and AKA (as discussed in 1.5) may lead to differences in lived experience and we do not know if people living with TKA interpret these differences as advantages or disadvantages compared to people with AKA. This current review will try to unpick these differences from the point of view of the individuals with amputations and aims to understand, on a deeper level, how factors such as these can impact on an individual’s experience living with amputation and the similarities and differences between how people adapt to the two types of amputation. While valuable research has been conducted to understand the experience of living with a lower limb amputation (e.g.,(Senra et al., 2012; Murray & Forshaw, 2013; MacKay et al., 2020)), less is known about the impact of level of amputation. Research exploring how the different amputation levels affects a person’s lived experience therefore needs to be identified. Service development and surgical decision making would also benefit from insights on this topic and areas for further research may be identified. In addition, to inform the qualitative element of this thesis it is essential to evaluate what is already known within the current qualitative literature regarding the lived experience of people with TKA and AKA. The most appropriate way to evaluate the current qualitative evidence and compare how life after the two types of amputation is experienced is with a qualitative evidence synthesis.

2.2 Aims of this review

The aims of this qualitative evidence synthesis were to:

- explore what is known about the lived experience of people with TKA and people with AKA
- to identify the main factors that are reported by people with TKA or AKA as impacting on their quality of life
- to summarize the research findings and present similarities and differences in the lived experiences of the two groups
- to identify gaps in the existing literature to inform design of the studies for this thesis.

2.3 Methods

This review followed a systematic review protocol (PROSPERO registration number: CRD42020169785).

2.3.1 Search strategy

A systematic literature search was conducted in February 2020 of the following databases: Embase, MEDLINE, CINAHL and PsycINFO. Database searches were limited to articles published after 1960. Cochrane databases, dissertation databases, and conference websites were searched for additional qualitative materials. Experts in the field were also contacted for unpublished data. Reference lists of included papers were studied for any potential additional papers, this included a manual forward search of citations using Google Scholar. In order to ensure that the included literature was up to date an updated search was repeated in March 2022; four articles were identified, and one met the inclusion criteria and was included.

The following search terms were used: "above knee amputation", "transfemoral amputation", “through knee", "through the knee", "knee disarticulation", "Gritti stokes", “knee amputation”, transgenicular. Terms were truncated where appropriate and the Boolean operator “OR” used to combine search terms. Medical Subject

Headings (MeSH) headings were exploded to expand the search. Clinical queries were used to filter the results for qualitative designs.

One included paper (Hafner et al., 2015) stated the following within the body of the article: “discussions unrelated to mobility, but related to the experience of living with amputation, were also noted, included in the analysis, and will be published in a separate article”. This article was searched for but not found.

2.3.2 Inclusion, exclusion, and selection criteria

Criteria for inclusion and exclusion are provided in Table 2.1.

Table 2.1 – inclusion and exclusion criteria

Inclusion criteria
Primary qualitative or mixed methods research where the methods of qualitative data collection and analysis are explicit
Included participants with AKA or TKA, living in the community having completed the initial stages of rehabilitation. If the study also contains participants with other levels or types of amputation, then it must be possible to extract the views and expressions of the participants with TKA and AKA within such studies.
The topic of interest was the lived experiences and perceptions of people with TKA or AKA. This includes psychosocial adjustment, activities and social interaction, prosthetic satisfaction, pain and self-image, or any other relevant topic.
Only studies investigating lived experience of people from high income countries. This is due to the specificity of the research question and the vast differences faced by people with amputations living in low to middle income countries, such as, lack of rehabilitation, prostheses, equal opportunities, and cause of amputation including war-related injuries (Staats, 1996; Jarnhammer et al., 2018; Shaw et al., 2018)
Exclusion criteria
Quantitative research
Mixed-methods studies that do not clearly present their qualitative analysis and data
Studies which collect qualitative data but use quantitative methods for analysis and therefore provide no qualitative results
Literature reviews and editorials
Studies where the full text is not available in English
Studies where the full text is not available
Studies where the person with the amputation is not the participant
Studies prior to 1960 - TKA was first described by Smith (1825) though it remained unpopular due to problems with wound healing. Adapted versions of the TKA were published in the 1960's (Middleton & Webster, 1962; Mazet, 1966; Burgess, 1977) and its popularity has slowly increased since then.
Papers that do not specify levels of amputation of included participants will not be included. Some papers describe their sample as "lower limb amputees", "major limb amputees" or just amputees. Definitions of a lower limb or major amputation can vary. Firstly, it will not be possible to identify if the sample contains participants with AKA and/or TKA or to extract the correct data from the study. Secondly, the lived experience of someone with a distal amputation, which may include a toe, or half a foot would be very different from someone with most of their leg amputated through or above the knee. Some minor amputations do not require a prosthesis to return to normal function once the wound is healed, this is very different to adapting to life as a prosthetic limb user, using a prosthetic knee and ankle joint, or becoming wheelchair dependent.

The literature search found 129 articles plus 22 from other sources. Fourteen duplicates were removed. Two reviewers (HC and GB) independently screened 137 titles and abstracts and 101 were excluded. Thirty-six full texts were reviewed and 27 excluded. Nine articles were included for review. A tenth paper was added in March 2022 following a repeat search.

2.3.2.1 PRISMA

Figure 2.1 demonstrates the screening process of this review as a PRISMA flow diagram.

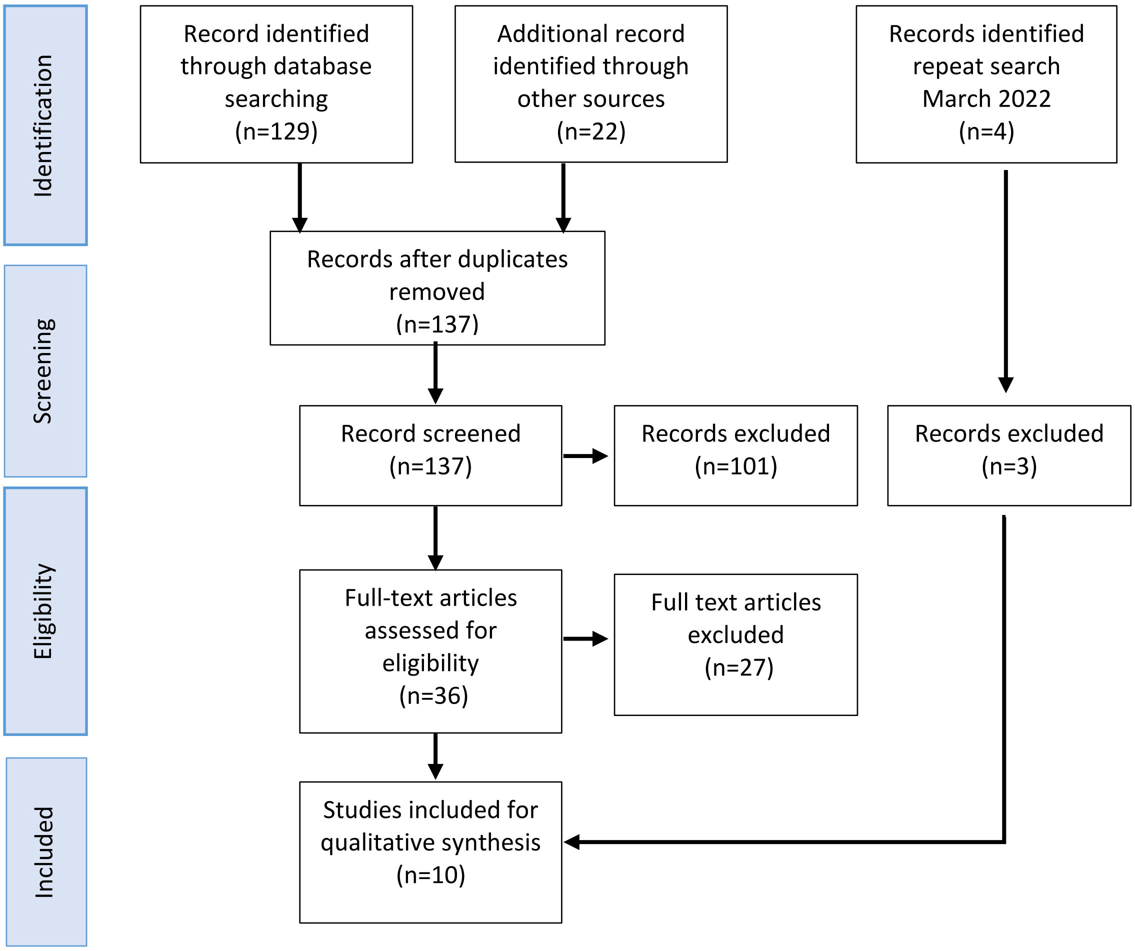


Figure 2.1 – PRISMA flow diagram

2.3.3 Data extraction, quality assessment and analysis

Full texts of the included articles were managed using NVivo 12 software. Data was extracted within NVivo using a method proposed by Houghton (2017), whereby nodes were created to manage descriptive data: author, year, location, setting, sample size, sample age, sample aetiology, sample ethnicity, sample gender, socio-economic status, and data collection method, and analytical data: aims and objectives, results, findings, quotes and further citations. Data was extracted to NVivo and organised using Schütz (1962) concepts of first and second order constructs. Direct quotes from people with a TKA or AKA were categorised as first order constructs (the participants interpretations in their own words), and data made of authors interpretation or description of the results relating to TKA or AKA was labelled as second order construct data (the researchers interpretations based on first order constructs).

All included studies were appraised for quality using the Critical Appraisal Skills Programme (CASP) tool for qualitative studies (2019). Two researchers, HC and GB, evaluated the studies separately. The appraisal was not used as a reason to exclude studies, as it can only assess the quality of the reporting of the study, and not the study itself. Even if the study was of poor quality that is not justification to remove the participants' voice from inclusion in this review. Quality was assessed to judge the weight given to a paper and any quality concerns are reported in Table 2.3.

The RETREAT framework (Booth et al., 2018) was used to determine the best method to use for this review with a quick scope of the literature to inform some of the responses to the RETREAT criteria as presented in Table 2.2.

Table 2.2 – Reponses to RETREAT questions

Retreat Criteria	Response
Review question	Explanatory - What factors impact the lived experience of people with TKA or AKA and do they differ between groups?
Epistemology	Neutral pragmatism – no studies will be excluded based on epistemological underpinning, but an inductive interpretive approach will be taken for analysis and synthesis to not just identify factors that impact lived experience but to explore how these factors act on the individual experience
Timeframe	One year to allow thorough review and analysis but also to allow results to inform remainder of PhD studies
Resources	Part of PhD funding with a second reviewer available and support of supervisors
Expertise	HC has no previous experience of qualitative evidence synthesis but good expertise of subject topic. Supervisor (MT) experienced in qualitative evidence synthesis and expert in qualitative research methods
Audience and purpose	Primarily an academic audience for the purpose of informing PhD study and assessment
Types of data	Small number of good quality studies with rich data

Considering the responses to the RETREAT framework in Table 2.2 the most appropriate method for this review is a thematic synthesis following the steps described by Thomas and Harden (2008). Thomas and Harden (2008) have used thematic synthesis for multiple reviews looking at experiences and perceptions of health promotion for school children. Data was coded in NVivo line by line, descriptive themes were developed, and analytical themes generated as the data allowed. A matrix was created to identify concepts, themes, and sub-themes that were common or similar across the included studies (Pope, 2007). Similar concepts were grouped together into categories. These categories were used as nodes to code the first construct data and themes developed. Then an inductive approach was taken to code any remaining data.

The main topic of interest in this study is the lived experience of people with TKA and people with AKA regarding their QoL. The WHOQOL definition has been used in research investigating QoL for people with amputation and its domains will be used in this review. The World Health Organisation (WHO) defines QoL as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.” (WHO 2020). This review aims to give a rich, detailed insight into the nuances of living with different types of amputation. Therefore, to understand the perceptions of the person with amputation and their lived experiences this definition will be used in its broadest sense and the domains specific to people post amputation of psychosocial adjustment, activities and social interaction, prosthetic satisfaction, pain and self-image will also be included.

2.3.4 Review author reflexivity statement

The impact of pre-existing views on design and conduct of a review must be considered in order to ensure that quality standards for rigour are upkept (Silverman 2017). By making the reader aware of the authors biases the audience can judge the degree of objectivity (Silverman 2017). Prior to commencing the review, the author HC considered their thoughts and opinions of TKA in comparison to AKA and produced the following reflexivity statement.

"I have reflected on my experience as a vascular and amputee physiotherapist, and from my clinical experience suspect that people with TKA have greater functional ability but are less satisfied with the cosmetic effect of a TKA prosthesis."

Having acknowledged this bias, the researcher ensured they conducted the review reflexively, and kept a diary to challenge their own thinking whilst undertaking the review (Finlay & Gough, 2003). In addition, a second, non-clinical researcher, assisted with the review to compensate for any pre-defined ideas; the addition of a second reviewer improves the reliability of the findings (Silverman 2017).

2.4 Results

2.4.1 What qualitative evidence is available that explores the experience of living with TKA or AKA from the patient's perspective?

Ten papers (Sjödahl et al., 2004; Bragaru et al., 2013; Washington & Williams, 2014; Hafner et al., 2015; Verschuren et al., 2015; Christensen et al., 2017; Day et al., 2019; Ward Khan et al., 2019; Kim et al., 2021; Roberts et al., 2021) were included. They were published between 2004 and 2021. Sample sizes ranged from six to 37. Out of the ten papers there were 58 people with AKA and 11 people with TKA. Characteristics are displayed in Table 2.3.

Table 2.3 – characteristics of included articles

Author and year	Research question/aim	Methodology	Participants	Quality comments/concerns	Themes
Bragaru (2013)	To identify the barriers and facilitators that influence participation in sports for individuals with lower limb amputation	Semi-structured interviews with thematic analysis - phenomenology	Sample size: n = 26; Age: 21-77; Sex: 19 males, 7 females. Aetiology: 7=trauma, 15=vascular, 4=cancer. Level: 7 AKA, 7 TKA, 12 other. Country: The Netherlands.	Did not consider the relationship between interviewer and participant but did undertake interview training and had an observer at the interviews. Used a predefined codebook for analysis but described methods as thematic analysis. Results clear but descriptive only.	Technical Social Personal
Christensen (2017)	To increase understanding of the military identity on the organization of rehabilitation and investigate factors of importance for successful rehabilitation services, including interprofessional collaboration between different sectors involved in the rehabilitation of Danish veterans with lower limb amputations	Interviews and observations with thematic analysis	Sample size: n = 6; Age: 25-46; Sex: 6 males, 0 females. Aetiology: all trauma. Level: 1 AKA, 0 TKA, 5 other. Country: Denmark.	No description given of background of researchers, specifically if they were military or not which could have influenced the interviews.	Experiencing different identities Experiencing discontinuity in rehabilitation

Author and year	Research question/aim	Methodology	Participants	Quality comments/concerns	Themes
Day (2019)	To explore the everyday experiences of people with lower limb amputations using a good/bad day approach	Focus groups with thematic analysis – relativist approach	Sample size: n = 22; Age: 23-60; Sex: 8 males, 14 females. Aetiology: 4=cancer, 9=trauma, 3=infection, 1=blood clot, 2=meningitis, 1=congenital, 2=diabetes. Level: 4 AKA, 0 TKA, 18 other. Country: United Kingdom.	Recruitment took place at a rehabilitation event, so they excluded any people who are not able to attend such an event due to poor mobility or lack of transport.	Pain Organisation and planning The embodied experience after amputation Interactions with others
Hafner (2015)	To solicit perspectives of prosthetic limb users about their mobility experiences and to inform development of an outcome measure	Focus groups	Sample size: n = 37; Age: 22-71; Sex: 26 males, 11 females. Aetiology: 3=diabetes, 22=trauma, 11=infection, 2=tumour, 3=military service, 3=other. Level: 11 AKA, 1 TKA, 25 other. Country: USA.	Well reported	Individual characteristics Forms of movement Environmental situations

Author and year	Research question/aim	Methodology	Participants	Quality comments/concerns	Themes
Kim (2021)	To explore lived experiences, and identify common themes as well as vocabulary associated with fall-related events in lower limb prostheses users	Focus groups with grounded theory	Sample size: n = 29; Age: 25-81; Sex: 20 males, 9 females. Aetiology: 6=diabetes, 14=trauma, 3=infection, 1=tumour, 1=other. Level: 9 AKA, 1 TKA, 19 other. Country: USA.	Lack of information about location of focus groups and sampling methods	Memories of fall-related events are shaped by time and context Location and ground conditions influence whether falls occur Some activities come with more risk Fall-related situations are multi-faceted, and often involve the prosthesis How lower limb prosthesis users land, but not the way they go down, tends to vary Not all falls affect lower limb prosthesis users, but some near falls do
Roberts (2021)	To describe how people with major LLAs use their prosthesis in everyday life and to describe barriers and facilitators that may influence prothesis use	Semi-structured interviews with thematic analysis – naturalistic inquiry	Sample size: n = 10; Age: 47-78; Sex: 6 males, 4 females. Aetiology: causes included traumatic accident, vascular disease, and infection. Level: 4 AKA, 1 TKA, 5 other. Country: Canada.	Not clear enough with interpretation of thematic analysis. Used a codebook and a team of researchers to reach consensus, and themes are more like categories. Concern that thematic analysis either not the correct choice or has been misinterpreted.	Everyday experiences using a prosthesis Extrinsic factors influencing prosthesis use Intrinsic factors influencing prosthesis use

Author and year	Research question/aim	Methodology	Participants	Quality comments/concerns	Themes
Sjödahl (2004)	To describe how relatively young people with AKA experience their amputation and their coping strategies in the acute phase and over time.	Semi-structured interviews - phenomenology	Sample size: n = 11; Age: 16-51; Sex: 6 males, 5 females. Aetiology: 6=tumour, 5=trauma. Level: 11 AKA, 0 TKA, 0 other. Country: Sweden.	Lack of detail about recruitment strategy. Authors mention participants were invited to a gait re-education clinic but do not explain the relevance of this.	Experiences of the amputation Coping strategies to relate to a new norm
Verschuren (2014)	To explore qualitatively how persons with a lower limb amputation describe and experience (changes in) sexual functioning and sexual well-being after lower limb amputation	Semi-structured interviews	Sample size: n = 26; Age: 22-71; Sex: 17 males, 9 females. Aetiology: 4=infection, 7=vascular/diabetes, 7=trauma, 6=oncology, 1=pain, 1=fibrous dysplasia. Level: 6 AKA, 1 TKA, 19 other. Country: the Netherlands.	No explanation of researcher background or relationship between researcher and participant.	Importance and description of sexuality Changes in sexual functioning Changes in sexual well-being Practical problems concerning sexuality Self-image Feelings of shame Role of the partner Communication about sexuality with professionals
Ward Khan (2019)	To capture the complexity of amputation on women's body image and sexuality, encompassing a broad scope of well-being, subjective experiences and appraisals including the formation and negotiation of relationships	Semi-structured interviews with interpretive phenomenological analysis – hermeneutic stance	Sample size: n = 9; Age: 35-62; Sex: 0 males, 9 females. Aetiology: 1=cancer, 3= acute ischaemia, 2=trauma, 1=nerve damage, 2=vascular/diabetes. Level: 2 AKA, 0 TKA, 7 other. Country: Ireland.	Well reported	"I don't like the way I am" "Broken/not wanted" "Same but different"

Author and year	Research question/aim	Methodology	Participants	Quality comments/concerns	Themes
Washington (2014)	To explore the experiences of people with diabetes and/or peripheral vascular disease following an amputation and the impact of this on their psychological well-being	Semi-structured interviews – interpretivist phenomenology	Sample size: n = 6; 4 males mean age 64.8 (SD=7.95), 2 females mean age 69 (SD=10.32). Aetiology: all vascular/diabetes. Level: 3 AKA, 0 TKA, 3 other. Country: UK.	Lack of detail regarding recruitment strategy	Being pre-prepared Adapting to a restricted life Ability to adapt Need for support versus independence Relationship with others

2.4.2 What are the main factors that impact lived experience post TKA, or AKA as identified in the literature?

Three distinct concepts were identified as the main factors that impact on the lived experience post TKA or AKA which were translated across all the papers: 1) Ability to identify and overcome obstacles, 2) Accepting new identity, and 3) Social interactions.

The ability to identify and overcome obstacles

Data from 30 participants with AKA and three participants with TKA contributed to this theme. This theme describes the obstacles people face after having an amputation and the methods they use to overcome these obstacles. A lack of awareness of obstacles can lead to falls, and the participants must learn how to avoid falls.

Fear of falls and falls avoidance were common topics across several studies. The participants described the need to have an increased awareness of where they are placing their foot in order to avoid having a fall. Before their amputation they would get sensory and proprioceptive feedback from their foot when walking, whereas now when walking with a prosthetic foot those feedback mechanisms are lost and they need to compensate with other means. Therefore, when walking outdoors the tendency is to look down at their feet which restricts conversation with others when walking and walking at night in somewhere with poor lighting is avoided.

"*for amputees, we're not talking back and forth when we are walking… there is not a lot of eye-to-eye contact*" (AKA, 49 year old male, trauma, 26.7 years post amputation) (Hafner et al., 2015)

"*If I'm walking and I'm not thinking about each step, and think of something else I almost stumble a bit and it's like, oh yeah, I've got to think about that*" (AKA, 57 year old male) (Roberts 2021).

Certain terrains are also avoided, such as gravel or slippery surfaces, because they are more challenging to walk on, as is walking in crowds "*walking in crowds is scary sometimes. [My daughter] runs interference for me so that I don't have to worry about tripping because people with two legs aren't paying any attention. They'll stop right in front of you and [I] have a hard time stopping [quickly]."* (AKA, 55 year old male, tumour, 12.8 years post amputation) (Hafner et al., 2015)

The mental effort required to maintain safety when walking means the participants are left with no capacity to enjoy the experience nor take in the world around them. The environment also restricts the routes they can take, forcing them to choose the well paved path rather than the interesting one. If situations cannot be avoided, the participant describes other methods used to prevent falls

"*when I go outdoors and it's either slippery or it's very uneven ground, I tend to take my crutches with me so that I don't fall*." (AKA, 81 year old male, 10 years post amputation) (Kim et al., 2021).

Some participants describe falling in familiar environments:

"*indoors, when you're not paying attention, when you're around comfortable surroundings, you start getting lax [and are more likely to fall*]" (AKA, 59 year old male, 50 years post amputation) (Kim et al., 2021).

The AKA participants in particular felt constantly aware and afraid of having a fall and felt that falling was a possibility wherever they are, suggesting that the need to identify and overcome obstacles is constant, even in their own home. New obstacles can still present themselves at home and can result in a fall if the participant is not constantly looking out for them. While the AKA participants describe falling as inevitable, the TKA participants took a more pragmatic approach to falls avoidance strategies as one participant with a TKA described:

"*If I have fallen inside, it's usually because my prosthetic foot has gotten caught on a rug or a towel or something that, you know, is loose*." (TKA, 71 year old male, 5 years post amputation) (Kim et al., 2021).

The way the participants in these studies describe their falls and this need to constantly assess the environment is that is it a challenge shared by all people living with amputation, it is not specific to the individual, they are facing these obstacles because they have had an amputation.

“that’s like the amputees’ nightmare, something you don’t see in the way, you know?” (AKA, 59 year old female, 44 years post amputation) (Kim et al., 2021)

“[*Amputees] tend to walk a little slower and damn straight. If we don’t, we find [we fall] more often than we like to claim.”* (AKA, 49 year old male, trauma, 26.7 years post amputation) (Hafner et al., 2015).

There is a learning curve to identifying and overcoming obstacles. Obstacles described at the first stage of rehabilitation, were not only more challenging to overcome as everything was new, but more difficult to identify because of lack of experience negotiating their surroundings as someone with an amputation. Some obstacles were unexpected because the person had been completely independent before the amputation.

“*you were used to, sort of be walking, right. So, it was really a hard time the first time…so that… you felt that, you couldn’t manage on your own…I mean physically. You couldn’t get anywhere and stuff like that*.” (AKA) (Sjödahl et al., 2004).

“But this… it’s such a big change… from one situation to the other, instantly, you see. That’s really quite tough, on Friday I was up fixing the roof and on Sunday I am lying in hospital and I can’t do a bloody thing. That’s what I mean. It’s one hell of a change” (AKA) (Sjödahl et al., 2004)

Several new obstacles came at once when the participant was discharged home from hospital, and new ways had to be found to overcome these obstacles, such as stairs and getting a wash. One participant reflected on how this was even more difficult due to a lack of strength from their time in hospital

“*So, it was pretty tough to come home, I mean when…you can’t take a shower an… well you can’t even bloody stand up straight and stuff like that. And walking up stairs, that was really tough. I know the first time I wanted to go up the stairs, I had to bloody sit down on the steps and sort of drag myself up. So, you couldn’t even sort of jump upstairs. You didn’t have that strength*.” (AKA) (Sjödahl et al., 2004).

Once they had completed their rehabilitation, and they had learnt how to overcome daily obstacles this provoked a sense of achievement. Assessing for obstacles became a regular part of everyday life, and they became experts at finding solutions.

"*So, it's planning your route, so you think there is a massive hill up there with railings going around, there's no way my chair is going to get up there. I'm going to have to go the long way around. It might take me another 10-15 minutes but hey, I got there* (AKA, 60 year old male, 1 year post amputation) (Day et al., 2019).

"*I think that the most important thing when you have a prosthesis is your attitude, right, because there is always a way of doing thing, you've just got to think outside of the box*" (AKA, 61 year old female) (Roberts 2021).

When discussing participation in work and sports, wearing the prosthesis itself sometimes became the obstacle. In some scenarios this can be overcome by removing the prosthesis in favour of the wheelchair, like for some sports:

"I feel better if I participate in sports without my prosthesis… I actually find it more comfortable, because the prosthesis just feels like a block on your leg… is not actually yours. If I participate in sports without the prosthesis I'm more relaxed, I don't have to think about it" (AKA, 21 year old female, cancer, 7 years post amputation) (Bragaru et al., 2013)

Or, if the participant does not want to opt for the wheelchair, other tactics were used to manage the problems caused by the prosthesis.

"*if I work at a desk for more than a couple of hours or more then, let's say, an hour without getting up and walking around the table or something like that, the socket gets loose and that's a real problem because then I am massively unstable*" (AKA, 81 year old male, 10 years post amputation) (Kim et al., 2021)

"*Some days I don't even put it on, don't even tell me to put it on, because I'll get mad at you. There's nothing worse than having a pain you can't control. You know, and the only way I can control it is to stay off both my feet*" (AKA, 65 year old female) (Roberts 2021).

These participants feel a lack of control regarding the performance of the prosthesis. They have learned the behaviour of the prosthesis, its quirks and problems, and they do what they can do to control the impact of these quirks. For others, a change in prosthetic componentry was the answer to obstacles caused by the prosthesis. The type of prosthetic knee or foot could restrict the person's ability if the prosthetic prescription did not match their physical ability, causing them to feel restricted and reduce their activity, as one participant with an AKA describes:

"*I had a first leg, my first knee was a hydraulic knee, and that had certain limitations…Then, I got a C-Leg which is [an] electronic [knee] and that's a lot more mobile. I mean, I can do almost anything that I choose to do*" (AKA, 55 year old male, tumour, 12.8 years post amputation) (Hafner et al., 2015).

Accepting a new identity

Data from 20 participants with AKA and two participants with TKA contributed to this theme. This theme incorporates the topics explored around body image and perception of self.

Participants talked about how their physical appearance had changed after the amputation. They described looking different from others and how they felt that the only way to deal with that is to learn to live with the fact. This was described as challenging initially by the AKA group, as the newly amputated limb looked worse than they expected it to

"*No, I… just cried right out… I was really scared… I thought… This isn't true. It isn't supposed to look like this*" (AKA) (Sjödahl et al., 2004)

Participants also described the unwanted sense of being stared at by others, and how they feel that this is something they must accept. In some scenarios, like swimming, getting stared at was considered inevitable

"*I could never go to the public baths on my own… it wouldn't sort of be possible… To have all those eyes following you…it's impossible*" (AKA) (Sjödahl et al., 2004).

Others prefer if people are going to look that they also come and ask them questions, so they can teach them about the amputation, maybe as an attempt to reduce the staring. Others would avoid situations they could get stared at, or particularly enjoyed experiences where lots of other prosthetic users were present so they could remove their prosthesis without feeling out of place. The participants described feeling more confident about their appearance when wearing the prosthesis because it is easier to hide the amputation from others

"someone trying to guess which leg is false, that's always good when you're wearing trousers" (AKA, 42 year old male, 11 years post amputation) (Day et al., 2019)

"*if I am wearing trousers, then I can go to physical training without problem… then it doesn't show… sort of… but to have it uncovered and then enter a swimming pool, that… I wouldn't do that*" (AKA) (Sjödahl et al., 2004).

The participants with AKA in particular described the vulnerability they felt without their prosthesis, and how they choose to avoid showing their residual limb wherever possible. This was also discussed in one study (Ward Khan et al., 2019) in the context of starting new relationships and when participants felt comfortable showing their residual limb to a new partner. One female participant with an AKA describes

"*no way I would have allowed myself to let somebody see me unless I was 100% sure about them, there's just no way I would have done that*" (AKA, 48 year old female, trauma, 31 years post amputation) (Ward Khan et al., 2019).

This participant described how revealing her residual limb to someone increases her feeling of vulnerability, as if revealing this imperfection to another person, especially someone they are developing feelings for, puts them at risk of being rejected because of their amputation. Another female participant in another study describes how she believed these feelings are more difficult for females than for males:

"*In the back of my head there's all that with hero, war and all that. It's masculine. But a woman. No, no, no, no. There's nothing attractive about a woman who has lost her leg*" (AKA) (Sjödahl et al., 2004).

These women talk about not just the fact that their amputation makes them look different, but that it makes them less attractive to others. Inferring that their feelings around looking different have negative associations and reduces their body confidence.

The participants also described how they felt being seen as or considered as a disabled person. Participants describe how they related more to this identity when they first lost their leg but once they were established prosthetic users, they describe the disconnect between how they see themselves, as not being disabled, against how others still see them, as a disabled person. Being disabled was described with negative associations, such as being a burden to others, being different to others, and being inept.

"*I was deeply embarrassed and all sorts of people were rushing up to me and saying "How can I help you? Are you feeling alright" I said, "Get out of my way. I just fell. I'm going to take care of it myself."* (AKA, 81 year old male, 10 years post amputation) (Kim et al., 2021)

"*you always need help [when participating in sports] … That's a disability… Now, I don't feel disabled, I can do everything*" (TKA, 69 year old man, vascular, 14 years post amputation) (Bragaru et al., 2013).

Furthermore, in the initial stages of amputation several participants described this feeling of helplessness, because they are dependent on the hospital staff and have not yet learnt how to do things for themselves.

"*I felt empty in a way… I wasn't whole, you know… in a way I wasn't a whole human being"* (AKA) (Sjödahl et al., 2004).

For some this changes the way they see themselves, as being disabled, or not capable of doing things and is a long way from how they thought about their pre-amputated self

"*I'm a hands-on fix-it guy. I can't do that stuff. I'm limited in what I can do because I can't climb a ladder and do stuff*" (AKA, 57 year old male) (Roberts 2021).

Social Interactions

Data from 11 participants with AKA and five participants with TKA contributed to this theme. This theme has strong connections with the first two themes as having a good social support network was commonly considered an advantage in helping the person to accept their new identity, feel less self-conscious, as well as helping to overcome obstacles. This theme also describes how the quality of the participants support network and good or bad experiences with social interactions can provoke positive or negative emotions.

Having someone they trust in situations they would normally avoid gives them the confidence to achieve things they might not normally do, as one female participant with an AKA described:

"*and then my husband says, let's dance…No, you know I don't do that, right… I would NEVER walk up there and stand on one leg… But, I mean, I don't want to be stared at…But, Jesus, what do it matter*?" (Sjödahl et al., 2004)

"*We do a lot of swimming, we do badminton, we played as a team outside the house, I play volleyball…*" (AKA, 47 year old female) (Roberts 2021).

Accepting help from strangers was met with contrasting reactions from the participants in the different studies. Some describe an "unpleasant feeling" when strangers offered to help, which seemed to be related to the persons lack of acceptance of the fact they are unable to achieve their task independently. Whereas by contrast others were pleased to be offered assistance.

"*When people put that effort in when actually they never had to. I'm not asking for your help but actually you don't mind going past and checking I'm Ok. You have put yourself out and actually that makes me feel quite worthwhile*" (AKA, 60 year old male, 1 year post amputation) (Day et al., 2019).

Several participants described a feeling of being isolated or being left out of a group because of their disability. For some it was the physical restrictions that meant they were unable to join in with their friends' activities “*well, it’s a lot… its much like… to be left sitting while the others went out, well… That… that feeling…they when went out to…go dancing or something else, right…before I got my prosthesis then, you see, then it felt really tough to be left sitting*” (AKA) (Sjödahl et al., 2004).

They felt abandoned by their friends as they were left sitting alone. This participant’s friends did not alter their activities in order to include their friend and the result was this participant could not join in. They described feeling like an outsider. In order to avoid these feelings, other participants chose activities with groups of people with similar ability, such as disabled sports, where they were able to make new friends.

2.4.3 What are the similarities and differences between groups?

It is not possible to be confident that the differences between groups noticed in this study are only due to the different amputation levels of the participants. This is largely because the numbers of participants with AKA outweigh the numbers of those with TKA by more than five to one. However, it is possible to apply some clinical knowledge to the quotes and authors results to identify some potentially clinically significant differences between the groups. For example, it is possible that the longer residual limb, that looks the same as the remaining thigh when sitting, makes it easier for the person to adjust to their altered body image after amputation. This is evidenced by the vastly different ways in which the participants describe their residual limbs. One AKA participants described their initial feeling towards their residual limb

“*It was swollen and things like that. You barely wanted to touch it. So, you thought, what the hell, this doesn’t belong to me, does it . .*” (Sjödahl et al., 2004)

Suggesting that the residual limb does not resemble the previous or remaining limb, most likely due to the loss of structure and shape of the limb from amputating through the femur and thigh muscles. In contrast, a quote from a participant with a TKA describes their residual limb:

“*But also, if I have taken my leg off so to speak, and I see my reflection in the window, it makes me think: oh! That’s weird. That I ... I’m used to seeing it from up here*, and even though ... yes, just to see my reflection with the amputation, that is still weird.* [*

i.e. looking down while standing or sitting down]" (TKA, 36 year old female, trauma) (Verschuren et al., 2015)

Even though this person still thinks their bodily appearance looks odd when they see themselves in the mirror with only one leg, they describe the sensation of looking at their leg from a seated position, which is how they normally view it, and how that view does not look odd. No quotes were found in the studies from the point of view of people with TKA criticising the appearance of the residual limb in the initial stages after amputation, whereas several AKA participants in Sjödahl's study describe their disappointment and distress caused by the appearance of their residual limb at time of amputation. This difference is also demonstrated by two female participants describing when they start to feel comfortable enough to show their residual limb to a new partner. While the person with an AKA described feeling vulnerable showing their residual limb to someone, and they would avoid it until they felt comfortable with the person, one woman with a TKA takes a different approach

"*So, ok, well, I took [my leg] off and I've shown it immediately. And my partner replied: ''Oh, ok. Well, fine.'' (laughs) But that was it*." (TKA, 36 year old female, trauma) (Verschuren et al., 2015).

This person feels confident to show their residual limb to someone they had just met. This may be due to the personality of the individual and how they approach most situations in their life. However, it could suggest that the more anatomical shape of the TKA residuum gives the participant more confidence when letting others see their residual limb.

As well as the longer residual limb of a TKA having a different appearance it also functions differently to an AKA residual limb. TKA has the potential to take weight through the end of the limb, and as all the muscles are left intact TKA provides a more powerful lever arm than an AKA. Some participants describe how they are unable to complete some physical tasks due to their AKA, or worry if they had a second AKA, they would not be able to walk at all

"*For one thing, I can't go upstairs because I have [an] above the knee [amputation*]" (AKA, 56 year old male, 7.1 years post amputation) (Hafner et al., 2015)

It is not possible to assess from this study if the participant may have managed stair climbing or have any more confidence had they had a TKA. No quotes were found from people with TKA attributing their physical limitations to their specific level of amputation. One participant with a TKA described how swimming is more challenging now

''*Now, if I swim, the speed is gone and you always have a disadvantage… swimming is not what it used to be, all elderly swim faster than me……I stopped with it…*'' (TKA, 59 year old male, trauma, 16 years post amputation) (Bragaru et al., 2013).

They describe their reason for stopping swimming is due to the physical limitations of their amputation. However, many with AKA explain how they won't attempt swimming solely due to their physical appearance.

The anatomical shape of the TKA also allows for self-suspension of the prosthesis. One participant with an AKA complained about the discomfort caused by ischial weight bearing and using a suspension belt:

"*it gets sharp around the waist sometimes, having all this stuff around your waist gets so cumbersome*" (AKA, 61 year old female) (Roberts et al., 2021)

As people with TKA have the potential to use a prosthesis without a waist belt, and the socket does not need to come as high into the groin, they could potentially find prosthetic limb use more comfortable than AKA.

Some differences between groups were observed when talking about falls. The AKA group describe their fear of falling, and how inevitable falls are if they are not always paying close attention, and how easily a fall can happen. The TKA group in comparison are more pragmatic in their feelings around falls; they assign their reason for falling is that their prosthetic foot can get caught on loose furnishings for example. The TKA participants also describe, if they do start to fall, they can move their body into a position to take the impact through their prosthesis and reduce their injury.

2.5 Discussion

Out of the 182 participants across all ten studies only 11 (6%) had a TKA. This is reflective of the small numbers of TKA performed each year and therefore representative of the population of people living with amputation. People with TKA are often grouped together with people with AKA or BKA in study samples, even though they have subtle but potentially significant differences with a TKA to other levels of amputation which may impact on the lived experience. This qualitative evidence synthesis highlights the lack of represented TKA voice in the current amputation qualitative literature and the need for further qualitative enquiry into this group of people.

A quality assessment was conducted on all the included studies, but none were excluded on the basis of quality. The quality assessment found that overall, the studies were reported well with clear description of methods and analysis. However, only four papers (Day, Hafner, Roberts, Ward Khan) included a description of the researcher's role and how this might influence the data collection or analysis. The act of considering how the researcher's background, preconceived ideas, ethnicity, profession, and several others factors can influence the outcome of the research is called reflexivity (Berger, 2013). Reflexivity within qualitative research ensures rigour and increases credibility of findings (Dodgson, 2019).Two papers (Kim, Washington) mentioned their role and reported that they considered it's influence, but did not give details of their reflexive process or outcome. The remaining four papers (Bragaru, Christensen, Sjödahl, Verschuren) did not mention the researcher's role or the possible impact this could have on the study.

The three factors identified in this review that impact the lived experience post amputation (the ability to identify and overcome obstacles, acceptance of a new identity, and social interactions) are similar to previous findings in other meta-syntheses exploring people's experiences living with all types of amputation. Behera and Dash (2021) collated qualitative findings using meta-aggregation to explore the lived experience post lower limb amputation and the use of a prosthetic limb. Behera and Dash's meta-aggregation of qualitative studies included eight studies, including two of the same articles as the current review (Sjödahl and Bragaru). They categorised their findings into two themes; the new identity with prosthesis and the new identity without prosthesis and discuss how people adapt to their new identity in terms of self-image, and altered physical function. These themes overlap with the themes of the current review regarding overcoming obstacles and accepting the new identity. A metasynthesis of qualitative studies by Murray (2013) included 15 studies, of which only one was also in the current review, in another review which also explored the experience of amputation and prosthesis use. Murray created a theme called “the role of valued relationships in recovery” which encompass similar ideas to the social interactions theme in the present review. Murray describes how friends and family members have the ability to recovery one’s self-worth and sense of normalcy after amputation through practical help and emotional encouragement. The unique difference between the current review and previous reviews is the focus on participants with TKA and AKA. Murray’s review included participants with all types of amputation, including foot amputations, BKA, and upper limb amputations. Behera and Dash’s review included people with all types of lower limb amputation. Both previous reviews included papers which did not define the type of amputation their participants had. It is difficult to assume that people with different types of amputation have similar experiences and therefore strong justification is needed to group these people together to draw a single conclusion. Someone living with a partial foot amputation, or an amputation at the wrist, would face very different daily challenges to someone with an amputation at or above the knee joint. Someone with a partial foot amputation for example, could mobilise without a prosthesis or a wheelchair, this is a very different post amputation experience to someone with a BKA, TKA, or AKA. The current review focused on the specific experiences of living with a TKA or AKA.

The present review pulled together findings that explored the person’s reaction to appearance of the residual limb and hypothesised how this may differ between people with TKA and AKA. Previous quantitative studies have found a negative association between residual limb pain, sweating, wound and skin irritation, and reduced satisfaction with the residual limb (Baars et al., 2018) but not appearance. The appearance of the TKA prostheses has been criticised (Albino et al., 2014; de Laat et al., 2014; Murakami & Murray, 2016) due to the position of the prosthetic knee on the end of the socket protruding past the length of the remaining knee and this has been suggested as a reason why TKA is not a popular amputation level among health care clinicians. It is well accepted that people with protheses experience greater satisfaction if they like the appearance of their prosthesis (Gauthier-Gagnon et al., 1999; Akarsu et al., 2013). It is also widely documented (Hagberg, 1992; Siev-Ner, 2000; Baumgartner, 2011; Murakami & Murray, 2016; Lim et al., 2018) that the residual limb of the TKA has several advantages over an AKA, but how the patient experiences these differences, and what differences they experience in terms of satisfaction with appearance has not been explored. Given these purported differences, and the findings from the current review which indicates little is known about how people with TKA feel about their prosthesis, suggest this is worth investigating; the theory that the residual limb of a TKA may be more attractive to the person after amputation, and how this impact their life is unknown. A more visibly pleasing residual limb could improve tolerance of early-stage rehabilitation better for acute post-operative patients.

The current review highlighted potential differences in perceived abilities from the point of view of people with TKA and AKA. There appears to be differences in how activities are approached which may be associated with greater confidence within the TKA group. The specific capabilities of having a long end-weight bearing TKA residual limb, and how these can impact lived experience when compared to AKA, has not been explored. Quantitative studies comparing function have focused on rates of achieving ambulation after amputation. So far no differences have been found between patient reported outcome measures (Polfer et al., 2019) or gait parameters (Schuett et al., 2019) between TKA and AKA. The difference in the ability to end-weight bear may be too subtle for current outcome measures to find a difference, but it is possible there are differences from the point of view of the individual living with the amputation and therefore qualitative research is more appropriate to investigate these functional differences.

Overall, there is very little in the current evidence base from the point of view of people with TKA. The included studies which included participants with TKA and participants with AKA did not compare or contrast the experiences of the two types of amputation. Therefore, differences between groups were found by comparing direct quotes, though there were insufficient quotes to draw solid conclusion.

2.6 Limitations of this review

The data presented in the primary data sources was not thick enough to allow for more interpretive analysis. This is because the criteria were restricted to papers that specified amputation level. Several other qualitative papers were found, and their inclusion would have allowed for richer data and therefore deeper analysis. However, they did not differentiate between levels of amputation therefore it would not have been possible to extract the relevant data specific to TKA or AKA to facilitate comparative analysis.

2.7 How this will impact the design of my study

This qualitative evidence synthesis has highlighted gaps in the qualitative literature that require further exploration. Firstly, the lived experience of people with TKA needs to be better understood to help inform patients and health professionals in terms of decision making related to level of amputation. Very little is known about the lived experience of people with TKA. If their experiences were better represented in the literature, other patients requiring amputation might be able to learn from these experiences, allowing them to prepare for their own amputation. Additionally, patients would be able to use this information to decide whether a TKA is right for them. Furthermore, research is needed into the similarities and differences in the experiences of people with TKA and AKA, and there are no available studies that have previously made these comparisons from the point of view of the people living with amputations. People with AKA must also be recruited to discuss similar topics in order to compare and contrast the subtle differences in functional ability between TKA and AKA. No studies were found exploring the satisfaction with appearance of the residual limb, but this qualitative evidence synthesis provided some tentative evidence to suggest that greater satisfaction with residuum appearance may help with acceptance of the new identity and comfort with one’s own bodily image. Comparisons between satisfaction of the appearance of the prosthesis between groups also needs to be explored in detail.

2.8 Conclusion

This qualitative evidence synthesis considered the findings of ten qualitative papers regarding the lived experience of people with TKA and AKA and identified three factors that impact on the quality of the experience. The factors were the ability to identify and overcome obstacles, the acceptance of the new identity, and social interactions. Similar themes have been presented in other qualitative reviews exploring all types of lower limb amputation. The similarities and differences between these factors for people with TKA and AKA have not been fully explored in the current literature, even when the evidence is integrated. More research is needed to further explore these two groups and how the different levels of amputation can impact on the lived experience of the individual.

Chapter 3 Methodology

3.1 Introduction

This chapter will present the aims and objectives of this project developed from the literature presented in Chapters 1 and 2. Justification for a mixed methods approach including an overview of how the findings of the different studies are synthesised will be presented. The rationale for the chosen quantitative and qualitative methods will be provided here and the philosophical standpoint and theoretical underpinning will also be described. The full details of the methods for each study will be described in Chapter 4, Chapter 5, Chapter 6, and Chapter 7.

3.1.1 Gaps in knowledge

Based on the evidence presented in Chapter 1 and the results of the qualitative evidence synthesis in Chapter 2 the current knowledge gaps in this area are as follows:

- There is a lack of good quality evidence comparing surgical and rehabilitation outcomes of TKA and AKA for all aetiologies, specifically detailed rehabilitation outcomes beyond the overly simple binary outcome of limb fitted or not.
- There is a need to understand the current UK practice regarding use of or averseness to TKA across all parts of the amputation pathway, including how decisions are made to perform TKA or AKA and how aftercare and rehabilitation differs between the two.
- There is a paucity of information from the point of view of clinicians regarding the perception of TKA in comparison to AKA, and the first-hand experiences of clinicians working with these patients.
- There is a lack of representation of people with TKA in qualitative studies in amputation research. Little is known or understood regarding the lived experience of someone with TKA including the specific differences in the experience of living with TKA compared to AKA.

3.1.2 Overall Aim

The overall aim of this project is to understand the similarities and differences of TKA and AKA by comparing surgical and rehabilitation outcomes of TKA and AKA, investigating the perceptions of specialist clinicians, and exploring the experiences of people living with TKA and AKA.

3.1.3 Research questions

1) How do the surgical and rehabilitation outcomes compare between TKA and AKA?
2) What does current practice of TKA and AKA look like in the UK and what are the influencing factors for choosing one over the other?
3) What are UK clinicians' perceptions of TKA compared with AKA?
4) What are the similarities and differences of the lived experiences of having a TKA or AKA?

3.2 Research paradigm

The research paradigm relates to the primary values and beliefs which comprise the ontological and epistemological position of the researcher. The researcher and their philosophical standpoint will inevitably shape the research, therefore is it essential to establish the position of the researcher within the project. By establishing the researchers position it is then possible to understand which paradigm fits with the beliefs of the researcher and the research aims. When first trying to identify which paradigm aligns with the researcher's perspectives, Braun and Clarke (2022) recommend following the order of influence set out by Lincoln and Guba (2018) whereby viewpoints are established in order of ontology, epistemology, and methodology. Therefore, an overview of these theoretical aspects, and the position of the researcher, will be described in that order below.

3.2.1 Ontology

Ontology relates to the study of reality, and whether reality is objective or subjective. At one end of the spectra is the concept of **realism**, which is the belief that reality exists separate to our research practice. The realist position states there is one truth, which can be uncovered through appropriate research methods (Braun and Clarke, 2022). **Critical realism** shares the concept that truth is 'out there' waiting to be discovered, like realism, but accepts that it may never be truly understood due to the influences and limitations of human understanding (Hesse-Biber & Leavy, 2006). The opposing end of the scale to realism, is relativism. **Relativism** disputes that there is a single truth that can be measured or uncovered, instead the relativist position is that reality is created by human action and interaction (Braun and Clarke, 2022).

The researcher believes that realities are constructed from individual experiences and differ depending on culture and context, and therefore take the relativism ontological position.

3.2.2 Epistemology

Epistemology relates to the production of knowledge, and what we consider to be real and valid information (Braun and Clarke, 2022). **Postpositivism**, a refined version of positivism, is the dominant framework (Braun and Clarke, 2022) and is closely linked with realism. A postpositivist approach strives for objective knowledge but accepts it is not possible to achieve perfect observations, only approximations (Lincoln & Guba, 2018; Braun and Clarke, 2022). **Contextualism** maintains a sense of truth by looking for knowledge grounded in the data (Madill et al., 2000) but with an understanding that knowledge can be shaped by the cultures of the participants and the interpretations of the researcher (Madill 2000). **Constructionism** is the belief that knowledge is co-created by the interactions of the subjects and the researcher (Lincoln & Guba, 2018).

The researcher believes that research produces knowledge rather than reveals truth so therefore takes a constructionist view. This means general research questions are asked and participant’s views are sought to construct meaning of the topic of interest (Creswell, 2013). Constructionists position themselves in the research to co-construct the data with the participants and use interpretation to make sense of the data (Creswell, 2013; Braun and Clarke, 2022). These interpretations are influenced by the researcher’s background and experiences, and the research process itself creates the findings (Hesse-Biber & Leavy, 2006).

3.2.3 Methodology

Once epistemological and ontological stances are established one recommended next step is to choose the methodology that sits within the philosophical standpoint. Another way is to consider a pragmatic paradigm which is not committed to a particular viewpoint (Creswell, 2013). Pragmatism gives the researcher the freedom to choose the methods that are simply the best to answer their research question and is a popular option in mixed methods research (Creswell & Plano Clark, 2011). That does not mean that pragmatism is separate to the researcher's philosophical standpoints, and these are still important to establish and explain to the reader and will influence data analysis.

The research paradigm pragmatic constructivism aligns with the researcher's beliefs about the social world, and therefore influences the choice of methods and interpretation in line with this paradigm. The researcher takes the ontological view of relativism and epistemological view of constructivism, but with a pragmatic approach to the methodology. The investigator and the object of the investigation are interactively linked so that the findings are literally created as the investigation proceeds (Hesse-Biber & Leavy, 2006). The pragmatic slant shifts the focus to the problem, the research questions, and the results, and gives the researcher the freedom to choose any method that produces results rather than being fixed to one method defined by philosophical paradigm (Creswell, 2013).

3.3 Reflexivity

Reflexivity is an essential part of qualitative research. The purpose of reflexivity is to critically assess the researcher's position within the research, in order to identify ways the researcher's beliefs and experiences may influence the research design or analysis (Finlay & Gough, 2003). Reflexivity can also be used as a tool to critique decisions made by the researcher (Finlay & Gough, 2003). By documenting reflexive accounts throughout the research process the researcher can read back and assess what influenced those decisions. Reflexivity is important because the researcher is co-constructing the data with the participants, this means the researcher's beliefs and experiences will influence the way this knowledge is constructed, therefore it is essential to share the researcher's beliefs and experiences with the reader (Guillemin & Gillam, 2016).

3.3.1 Reflections from the researcher

Reflections from the researcher regarding the project as a whole are provided here. Reflections regarding the two qualitative studies and how the researcher's background, as described below, could impact the individual studies, are provided in the corresponding chapters (see sections 6.9.3 and 7.7.3) as are reflections of the methods used in those chapters. The reflection below provides the readers with an introduction to the researcher's beliefs and experiences which will likely have an effect on the research process (Finlay & Gough, 2003). This reflection was written by the researcher at the beginning of this project in 2018.

I have been working as an NHS physiotherapist for more than five years. I have worked across all areas, from community to intensive care, but always wanted to specialise in amputee rehabilitation. While I training to be a physiotherapist, I was actively involved in disability sports, in particular sitting volleyball, a game played predominantly by people with lower limb amputation. I have two years' experience as a specialist amputee rehabilitation physiotherapist and during this time I started to become interested in TKA. I remember seeing approximately ten people with TKA during my time as an amputee physiotherapist. The senior physiotherapist I worked with taught me her views on TKA, that TKA is a bad operation, patients don't like them, and it is our duty to dissuade the surgeons from doing a TKA. However, when that senior physiotherapist left, I remember seeing two people with TKA and I remember thinking that the suspension method and donning technique looked preferable to AKA. I also remember another person with TKA who showed me how she would transfer by weight bearing though the end of her residuum on the chair or bed. These experiences led me to believe that there may be some subtle differences between TKA and AKA for the people living with them and made me curious to hear their stories.

The researcher documented regular reflections in a diary throughout the research. These solitary reflections included how the researcher's opinion of TKA was changing, reflections on quality of interviews, and general thoughts around the project. These reflections were reviewed during data analysis to map how the researcher's thoughts and opinions had evolved over the data collection phase, and to assess how the researcher's experiences and personal values influenced the interpretation of the data and final conclusions.

3.4 Mixed Methodology

In line with recommendations by Creswell and Plano Clark (2011) a mixed methods approach was used because the research aim could not be answered with a single method alone. Mixed methods improve the quality of inferences we make from data

(Creswell & Plano Clark, 2011). As discussed in Chapter 1 inferences made from quantitative data may suggest TKA has minimal benefits compared to AKA, but the results of the qualitative evidence synthesis in Chapter 2 suggest there may be differences in the lived experience of TKA and AKA which need exploring.

This project employed a convergent parallel design (Figure 3.1). Convergent designs were initially developed as a type of triangulation, a popular approach with constructivist researchers. It allows the researcher to consider multiple perspectives and realities, and gives voice to individuals who are traditionally overlooked in research (Salkind, 2010), an appropriate approach for the population to be studied. A convergent design involves the simultaneous collection of qualitative and quantitative data, separate analysis using traditional analysis techniques for each data type, and integration of findings to produce an overall interpretation (Creswell & Plano Clark, 2011). It allows an improved understanding of the research topic through the collection and analysis of separate but complimentary data (Morse, 1991). For this thesis, qualitative and quantitative methods have been used to address the four research questions, and the results integrated to address the project aim in Chapter 8.

Other possible mixed methods approaches include explanatory or exploratory designs, or different variants of a convergent design (Creswell & Plano Clark, 2011). An explanatory design was not appropriate as explanatory designs prioritise the quantitative data above the qualitative, the current study places equal emphasis on both data types. An exploratory design was not appropriate as it involves using the qualitative findings to inform the quantitative data collection, which was not necessary for the current study; instead, the current study aimed to explore how the findings across the quantitative and qualitative data confirm, explain, or contradict one another. Other variants of convergent designs (Creswell, 2013) were also not appropriate; a data-transformation design requires qualitative data to be transformed to quantitative data to merge the results, and a data-validation design does not allow for full analysis of qualitative data. In depth qualitative analysis of the qualitative datasets were required to fully answer research questions three and four: what are UK clinicians’ perceptions of TKA compared with AKA? And what are the similarities and differences of the lived experiences of TKA and AKA?

As described above four separate studies are required to address the four research questions. The methodology to address each research question is discussed in the following sections. Figure 3.1 shows the overall project design, and how the four studies, completed and analysed separately, were merged in a narrative discussion. Each of the four studies were completed separately, though the results of study 2 did inform parts of the design and analysis for study 3.

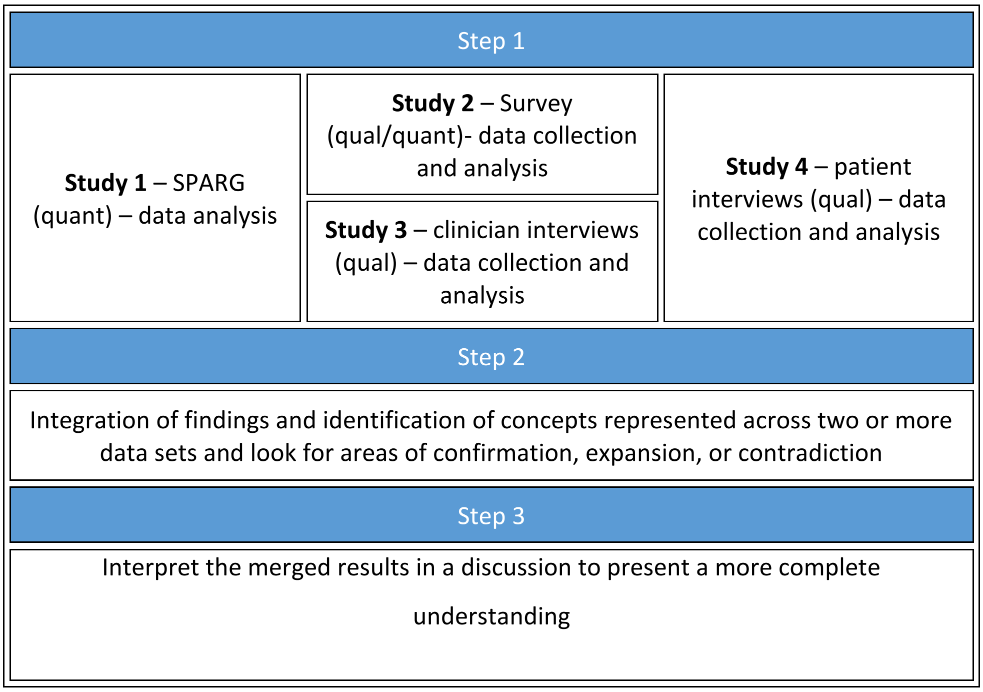


Figure 3.1 – project design

3.4.1 Question 1 - How do the surgical and rehabilitation outcomes of patients undergoing TKA compare to AKA?

To answer this question a retrospective comparative cohort study (study 1) analysing a large dataset collected by the Scottish Physiotherapy Amputee Research Group (SPARG) was conducted (full details in Chapter 4). As the SPARG data is collected by a group of physiotherapists it offers a greater insight into the rehabilitation outcomes of people post amputation than other data sources. Another large source for data on amputations is the National Vascular Registry (NVR) which collects data from 75 NHS hospitals across the UK. While the NVR provides data on larger patient numbers the only rehabilitation information it collects is whether patients are referred to their local limb fitting centre or not. Unfortunately, this information cannot be used to reliably infer meaning as patients can be referred to their limb fitting service for several reasons, which differ from centre to centre, it does not mean that patient will be limb fitted.

One problem with database studies is the risk of missing or incorrect data (Mirkes et al., 2016). One solution to this would have been to use an observational prospective design and collect data in real time (Salkind, 2010) allowing for a more accurate collection of data but at the cost of taking considerable more time, most probably more time than is available for the completion of a PhD considering the current rates of TKA. A prospective intervention study was also deemed inappropriate as the number of unknowns regarding TKA is too high to design a suitable trial. This will be discussed further in 8.8. The SPARG data was therefore a suitable option as the dataset included over a decade worth of data and could therefore provide sufficient numbers of TKA for meaningful analysis without intervention. Missing data is a common problem when using registry data but was not considered a problem due to the impressive level of completeness of the dataset (which is reported in 4.3.1), though it must be acknowledged that there may be missing cases that were not reported (Mack et al., 2018).

3.4.2 Question 2 - What does current practice of TKA and AKA look like in the UK and what are the influencing factors for choosing one over the other?

A descriptive, cross-sectional, online survey (study 2) was used to address this question (full details in Chapter 5). The survey used open and closed questions with cross-group comparison joint displays to merge the qualitative and quantitative data. Other survey methods that were considered but not used were paper surveys, or surveys comprised of only closed or only open questions. Paper surveys were not used because of the cost, time delays, and inconvenience to participants to return them via post (Andres, 2012). A mix of open and closed questions were used because restricting the survey to using only closed questions, while shortening the time taken to answer the survey and therefore potentially increasing response rate (Foddy, 1993; Hissong et al., 2015) it would not have generated new knowledge (Foddy, 1993; De Vaus, 1996). While using only open questions allows the participants to provide any answer, and therefore providing the researcher with new information, they are more time consuming to complete and therefore it less likely busy clinicians would complete the survey (Hissong et al., 2015). One problem with online surveys for clinicians is poor response rate (Dykema et al., 2013). Strategies to optimise returns are discussed in Chapter 5, and the follow up interviews in study 3 were also used to gather more details for this question.

Qualitative methods such as focus groups or ethnography can also be used to collect information about current practice in healthcare (Kitzinger, 1995; Hughes, 2019). Ethnographic studies involve direct observations of subjects in their natural environment to observe their actions and try to understand the meaning behind their actions (Silverman, 2011). An ethnographical study would have given deep insight into the decision making at the observed hospital, but does not allow for a general understanding of a large number of centres across the UK (Hughes, 2019), which was an objective of this study. Similarly, the use of focus groups would have gained more depth into the topic but restricted the breadth of participation from number of centres.

3.4.3 Question 3 - What are UK clinicians' perceptions of TKA compared with AKA?

A qualitative cross-sectional comparative interview study (study 3) was conducted to answer this research question (Chapter 6). The methods for conducting the interview were largely determined by the restrictions of the COVID-19 pandemic at the time of data collection, which will be discussed in 6.3.4. Focus groups may have been an appropriate method to address this question but a risk to the findings would be the effect of the power dynamic and hierarchy of a focus group of different clinicians (Kitzinger, 1995). To remove the threat of hierarchical influence focus groups could have been formed with participants from each clinical group. However, the COVID-19 pandemic would have placed barriers to their completion, due to the increased workload and redeployment of clinicians.

Other potential methods were online or email interviews, which would have been less demanding on clinician's time than focus groups, however, online interviews are still time consuming as they involve emails being sent back and forth between participant and researcher (Fritz & Vandermause, 2018). Timing issues are an important consideration in a mixed methods study involving several elements to ensure completion of all studies. Also, even though email interviews have been reported to be convenient to the participant because they can respond in their own time, it has also been argued that they can be more time consuming for the participant as it takes longer to type out their response as it would be to say it out loud (McCoyd & Kerson, 2016). Therefore, to ensure rich data was collected while accommodating participant preferences three interview options were offered: telephone, face-to-face, and virtual video call. These mediums for conducting interviews have been shown to result in good quality data (Ryan, 2009; Block & Erskine, 2012; Saarijarvi & Bratt, 2021).

3.4.4 Question 4 - What are the similarities and differences of the lived experiences of TKA and AKA?

A qualitative cross-sectional comparative interview study (study 4) was conducted to answer this research question (Chapter 7). Face to face interviews and focus groups were originally planned for this study but the focus groups had to be cancelled and telephone interviews used instead due to restrictions caused by the COVID-19 pandemic, full details in 7.3.4.

Thematic analysis was used for this study, (as described in 7.4) but alternative methodologies were considered and rejected. Grounded theory may have been appropriate because little is known about the experiences of TKA, but recruitment can be more difficult as you must recruit using theoretical sampling based on ongoing analysis; the population of people with TKA is small which would have made the identification of additional participants very challenging.

Content analysis may have been appropriate but does not allow analysis to look for deeper meaning between the groups. Content analysis is defined as “a research technique for making replicable and valid inferenced from texts (and other meaningful matter) in the contexts of their use”(Salkind, 2010:234). It is a technique designed to remove influence from the researcher, to reinforce reliability and reproducibility (Krippendorff, 2004). These values do not sit within the philosophical beliefs of this researcher (as described in 3.2).

Interpretative phenomenological analysis (IPA) is a bottom-up approach which focuses on how people make sense of their lived experiences (Smith et al., 2009) but is more suitable for homogenous samples. The current study needed to explore the lived experience of those with TKA and AKA, and so this approach was not appropriate. The current study needed a large sample, and used a sampling frame, to explore the differences between two groups of people (people with TKA and people with AKA). IPA research uses small samples of participants because it takes an idiographic rather than nomothetic approach and aims only to explore and understand the detailed experience of the individual participant (Smith et al., 2009). Phenomenology is the philosophical approach to IPA whereby the focus of the research is the lived experience of the participant and attempts to make meanings out of individuals activities and experiences (Smith et al., 2009). This approach would not answer the research question which is specifically investigating the impact of the different amputation levels on the lived experience.

3.5 Data analysis

Data from the four studies was analysed separately and then integrated for joint interpretation in a convergent design (Creswell & Plano Clark, 2011). How the results are synthesised for the thesis discussion is described in Chapter 8. Details of the analysis process for each study is described in the relevant chapters (4.3.6, 5.3, 6.4, 7.4). The justification for the choice of thematic analysis for the qualitative studies is provided here.

Reflexive thematic analysis (TA) was used to analyse the qualitative data in study 3 and study 4. TA is a flexible methodology used to analyse qualitative data by identifying and interpreting patterns to develop themes (Braun and Clarke 2022). Reflexive TA considers the researcher’s influence within data collection and analysis, and how their background will influence the way they ask questions and interpret the data. The researcher must practice reflexivity at each stage of the study, so the subjectivity of the researcher can be recognised and utilised as a resource for analysis.

Reflexive TA is appropriate when little is known about a topic area and, as in the case for this study, no existing framework is available to use for analysis. It is suitable for a single researcher, and for researchers with no previous qualitative research experience, but still allows for interpretive analysis of the data to explore the deeper meaning behind the data (Braun and Clarke, 2022). TA was used because little is known about the experiences of people with TKA from the point of view of the person with the TKA. As there are so few people with TKA compared to those with AKA and BKA, very small numbers of people with TKA have taken part in any qualitative research. Therefore, an inductive approach, without a framework, was appropriate for this study.

Codebook thematic analysis, or the similar framework analysis, are also good methods for comparing groups in large data sets (Braun and Clarke, 2022). Codebook thematic analysis takes an organised approach to mapping data in methodical steps but requires some themes to be developed a priori from the literature, which was not possible for this group (Braun and Clarke 2022). As there are no existing theories describing the lived experience of people with TKA or how they are similar or different to people with AKA, no top-down analysis approach would have been suitable.

The analysis aimed to explore different people's unique realities and how these can change depending on the scenario, not to seek one truth. Reflexive TA requires interpretation of the data to realise it's meaning, and this interpretation will always be influenced by the unique insights of the researcher (Braun & Clarke, 2019). TA is theoretically flexible and should be conducted theoretically knowingly, meaning that theoretical assumptions will always be applied to methods and analysis and should therefore be acknowledged (Braun and Clarke, 2022). Theory provides TA with analytic power and analytic validity (Braun and Clarke, 2022).

3.6 Presented studies

For ease of reading and interpretation, and because each study answers a separate question, each study will be presented in a standalone chapter with methods and results. The results will be synthesised in a discussion in Chapter 8.

Chapter 4 Surgical and Rehabilitation Outcomes of Patients Undergoing TKA Compared to AKA

4.1 Introduction

This chapter describes the methods and results of study 1: a retrospective comparative cohort study using SPARG data.

Every year more than 5,000 patients undergo a major lower limb amputation in the UK (Moxey et al., 2010; NHS Digital, 2020; Waton, 2021). Major lower limb amputation is a pivotal life changing event which can result in significant physical and psychological impairment. The size of impact varies considerably, depending on the persons functional ability pre-amputation, the cause of their amputation, their co-morbidities, and the level of amputation (Sansam et al., 2009; Bowrey et al., 2019).

BKA offers the greatest chance of using a prosthesis and makes up slightly more than 50% of all major lower amputations performed in the UK each year (Moxey et al., 2010; Davie-Smith et al., 2020; Waton, 2021). When injury or disease has progressed such that a BKA is not viable, an AKA is routinely performed (Moxey et al., 2010; Davie-Smith et al., 2020; Waton, 2021). The removal of the knee joint, loss of the majority of the muscular insertions of the thigh, loss of power and control, means that people with AKA face considerable challenges to achieve mobility with a prosthesis (Aulivola et al., 2004; Göktepe et al., 2010).

TKA is an infrequently used alternative to AKA. Less than 4% of UK amputations are TKA (Moxey et al., 2010; Davie-Smith et al., 2020; Waton, 2021) despite recommendations for its use in several guidelines (BSRM, 2018; Conte et al., 2019). The long, end-weight bearing residuum offers several theoretical advantages over AKA for the prosthetic and non-prosthetic user. The shape of the residuum allows for a more comfortable prosthesis and a superior method for attaching the prosthesis to the residuum than with AKA. However, healing complications following TKA are often considered too high, even though they have previously been reported to be similar to BKA (Lim et al., 2006; Schmiegelow et al., 2018). Previous studies investigating outcomes of TKA have been limited by small and homogenous samples (Met, 2008;

Morse et al., 2008; Ten Duis et al., 2009; Nijmeijer et al., 2017). Often rehabilitation outcomes have been overlooked and only the surgical outcomes investigated (Albino et al., 2014; Lim et al., 2018; Schmiegelow et al., 2018).

4.2 Aim

To compare surgical and rehabilitation outcomes following TKA and AKA.

4.3 Methods

4.3.1 Materials

This retrospective analysis examined data held in the Scottish Physiotherapy Amputee Research Group (SPARG) database for all TKA and AKA patients from 1 January 2007 to 31 December 2017. SPARG complete a national audit of anonymised data on every major lower limb amputation performed in Scotland. Collected data includes demographical information such as age, sex, co-comorbidities, the centre that performed the amputation, aetiology, need for further surgery, and inpatient length of stay. Rehabilitation data includes limb fitting outcomes including time to cast and time to fit delivery, time to start compression therapy and type of compression therapy, time to commence early walking aids and type of early walking aids, falls, change in mobility scores, and time to complete prosthetic rehabilitation. All data is entered locally onto the SPARG web-based database and data forms are 97.8% complete in every respect (Davie-Smith et al., 2020).

4.3.2 Study design

A retrospective comparative cohort study using a large dataset.

4.3.3 Participants

BKA and through hip amputations were excluded, however, patients revised to TKA or AKA from BKA, and those who had TKA or AKA and were revised to hip or pelvic levels were included. Amputations of all causes were included as were patients with bilateral amputations, whether both amputations were done in the same episode, or if they already had an amputation and this episode recorded their second amputation. Each amputation was considered as a unit of analysis for surgical outcomes, patients with bilateral amputations were excluded from analysis of rehabilitation outcomes, where the patient was used as the unit of analysis.

4.3.4 Ethical approval

Anonymised data is entered onto the secure SPARG database by a member of the patient's care team. Only routine clinical data is recorded for the purpose of auditing services, supporting health surveillance and clinical decision-making. No patient identifiable data was required for this study and no additional data was collected. Therefore, no additional ethical approval for this analysis was sought.

4.3.5 Variables

The following outcomes are collected by SPARG and were available for analysis

4.3.5.1 Amputations

The date of the amputation, which leg (right or left), and the level of amputation (i.e., BKA, AKA, transpelvic, hip disarticulation, TKA, ankle disarticulation) are recorded as the initial amputation level. Final level of amputation is also recorded to account for patients who had reamputation, or contralateral amputations during their admission. Amputations are recorded as unilateral or bilateral, it is specified if the bilateral amputations occurred in the same admission, or if a patient was admitted with one lower limb amputation and had an amputation on the other side during their admission.

4.3.5.2 Demographics

Patient demographics collected by SPARG are sex and age at time of amputation. The centre where the surgery was performed is recorded as a numerical code.

4.3.5.3 Aetiology

Aetiology of amputation is reported as one out a possible 15 categories (PAD without diabetes, diabetes, trauma or burns, tumour, congenital deformity, drug abuse, venous disease, orthopaedic non-union, orthopaedic failed joint, orthopaedic acquired deformity, blood-borne infection, renal failure, complex regional pain syndrome, acute vascular incidence).

4.3.5.4 Co-morbidities

Co-morbidities are reported and measured using the functional co-morbidities index (FCI) (Groll, 2005) which includes only co-morbidities which impact on function, with each morbidity scoring a 1, if documented in the medical notes, 18 is the highest possible score. Co-morbidities in the FCI are arthritis, osteoporosis, asthma, chronic obstructive pulmonary disease, acquired respiratory distress syndrome, emphysema, angina, congestive heart failure, myocardial infarction, neurological disease, cerebrovascular accident, PAD, diabetes, upper gastrointestinal disease, depression, anxiety, visual impairment, hearing impairment, degenerative disc disease, or obesity.

4.3.5.5 Further surgery

Incidences of return to theatre including the date of the operation are recorded. Return to theatre is specified as a debridement (involving soft tissue only), a revision (including bone but not change of level), or a reamputation (revision including bone and results in a higher level of amputation).

4.3.5.6 Length of stay

Length of stay is calculated from date of operation to the date of inpatient discharge.

4.3.5.7 Survival

Survival data was collected until the patient was discharged from rehabilitation, either as an inpatient or outpatient.

4.3.5.8 Limb fitted

Limb fitting outcomes are collected at time of inpatient discharge, and for those referred to prosthetic rehabilitation, outcomes are recorded again at time of prosthetic rehabilitation discharge. Possible limb fitting outcomes are limb fitted (for patients who were successfully discharged using a prosthetic limb safely), not limb fitted (for patients who were assessed as not suitable for a prosthesis) or abandoned (for patients who started prosthetic rehabilitation but were discharged from rehabilitation without a prosthesis).

4.3.5.9 Compression therapy

Date compression therapy is started post-operatively is reported as well as the type of compression therapy used (i.e., PPAM aid bag, elastic bandage, shrinker sock, rigid dressing, silicon sleeve, Flowtrons, or other). Guidelines state that compression therapy should be commenced within ten days post-operatively (Smith, 2016). The use of compression therapy has been shown to reduce the time between operation and prosthetic rehabilitation (Condie et al., 1998).

4.3.5.10 Early walking aids

Date of first early walking aid use was recorded and the type of early walking aid (PPAM aid, Femurett, Saarbrucken, temporary prosthesis, or amputee mobility aid). Early walking aids are used as an assessment tool to determine if a patient should be cast for a prosthesis, and as a rehabilitation tool in preparation for using the prosthesis (Smith, 2016). The PPAM aid and Femurett are the most common early walking aids found in NHS rehabilitation departments; the Femurett has an articulating knee joint and the PPAM aid does not.

4.3.5.11 Falls

Falls were reported for all patients during their admission. For patients who were referred for prosthetic rehabilitation, and were therefore still involved in data collection, any falls that occurred at home during this period were reported as a fall at home.

4.3.5.12 LCI-5

Pre- and post-amputation mobility scores are calculated using the Locomotor Capabilities Index-5 (LCI-5) (Franchignoni et al., 2004). The LCI-5 is a self-reporting tool which measures perceived ability to complete activities.

4.3.5.13 Prosthesis

Data is collected for the time points of making the prosthesis; the date of casting the leg (the process of taking a plaster cast mould of the residual limb to start building the prosthesis), fitting dates, and the date the finished prosthesis is given to the physiotherapist to start prosthetic rehabilitation with the patient (delivery date) are all recorded.

4.3.5.14 Prosthetic rehabilitation

Time to complete prosthetic rehabilitation is recorded as the date of inpatient discharge to the date of discharge from prosthetic rehabilitation.

4.3.6 Data management and statistical methods

Data analysis was performed using SPSS Version 25 (IBM Corp, Armonk, NY). Statistical significance was set at $p<0.05$ for all analyses. Continuous variables are expressed as mean ± standard deviation (SD). All continuous data was tested for normality. If normal, hypothesis testing was with students *t*-test. Medians and interquartile ranges are used for non-normally distributed data and hypothesis testing used Mann-Whitney

U test. Chi-squared were used for cohorts with categorical variables. Fishers-exact was used for variables with small sample sizes. Survival analyses and hazard analyses for further surgery to the amputated limb were assessed by Kaplan–Meier curves and Log-rank statistics. Multivariate logistic regression analysis was used to identify risk factors for further surgery and mortality.

Descriptive statistics and surgical outcomes are presented in comparative groups of “initial AKA” or “initial TKA” meaning all amputations initially done at that level, including bilateral procedures.

Rehabilitation outcomes were analysed only in unilateral patient episodes due to complexity of rehabilitation with patients with bilateral amputation. The comparative groups are “final uni AKA” or “final uni TKA” meaning all patients who left the hospital with a unilateral amputation at that level.

4.4 Results

4.4.1 Amputations

There were 4,197 AKA or TKA performed as a primary (86%) or reamputation (9%) procedure in Scotland between 1 January 2007 and 31 December 2017. A total of 3,471 (83%) initial AKA, including 885 (25% of initial AKA) which were part of a bilateral procedure, were included. 381 revisions were made to AKA and 5 of the initial AKA were revised to hip disarticulation amputations leaving 2,967 unilateral final level AKA, 482 of those did not survive their hospital admission therefore 2,485 people with unilateral AKA were discharged from hospital. A total of 146 (3.5%) initial TKA, 46 (33% of initial TKA) of which part of bilateral procedures, were included. Six revisions were made to TKA and 16 TKA were revised to AKA leaving 91 unilateral final level TKA, of whom 16 did not survive their hospital stay, leaving 75 people with TKA who were discharged from hospital see Figure 4.1.

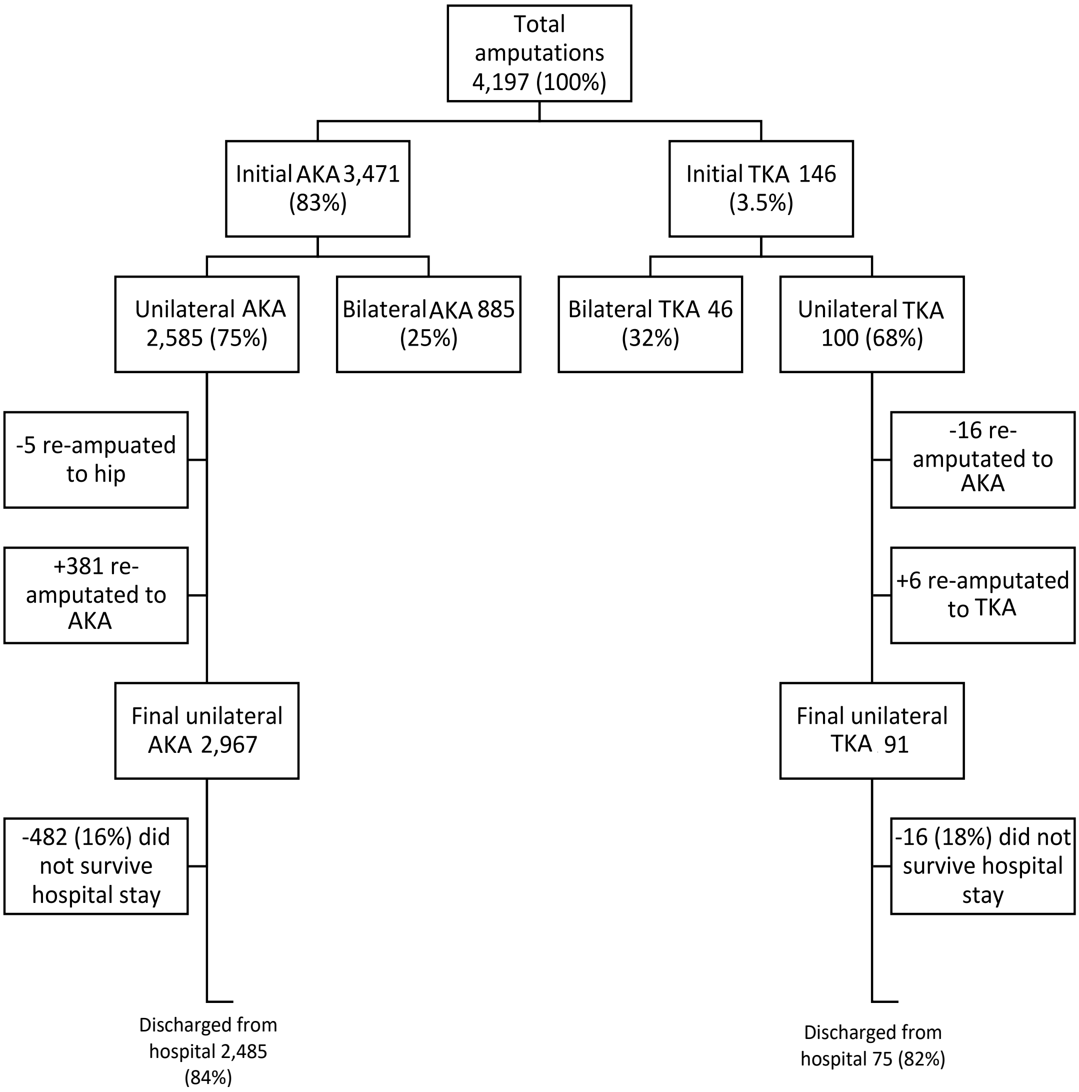


Figure 4.1 – flowchart showing numbers of amputation levels at each stage

4.4.2 Demographics

The majority of the study population were male (62%). The mean population age was 69 (±13) years. The mean age for the AKA group was 69 (±13) years and for the TKA was 67 (±15) years (*p* = 0.058).

Over 50% of all TKA were performed in three out of 21 possible centres. The remaining procedures were performed in 11 centres. The remaining seven centres did not perform any TKA. We classified the top three centres as “high volume” centres and the other 11 as “low volume” centres for comparison of surgical and rehabilitation outcomes.

4.4.3 Co-morbidities

The TKA group were significantly more likely to have a diagnosis of diabetes (*p* = 0.0) or obesity (*p* = 0.012) (Table 4.1). Functional co-morbidity index (FCI) median scored were the same between groups 3 (2 - 4).

Table 4.1 – past medical history per amputation level

	All, n (%)	**Initial AKA, n (%)**	**Initial TKA, n (%)**	***p*-value**
Total	4197	3471	146	--
Past Medical History				
PAD	3005 (78)	2430 (77)	105 (75)	0.565
DM	1424 (37)	1098 (35)	61 (44)	0.034
CHF	1114 (29)	910 (29)	31 (22)	0.085
CVA/TIA	863 (22)	711 (23)	38 (27)	0.205
Asthma	704 (18)	596 (19)	26 (19)	0.921
Obesity	449 (12)	358 (11)	26 (19)	0.012
Missing	344*	319 (9%)	6 (4%)	--

*PMH data not collected for 2007 (280 cases)

4.4.4 Aetiology

More than half of all amputations were due to peripheral arterial disease (PAD). The most common causes of amputation are displayed in

Table 4.2. Aetiology between groups was similar. Other reasons for amputation include tumour, congenital deformity, blood borne infection, renal disease, drug use and complex regional pain syndrome.

Table 4.2 – aetiology per amputation level

	All, n (%)	**Initial AKA, n (%)**	**Initial TKA, n (%)**	***p*-value**
Total	4197	3471	146	--
Aetiology				
PAD	2223 (53)	1869 (54)	69 (47)	0.118
DM	1417 (34)	1097 (32)	55 (38)	0.123
Other	557 (13)	505 (14)	22 (15)	0.862

4.4.5 Further surgery

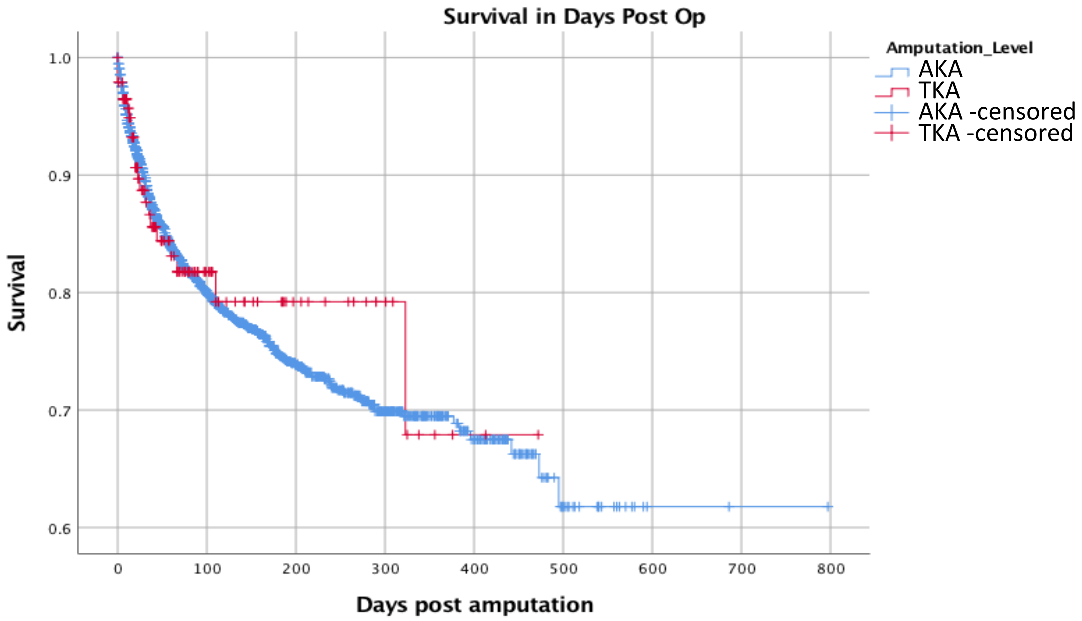
A higher proportion of patients following TKA required further surgery 13% (19/146) vs 4% (151/3471) in the AKA group ($p < 0.001$). Of those who underwent further surgery 2% of each group (57 AKA, 3 TKA) had further surgery involving only soft tissue ($p = 0.734$). 3% (94) of AKA and 11% (16) of TKA had revision involving bone including some which were reclassified as a higher level of amputation ($p < 0.001$). Only 8% of TKA done in high volume centres required further surgery compared to 19% in low volume centres ($p = 0.048$).

4.4.6 Length of stay

Despite more TKA requiring further surgery their inpatient length of stay (LOS) was similar 35 (17 - 72) days compared with AKA 42 (20 - 78) days ($p=0.696$).

4.4.7 Survival

The proportion of patients who died during their hospital admission was similar between groups (18% AKA Vs 16% TKA $p = 0.870$). Survival in days was also similar between groups (log-rank 0.809) (Figure 4.2). In the multivariable cox regression, the significant predictors of mortality were sex, age, and history of diabetes or obesity, but level of amputation was not a significant predictor.



Numbers	AKA	1140	491	221	90	21
At risk	TKA	38	17	9	2	0

Figure 4.2 - Kaplan–Meier curve for TKA and AKA

4.4.8 Limb fitted

Limb fitting outcomes were similar between TKA and AKA (Figure 3). Those classed as “abandoned” commenced prosthetic rehabilitation but did not achieve independent mobility with their prosthesis. Those “not limb fitted” were not referred for prosthetic rehabilitation.

Only 12% (9/77) of TKA from high volume centres limb fitted compared to 25% (17/69) from low volume centres (*p* = 0.041). Which may suggest that high volume centres are choosing to perform TKA for patients they do not expect to limb fit.

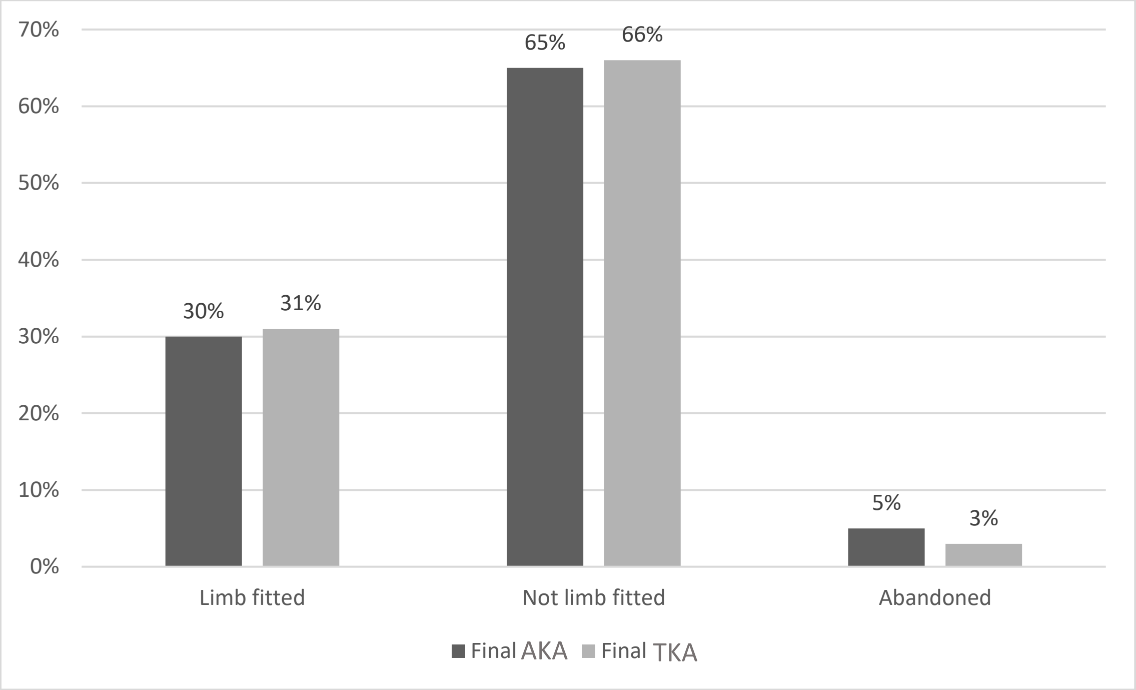


Figure 4.3 – proportion of limb fitting outcomes per group

4.4.9 Compression therapy

Median number of days between operation date and commencing compression therapy were similar between groups (10 (7 – 25)) compared to the AKA group (13 (7 – 26)) (*p* = 0.485). Shrinker socks were the most common method of compression therapy used in all centres. 82% of AKA used shrinker socks as their method of compression therapy, whereas only 54% of TKA used shrinker socks; 21% used the PPAM aid bag, 18% used a rigid dressing and 7% used an elastic bandage.

4.4.10 Early walking aids

Time to start early walking aids was similar between the TKA and AKA group (22 and 21 days) (*p* = 0.426). TKA favoured the PPAM aid (89%) over the Femurett (11%) for early walking aid, whereas 59% of the AKA group used the PPAM aid and 41% the Femurett.

4.4.11 Falls

There were a similar number of in hospital falls recorded between groups, 12% of AKA, and 11% of TKA fell during their inpatient stay. Fewer at home falls were recorded in the TKA group, 11% of TKA compared to 15% of AKA, but this difference was not statistically significant (*p* = 0.355).

4.4.12 LCI-5

The Locomotor Capabilities Index-5 (LCI-5) is completed retrospectively for the patient's mobility six months prior to their amputation and prospectively on final discharge from prosthetic rehabilitation. The difference between these two scores is calculated for each patient to give a score for their change in mobility. A positive score indicates an improvement in mobility and a negative score deterioration. The change in pre-amputation and final discharge scores for both groups are presented in Figure 4.4.

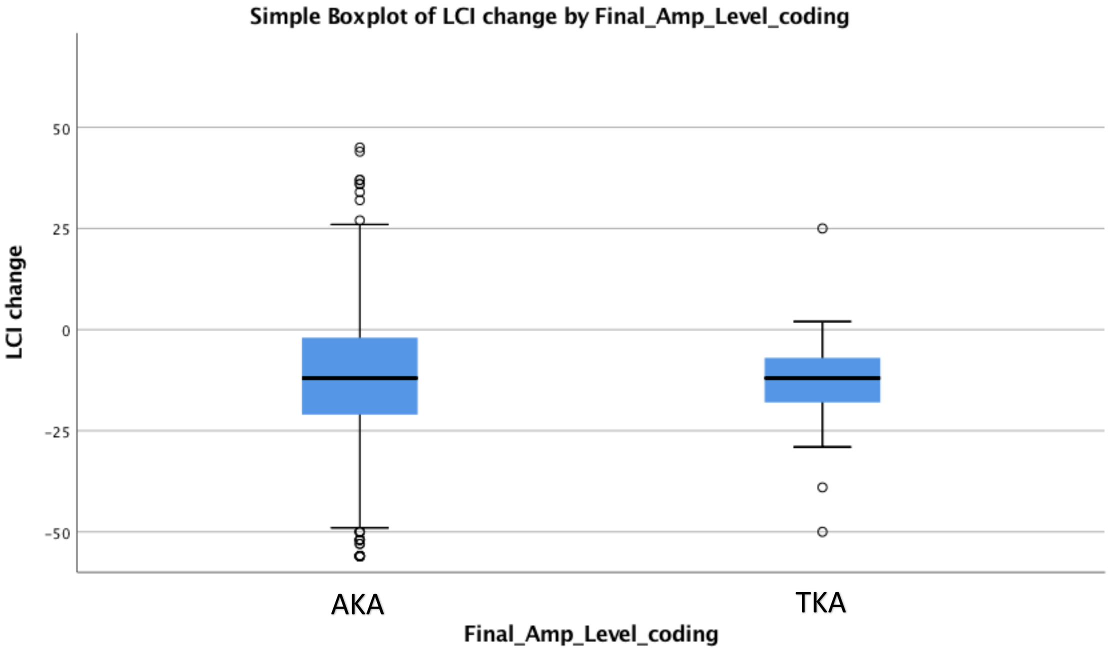


Figure 4.4 – boxplot of LCI change by final amputation level

4.4.13 Prosthesis

The median days from operation to being cast for a prosthetic limb was the same for both groups (55 days). Days from casting to receiving the finished prosthetic leg were also similar, AKA took 14 (8 – 21) days and TKA 12 (6 – 16) days (*p* = 0.084).

4.4.14 Prosthetic rehabilitation

TKA were quicker to be discharged from prosthetic rehabilitation than AKA. Of the 23 patients who were limb fitted they took 99 days (5 – 207) from inpatient discharge to complete prosthetic rehabilitation. Whereas the 725 AKA who limb fitted took 133 (45 – 230) days (*p* = 0.609).

4.5 Discussion

This retrospective study examined demographics and outcomes from all patients who underwent TKA or AKA amputation over an eleven-year period in Scotland. Baseline characteristics (age, gender and rates of PAD and DM) were comparable to similar studies (Morse et al., 2008; Ten Duis et al., 2009; Nijmeijer et al., 2017). Similarities were observed between groups in the current study for survival, inpatient length of stay, limb fitting rates, mobility scores, and time to complete prosthetic rehabilitation, but significant differences between groups were found for co-morbidities and further surgery.

Reoperation rates in the TKA group were significantly higher than the AKA group, however the rates of reoperation post TKA in the current study are lower than those reported in older studies (Lim et al., 2018; Schmiegelow et al., 2018) 34% and 29.9% respectively. Furthermore, this study showed that high volume centres are capable of getting much better results which suggests there is a scope of optimisation of patient selection, operative technique and/or peri-operative care.

Limb fitting rates in the TKA group were lower in the current study than have been reported in similar studies and particularly low in high volume centres. This may suggest that TKA is being chosen for patients not expected to mobilise but there is no way of knowing the selection process for this procedure from this data. Nijmeijer et al. (2017) and Ten Duis et al. (2009) reported limb fitting rates of 61% and 59% respectively in their TKA groups, however, only 34% and 35% of those actually achieved household mobility with their prosthesis. This dataset only includes data up to the point of discharge from rehabilitation, therefore information regarding long term prosthetic use at home was unavailable. It is known that up to 50% of limb fitted AKA patients stop using their prosthesis within the first year (Hagberg, 1992; Basu et al., 2008; MacCallum et al., 2019). The reduced energy requirements (Pinzur, 1992) and superior socket comfort from a TKA prosthesis (Smith, 2004; Murakami & Murray, 2016) has the potential to improve long-term maintenance of prosthetic mobility.

The British Society of Rehabilitation Medicine (BSRM, 2018) guidelines recommend TKA for patients with existing contralateral amputation to improve bed mobility, transfer ability and leave the patient with a lap to help with carrying objects when in a wheelchair. Despite this, 494 analysed patients underwent AKA for their second amputation compared to only 35 receiving TKA. This data suggests that considerable numbers of patients undergoing bilateral amputation are potentially missing out on significant advantages offered by TKA. The numbers of bilateral cases with one or two TKA were too small to compare rehabilitation outcomes in this study. Inderbitzi et al. (2003) compared outcomes of bilateral patients at different levels. They found the higher the amputation level the worse the rehabilitation outcome and concluded that despite the high revision rates they observed in their TKA cohort they would still advise amputation at the most distal point possible to improve rehabilitation outcomes.

It is unknown which type of TKA is best with several techniques being described in the literature (Middleton & Webster, 1962; Mazet, 1966; Cull et al., 2001; Murakami & Murray, 2016; Eid-Arimoku & Brooks, 2020). With so many techniques to choose from surgeons may be more likely to opt for the familiar AKA. Amputation surgery should only be performed by suitably experienced surgeons to ensure a good quality residuum (Cosgrove et al., 2002; Gough et al., 2014). As such small numbers of TKA are being performed, there will be very few surgeons with adequate experience to create an acceptable TKA residuum. This could hinder limb fitting and contribute to poorer healing rates.

Murakami and Murray (2016) suggest high reoperation rates post TKA are due to poor patient selection and a lack of physiological measures used to decide level of amputation. The absence of defined selection criteria for each level of amputation is another limitation of this retrospective study.

Comparing TKA with AKA has always been challenging due to sample size differences. Even when using eleven years' worth of data only 146 initial TKA were available for analysis. Of these only 23 were fitted with a prosthesis making comparisons of rehabilitation outcomes difficult. Some analysis was not possible due to the small numbers of TKA referred for limb fitting, such as frequency of falls at home and comparisons of different bilateral combinations.

A larger sample could have been found had the National Vascular Registry (NVR) dataset been used for analysis. The NVR collects amputation data from vascular centres across Great Britain to include over 3,000 major lower limb amputations, approximately 100 TKA, each year (Waton, 2021). This is a similar proportion of TKA compared to the SPARG dataset. Like SPARG, NVR choose to combine the TKA data with another group for annual analysis. Where SPARG group TKA with AKA, due to similar rehabilitation processes, NVR group TKA with BKA for analysis and reporting and no further information about TKA is freely available from the annual NVR report. The NVR dataset was not used for the current analysis as its data is limited to amputations performed by vascular surgeons only, and no rehabilitation outcomes are reported, apart from the outcome of whether a patient is referred to the artificial limb centre or not. Criteria for a referral to the artificial limb centre vary between vascular centres with some centres referring all patients post amputation, meaning little can be learned from this outcome.

4.6 Strengths and Limitations

A limitation of this study is its retrospective cohort design. Missing data, and unknown confounders are faults with any retrospective study; however, a strength is that the SPARG dataset was used. The purpose of collecting this data is for similar analyses meaning the data is of good quality and it has very little missing data.

Another consideration is that variations of TKA, such as Gritti-Stokes, are included in the TKA group so their outcomes cannot be analysed separately. There is no way of knowing what percentage of the TKA group are Gritti-Stokes or any other variation of TKA.

It is not possible to know from the dataset what proportion of patients who underwent AKA, if any, would have been suitable to TKA. No detail is available regarding how decisions between TKA and AKA are made. This must be considered as a factor when comparing the two groups.

4.7 Conclusion

This study shows that TKA remains an underused option for major lower limb amputation. High volume centres have better surgical outcomes but appear to select patients not likely to limb fit. Despite this, similar proportions of patients did subsequently limb fit between groups which may suggest superior rehabilitation potential for TKA compared to AKA. Details of current practice and level selection need investigation to determine how best to select patients who would benefit from TKA as opposed to AKA but with a low risk of need for reoperation.

Chapter 5 Clinician's Views of TKA in the UK: A content analysis of survey data

This chapter describes the methods and results of study 2: a descriptive, cross-sectional, online survey which invited vascular surgeons, physiotherapists and prosthetists to share their views on TKA and their experiences compared to AKA. The survey questions were based on the relevant literature as described in Chapter 1 and the results used to design the topic guides for the clinician interviews, which will be described in Chapter 6.

5.1 Introduction

TKA is an uncommon level of amputation in the UK (Moxey et al., 2010; Waton, 2021). Suggested reasons for this are problems with prosthetic limb fitting, poor cosmetic appearance of prosthesis, and bad reputation for primary wound healing (Murakami & Murray, 2016) but the true factors that influence practice have not been formally identified. Promising outcomes have been shown for TKA (Morse et al., 2008; Ten Duis et al., 2009; Nijmeijer et al., 2017) and in Chapter 4, but small sample sizes limit the power of these findings. It is important to understand how TKA is perceived by clinicians and what the real-world differences between TKA and AKA are as experienced first-hand by frontline clinicians. This study aimed to establish the views around the utility of TKA from UK vascular and amputation rehabilitation clinicians.

Despite being recommended as a suitable option for patients with vascular disease in both national and international guidelines (BSRM, 2018; Conte et al., 2019) TKA remains infrequently used. TKA and its place as an amputation method in vascular surgery drift in and out of favour and often causes disagreement within clinical teams, (Smith, 2004). Thus, it seems possible that clinicians' experiences and attitudes are driving practice rather than robust evidence. No quality prospective trials have yet been done to examine the worth of TKA compared to AKA, and while current retrospective studies suggest patient benefit with TKA, further research is needed (Ten Duis et al., 2009; Nijmeijer et al., 2017; Polfer et al., 2019).

5.1.1 Aims

To understand how TKA is viewed by the UK clinical workforce in vascular surgery and amputee rehabilitation. Specifically, what are their first-hand observations of the advantages and disadvantages of TKA when compared to AKA? What does current practice of TKA look like in the UK? And what are the influencing factors for choosing one type of amputation over the other?

5.2 Methodology

A descriptive, cross-sectional survey was designed to collect information from clinicians. It allowed anonymised data from the whole UK to be collected in a cost-effective way (Kelley, 2003). The results of the survey were used to design the topic guides for the clinician's interviews and informed the research with context and explanations of the current UK practice.

Surveys are an established method used to question health clinicians about their knowledge, attitudes, and practice in order to guide research design (Burns et al., 2008). Other methods were considered to address this question, such as a Delphi study, interviews, or focus groups. However, this study was needed to inform the clinician interviews, so a survey was better suited to the time constraints. Delphi studies take more time to complete than surveys as they need successive rounds of questionnaires (Beiderbeck et al., 2021). Delphi studies aim to come to a decision about a topic from experts, however the literature on this topic, and clinical experience suggests diverse views exist with potentially few centres performing TKA, and often using differing surgical techniques, which would make it difficult to reach a consensus. The survey was used to gain views from clinicians across the country and compare thoughts from different clinical groups. The views of clinicians who would not consider themselves experts on TKA were important, to assess how TKA is experienced from rehabilitation clinicians who do not often see TKA. Interviews and focus groups were also not appropriate as part of this study was looking for breadth of experiences across the country rather than depth.

5.2.1 Survey design

Surveys are an efficient and cost-effective method of data collection (Kelley, 2003; Jones et al., 2013). Until the early 2000's paper surveys were the unchallenged and unquestioned primary method in survey research (Hooley, 2012). However, paper surveys had several problems such as long response and delivery time, costs of printing and posting, and low response rates (Jones et al., 2013). Consequently, paper surveys have been largely replaced by online surveys, which are now common practice within health research (Burns et al., 2008). Online surveys can easily be sent to large audiences, they offer quick completion times for the responder and fast response times for the researcher, at relatively low cost (Jones et al., 2013).

Qualtrics software (Provo UT, 2020) was used for this survey. Survey items were generated from a review of the literature, as described in Chapters 1 and 2, discussions with experts and reflections of personal clinical experience. Initially, all questions were open-ended to allow for a wide range of answers, or answers the researcher had not yet considered (Allen, 2017). Phrasing of the questions was neutral to avoid any inferences from the researcher.

5.2.2 Pilot

Before dissemination the survey underwent pre-testing and pilot phases. Pre-testing is important to ensure questions are asking what they are intended to ask and to ensure clarity (Burns et al., 2008). Pre-testing (appendix 1) and review of the questions was completed by vascular consultant surgeons at the 2018 Vascular Societies Annual Scientific Meeting, prosthetists at Hull University Teaching Hospitals NHS Trust and by the BACPAR research officers, who are specialist physiotherapists in amputation rehabilitation. Changes were made to the prosthetist survey to ask how many TKA patients had they had seen in the last 3 months, as the feedback from the reviewing prosthetists was that they see such high numbers of people with amputations daily, it would be difficult to accurately answer how many they had seen in 12 months. The physiotherapist feedback prompted the addition of a definition of TKA at the start of the survey explaining the researchers are referring to any amputation at the level of the knee, including Gritti-Stokes. Feedback from surgeons strongly suggested the need for a short, closed-question survey. They felt that due to surgeon’s busy schedule, and the large number of surveys they get asked to complete, they were more likely to complete a short survey with closed questions. It was decided that a larger number of responses was more important than detail, as the detail could be explored in the follow up interviews. Therefore, in response to their feedback a closed response version of the questionnaire was constructed specifically for the surgeon respondents. Open questions were retained for physiotherapists and prosthetists to gain a detailed understanding of their views about TKA. Open questions are more appropriate when all the possible responses are unknown (Kelley, 2003), as the purpose of this survey was to identify all the different positions held by health professionals around TKA, despite the increased time needed for analysis, this was appropriate. The pilot provided the possible responses for the surgeon's survey and an "other" option was added to all closed question options to allow for unanticipated answers. Providing this option, and a "don't know" option has been shown to improve survey response rates (Burns et al., 2008), therefore a "don't know" option was also added.

The final survey consisted of the following core questions:

1. Approximately how many patients with THROUGH KNEE amputation have you seen/performed in the last 3/12 months?
2. In your opinion, what are the **advantages** of THROUGH KNEE amputation?
3. In your opinion, what are the **disadvantages** of THROUGH KNEE amputation?
4. Please list any patient groups who, from your experience, **benefit** from a THROUGH KNEE amputation rather than an ABOVE KNEE amputation.
5. Please list any patient groups who, in your opinion, **should not** be considered for a THROUGH KNEE amputation, and should undergo ABOVE KNEE amputation instead?
6. Do you think THROUGH KNEE amputation is uncommon, and if so, why?

Additional questions specific to each clinical group were added to the core questions; surgeons were asked which type of TKA they perform and why; physiotherapists and prosthetists were asked what feedback they get from patients, and their personal thoughts regarding the cosmetic appearance of TKA. At the start of the survey, participants were advised that the term "through-knee amputation", for the purposes of the survey, referred to all types of TKA including Gritti-Stokes. They were also told that "participation in the survey is voluntary and data will be processed on the basis of participant consent". The invitation emails and surveys for each group can be found in appendix 2 and 3 respectively. Demographic data of respondents was collecting including region, years' experience and job role to allow the reader to consider how representable the sample is (Campbell, 1997) but no identifiable information was collected as part of the survey; responses were completely anonymous. Prior ethical approval was not required as no sensitive, identifiable or patient information was collected.

5.2.3 Distribution

The population to be studied is relatively small and clinician surveys often have low response rates (Cho et al., 2013) therefore a targeted convenience sampling approach was adopted. All specialist surgeons, prosthetists and physiotherapists who were members of specialist professional networks with first-hand experience working with people pre and post TKA were asked to take part. Surveys were disseminated through professional networks to all their members. Anonymous links were sent to members via email from network administrators of the Vascular Society for Great Britain and Ireland (VSGBI), British Association of Chartered Physiotherapists in Amputee Rehabilitation (BACPAR), the Scottish Physiotherapy Amputee Research Group (SPARG), and the British Association of Prosthetists and Orthotists (BAPO). Emails asking to complete the survey were personalised for each clinical group.

The survey link was also shared on the BACPAR members only Facebook group. The survey was open for 12 months from May 2019 with regular reminders sent as this has been shown to be effective (Klabunde et al., 2012). The decision to close the survey, and not extend to get more responses, was made in April 2020 in response to the COVID-19 pandemic.

5.3 Analysis

The survey produced both quantitative and qualitative data. Quantitative data from the closed questions are presented using descriptive statistics (percentages). Open questions were analysed using content analysis to describe meaning and calculate frequencies of categories (Ahuvia, 2001; Drisko, 2015). Qualitative data was organised using NVivo 12 software and analysed question by question. Codes were generated from answers and themes identified. Cross-group comparison joint displays present corresponding quantitative variables within the qualitative code (Guetterman et al., 2015). Frequencies of each category are presented as percentages calculated from the whole sample of that clinical group and direct quotes are provided to demonstrate categories. Participants could give multiple answers to each question therefore percentages may total more than 100%. The convergent design joint display described by Guetterman et al. (2015), first used by Dickson (2011) for cross case comparison, clearly shows concordance or inconsistency between groups. The qualitative quotes support the theme counts. Questions not answered by all groups are presented in a narrative.

Content analysis is “a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts or their use” (Krippendorff, 2004). It is most suited to analyse texts that describe concepts, attitudes, beliefs and cognitive processes (Krippendorff, 2004) and can be used to synthesise quantitative and qualitative data (Dixon-Woods, 2005). Using content analysis to quantify responses of qualitative data is appropriate when the whole population has been given equal opportunity to take part and been asked the same questions in the same manner (Pope & Mays, 2006) and especially when there is a large number of cases (Dixon-Woods, 2005), such as survey research. A second researcher assisted with some coding to ensure the coding was replicable. Replicability is indicative of reliability (Krippendorff, 2004). Coding between the two researchers had a percent agreement of 0.90 which is an acceptable level of intercoder reliability (Lombard et al., 2002).

5.4 Results

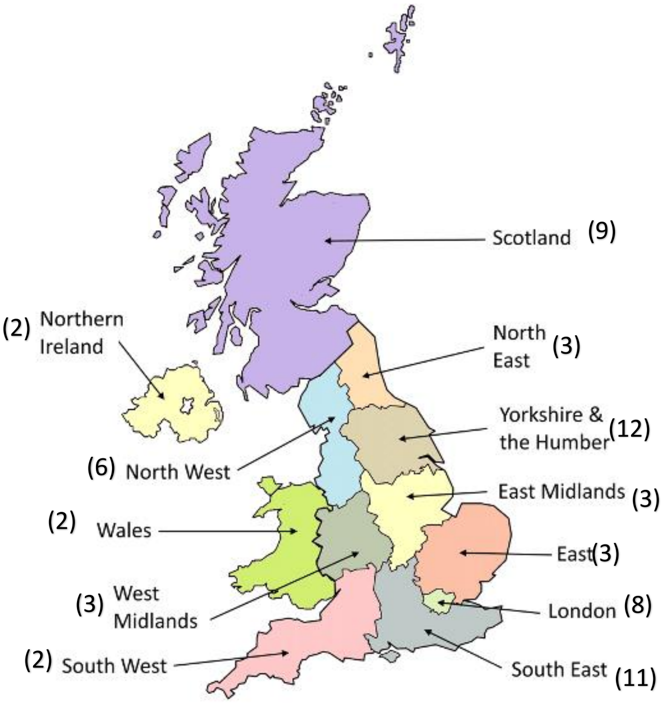
5.4.1 Responses

Seventy-eight responses were received in total, from 22 (28%) vascular surgeons, 43 (55%) physiotherapists, and 13 (17%) prosthetists. The survey was sent to 403 VS members, 305 BACPAR and SPARG members, and 600 BAPO members. The survey would only be relevant to prosthetic members of BAPO (not orthotist members), it was not possible to clarify how many of BAPO’s members are prosthetists.

The response rate was low but rich data provided to open-ended questions allowed conclusions to be drawn. Clinicians are known for low response rates but surveying clinicians remains important (Cho et al., 2013). A low response rate on its own is not proof of a poor quality survey (Cho et al., 2013). The best way to improve response rate is with a financial incentive (Cho et al., 2013) but this was not possible.

5.4.2 Demographics

Responses came from clinicians across the UK (Figure 5.1). Most vascular surgeons were consultants (86%), and though 93% of the physiotherapists work in amputee outpatients, many of them had a combined role with vascular inpatients or another specialty area. The prosthetists had an average of 23 years of clinical experience and most of them (77%) worked in the NHS rather than private practice.



Regional demographics not collected for prosthetists

Figure 5.1 Distribution of surgeon and physiotherapist responses by region

5.4.3 Types of TKA

Ten surgeons provided data on the type of TKA they perform and the reasons for their choice. Five vascular surgeons perform a knee disarticulation amputation (KDA), either at the request of their rehabilitation team or because it can be performed quickly. Two prefer Gritti-Stokes, due to previous concerns with wound healing following KDA, the remaining three perform both types and choose depending on the patient's suitability for each technique, "*depends on skin condition, presence of other leg and likelihood of prosthetic fitting*" (surgeon). Only surgeons were asked specifically about variations of TKA, but all groups commented on the differences. Some surgeons and physiotherapists felt strongly that a Gritti-Stokes is not a type of TKA "*The Gritty is not a through knee amputation. It requires bone section through the femoral condyles*" (surgeon), "*As soon as the femur is modified all advantages of a through knee are lost and none of the disadvantages resolved*" (physio). A prosthetist commented that the differences between Gritti-Stokes and KDA on rehabilitation are significant and it should be made "*clear about which technique has been used and if pre-amputation consultations take place, that all parties know which surgery they are expecting to occur or has been recommended*" (prosthetist).

Surgeons report that end-weight bearing is only possible with Gritti-Stokes, whereas physiotherapists and prosthetists disagree "*Gritti-Stokes get poor end-bearing so end up with an ischial containment socket*" (physio) and state only KDA can offer successful end-weight bearing.

A lot of uncertainty exists around the variations of TKA "*Should the patella stay or not? I always get asked and am unsure of the answer*" (physio) and "*Variety of techniques make assessment of evidence difficult*" (surgeon).

5.4.4 Advantages and disadvantages of TKA compared to other levels of major lower limb amputation

The key advantage of TKA cited by physiotherapists was sitting balance, while surgeons prioritised getting the patient into rehabilitation earlier, and prosthetists find the suspension methods achieved with a TKA to be its best quality. Few surgeons mentioned the impact of TKA on how the patient would manage with their prosthetic limb, whereas physios and prosthetists were aware of the surgical benefits of TKA (

Table 5.2).

Relatively few disadvantages of TKA were reported, but surgeons and physiotherapists recognised issues around wound healing. A key disadvantage from the perspective of physiotherapists and prosthetists was the functional and cosmetic challenges of asymmetrical knees. Again, very few surgeons considered the impact TKA has on prosthetics (Table 5.3).

5.4.5 Who TKA is for

There was no consensus about which patients should be considered for TKA and which should not, with respondents across the disciplines suggesting those with particularly good or poor rehabilitation potential were more appropriate for TKA or AKA (

Table 5.4, Table 5.5). TKA was thought by some to benefit unfit and immobile patients by offering a longer lever for transfers and sitting balance, whilst others felt it is more suited to the young, active, trauma patient due to the powerful stump.

The physiotherapists who felt that TKA was not the right option for a high functioning limb wearer argued that TKA does not allow the clearance for a microprocessor knee (MPK) "*with the ever-developing microprocessor knees I do feel that patient groups are doing better with these and therefore a through knee can hinder the options due to the length of these units*" (physio). Those who thought TKA was not suitable for patients with poor rehabilitation potential were mainly concerned about the weight of the prosthesis, as a TKA prosthesis is heavier than an AKA prosthesis an unfit patient may struggle to don, doff, and walk. On the other hand, more clinicians felt that a TKA prosthesis is easier to walk on than an AKA prosthesis and that TKA would suit "*elderly patients who have potential to manage a prosthesis but would have better outcome with a longer lever, better control of residuum*" (physio). They also reported benefits for patients who are not suitable for a prosthetic limb "*they then have a full length thigh for balancing things on their lap when in a wheelchair*" (prosthetist) and "*they can still weight bear on the stump for transfers*" (prosthetist).

Surgeons felt that the decision for TKA should be made based upon the condition of the lower limb, whereas physiotherapists and prosthetists felt the importance of the cosmetic appearance to the patients was an important deciding factor. Patient involvement in the decision of TKA or AKA was mentioned by all clinical groups. The surgeons stated they would not perform a TKA if it was not the patients preferred option. The physiotherapists and prosthetists reported that each patient should be assessed on an individual basis "*as our population can be very diverse*" (physio) and that patients should be involved "*the options should be presented and discussed so they can make an educated decision about their level of amputation*" (prosthetist).

5.4.6 The cosmetic appearance of TKA

Prosthetists and physiotherapists held strong personal opinions regarding the cosmetic appearance of TKA. Prosthetists were more likely than physiotherapists to report that they do not like the way the TKA prosthesis looks. Both physiotherapists and prosthetists agree that functional benefits outweigh appearance, "*although I might not feel like that if it were my own leg*" (physio).

Both groups reported receiving complaints from their patients about the bulky socket and asymmetrical knees "*they have commented that the socket of prosthesis is very large and don't like it's appearance*" (physio), "*patients do not like a limb that sticks out when sitting especially if they are bothered by appearance*" (prosthetist). However, a similar number of physiotherapists and prosthetists reported that their patients are not concerned about the cosmetic appearance, in fact, "*most report that the functional advantages outweigh the cosmetic disadvantag*e" (prosthetist). Finally, others felt it depends on the individual, and claimed women struggle to accept the altered cosmetic finish more than men.

5.4.7 Why TKA is uncommon

Respondents had seen relatively few TKA patients in the previous 12 months (Table 5.1).

Table 5.1 - Number of TKAs seen in practice

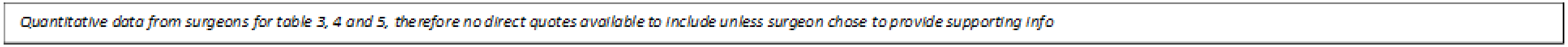
How many TKA have been…	Min.	Max.	Median.
Performed by surgeons in 12 months	0	15	1.5
Seen by physios in 12 months	0	15	3
Seen by prosthetists in 3 months	0	11	3

Surgeons felt unable to perform TKA due to unfamiliarity with the techniques, lack of training and described it as a difficult surgery to perform. Physiotherapists and some prosthetists also reported these concerns and commented that as surgeons are frequently unaware of the functional advantages and recent advances in componentry, it is therefore not surprising that TKAs are performed so rarely in some centres. More than a third of prosthetists said that TKA is uncommon due to the cosmetic appearance "*schools teach prosthetists that cosmetic outcome is as important as the functional outcome*" (prosthetist), however, no surgeon said they would not perform TKA for cosmetic reasons. Physiotherapists and prosthetists also reported challenges with the prosthesis "*some prosthetists are never comfortable fitting any disarticulation*" (prosthetist). Some surgeons confirmed the reason they do not perform TKA is because their prosthetists do not like them. However, a small group of prosthetists reported this is a historic view or just a perception of what prosthetists think about TKA.

Table 5.2 – In your opinion, what are the **advantages** of TKA?

		Qual data	**Qual data**	**Qual data**	
Code	Category	Surgeon *n (%)*	Physio *n (%)*	Prosthetist *n (%)*	Example from qualitative data
Rehabilitation	Sitting balance	8 (36)	24 (56)	3 (23)	*"Longer thigh stump length which is good for sitting stability"* (surgeon)
	Long lever	9 (41)	17 (40)	3 (23)	*"Longer limb, improved muscle power and mechanics due to length"* (physio)
	Residual limb	0 (0)	14 (33)	5 (38)	*"easier to turn over in bed and aid transfers"* (prosthetist)
	Early rehab	5 (23)	7 (16)	1 (7)	*"easier to PPAM aid"* (physio)
Prosthetics	Prosthetic function	4 (18)	18 (42)	6 (46)	*"Limbs easier to put on by the patient"* (physio)
	Suspension	0 (0)	11 (26)	11 (85)	*"Self suspending socket possible over femoral condyles and patella Belts and straps can be unnecessary"* (prosthetist)
	Socket comfort	0 (0)	7 (16)	7 (54)	*"the prosthetic socket does not have to come up as high in order to utilise the ischium for weight bearing"* (prosthetist)
Surgical	Quick and easy procedure	7 (32)	8 (19)	6 (46)	*"Less trauma, less blood loss"* (surgeon)
	Muscles left intact	2 (9)	12 (28)	6 (46)	*"reduced imbalance of hip adductors and abductors as a result of intact femur"* (physio)

		Qual data	**Qual data**	**Qual data**	
	Pain	0 (0)	1 (2)	3 (23)	*“No discomfort at the distal femoral end when wearing a limb and also no bone spurs”* (prosthetist*)*
End-weight bearing	Improves function for non-limb wearers	0 (0)	11 (26)	2 (15)	*“may balance on their stump through the wheelchair when dressing/doing washing up/reaching into a cupboard”* (physio*)*
	Improves comfort and gait for limb wearers	0 (0)	4 (9)	2 (15)	*“End bearing socket allows improved control of knee mechanism (from sensory feedback loop and mechanical advantage of longer lever)” (*prosthetist*)*
	Only is knee disarticulation	0 (0)	2 (5)	2 (15)	*“If the operation has been performed correctly (ie the patella removed and the femoral condyles left intact) the patient should be able to weight bear on the residuum”* (prosthetist*)*
	Only if Gritti-Stokes	2 (9)	1 (2)	0 (0)	*“ability to end bare if gritty stokes” (*surgeon*)*



Quantitative data from surgeons for table 3, 4 and 5, therefore no direct quotes available to include unless surgeon chose to provide supporting info

Table 5.3 – In your opinion, what are the **disadvantages** of TKA?

		Qual data	**Qual data**	**Qual data**	
Code	Category	Surgeon	Physio	Prosthetist	Example
		n (%)	*n (%)*	*n (%)*	
Surgical	Poor wound healing	14 (64)	9 (21)	0 (0)	*"increased chances of wound problems"* (surgeon)
	Poor surgical technique	2 (9)	4 (9)	1 (8)	*"a badly performed TKA is no better than a well performed TFA [AKA]"* (physio)
	Difficult surgery	6 (27)	0 (0)	1 (8)	*"technically more difficult than AKA"* (surgeon)
	Uncommon practice	5 (23)	0 (0)	0 (0)	*"rarely considered option"* (surgeon)
	Unable to end-weight bear	0 (0)	3 (7)	2 (15)	*"Not always able to end bear and if not then no advantage in it at all"* (prosthetist)
Asymmetrical knees	Uncosmetic	4 (18)	29 (67)	11 (85)	*"can be large around knee and stick out further than contralateral side when sitting"* (physio)
	Uneven knee centres	1 (5)	11 (26)	6 (46)	*"protruding knee can be difficult in cars / on stair lifts / planes / cinemas etc"* (physio)
Prosthetics	Componentry limitations	1 (5)	18 (42)	12 (92)	*"less space for componentry under socket therefore limits choice of componentry"* (prosthetist)
	Socket challenges	2 (9)	9 (21)	1 (8)	*"Bulbous residuum main issue for fitting"* (physio)

Table 5.4 – In your opinion, which patient groups **should not be considered** for TKA?

		Quant data	**Qual data**	**Qual data**	
Code	Category	Surgeon	Physio	Prosthetist	Example
		n (%)	*n* (%)	*n* (%)	
Lower limb problems	Tissue loss around knee	20 (91)	4 (9)	1 (8)	*"If not enough healthy skin around knee"* (physio)
	Poor circulation	14 (64)	8 (19)	1 (8)	*"Inadequate circulation to heal"* (physio)
	Previous joint problems	18 (82)	4 (9)	0	*"Those with metalwork e.g. TKR"* (physio)
Patient opinion	Importance of cosmetic finish	---	14 (33)	10 (77)	*"Those where cosmetic finish is of high importance and has not been discussed pre surgery"* (prosthetist)
Rehab potential	Good rehab potential	2 (9)	9 (21)	1 (8)	*"Young patients who are likely to be fitted with a dynamic prosthetic knee in the future that requires sufficient space"* (physio)
	Poor rehab potential	4 (18)	1 (2)	2 (15)	*"Those who may struggle with the strength required for donning and doffing"* (prosthetist)
None	No specific factors	0	5 (12)	1 (8)	*"Could be considered for all"* (physio)

Table 5.5 – From your experience, which patients **benefit** from TKA?

		Quant data	**Qual data**	**Qual data**	
Code	Category	Surgeon	Physio	Prosthetist	Example
		n (%)	*n* (%)	*n* (%)	
Poor rehab potential	Non-limb wearers	11 (50)	18 (42)	8 (62)	*"If prosthetic use us not possible or very unlikely then a through knee will give a longer sitting support and more stability in both sitting and transfers"* (prosthetist)
	Unfit	11 (50)	13 (30)	2 (15)	*"More elderly patients, that may not manage a limb with a trans femoral but have potential if have a longer better functioning as a through knee"* (physio)
	Bilateral	18 (82)	4 (9)	1 (8)	*"Pt who is an existing amputee and requires further amputation, having TKA rather than AKA helps sitting balance"* (physio)
Good rehab potential	Young	14 (64)	5 (12)	0	*"Young active pt who not so concerned re cosmesis, would benefit from more powerful stump"* (physio)
	Paediatrics	---	8 (19)	8 (62)	*"Brilliant in children where growth plates are retained and often results in a slightly shorter limb but still with all the advantages of a through knee amputation"* (prosthetist)
	Traumatic amputation	10 (45)	2 (5)	1 (8)	*"Young traumatic male amputees"* (prosthetist)
	High activity	---	5 (12)	0	*"fitter patients who are more likely to be functioning at a higher level and evening running"* (physio)
All	All patients	2 (9)	5 (12)	3 (23)	*"All- where BKA inappropriate"* (surgeon)

Table 5.6 – Why do you think TKA is **uncommon**?

		Quant data	**Qual data**	**Qual data**	
Code	Category	Surgeon	Physio	Prosthetist	Example
		n (%)	*n (%)*	*n (%)*	
Surgical expertise	Unfamiliarity with technique	20 (91)	11 (26)	3 (23)	*"not common practise so surgeons stick to what they know"* (prosthetist)
	Lack of training	16 (73)	3 (7)	1 (8)	*"Dependant of surgeons training, Older vascular surgeons seem more likely to have the training, perhaps it fallen out of favour"* (physio)
	Difficult to perform	5 (23)	5 (12)	1 (8)	*"Possibly more time consuming. Surgical methods such as, trimming the condyles or decision to leave or remove the patellar can be daunting. Easier to perform a trans-femoral amputation"* (prosthetist)
	Surgeon preference	---	5 (12)	1 (8)	*"primarily down to surgical preference" (physio)*
	Surgeons not aware of functional gains	---	5 (12)	1 (8)	*"I think our vascular surgeons are … not really aware / care about the physical plus psychological benefits of this type of surgery"* (physio)
Prosthetics	Issues with prosthetics	10 (45)	4 (9)	4 (31)	*"limited choice of prosthetic components"* (prosthetist)
	Prosthetist experience	1 (5)	6 (14)	3 (23)	*"There is a perception that prosthetists don't like it"* (physio)
No clear guidance	Lack of evidence	12 (55)	3 (7)	0 (0)	*"Variety of techniques make assessment of evidence difficult"* (surgeon)

		Quant data	Qual data	Qual data	
Poor patient outcomes	Poor cosmetic outcomes	---	7 (16)	5 (38)	*"I was always told a TKD [TKA] is too unsightly and awkward therefore not done"* (physio)
	Poor surgical outcomes	6 (27)	2 (5)	0 (0)	*"Surgeons may prefer to do an AK on an older person for assured wound healing"* (physio)
	Poor functional outcomes	4 (18)	1 (2)	0 (0)	*"Besides length, I don't see much of an advantage over AKA"* (surgeon)

5.5 Discussion

Overall, clinician's opinion of TKA is divided. Some clinicians observe poor outcomes in terms of wound healing and patient satisfaction with their prosthesis, and recommend TKA only for bedbound patients, whereas others feel TKA is an excellent, underused procedure with many functional benefits.

There are clear differences in priorities between the vascular surgeons and the outpatient prosthetists with overlap from the physiotherapists who cover both areas. This is understandable as each group is responsible for a different element of the patient's care. However, the lack of understanding of each other's priorities is evidence of poor communication along the amputation pathway and a compartmentalised approach to surgery and rehabilitation. Even when strict patient pathways are implemented strong compartmentalisation of responsibilities between care teams has restricted the development of integrated working. This fragmented care has been claimed to put patients at risk of poor outcomes (Curry, 2010). This also may be due, in part, to the fact that prosthetic services are rarely on the same site as the surgical ward. Eighty percent of UK vascular centres prosthetic services are off site, the distance away from the surgical ward is an average of 21 miles (Gough et al., 2014) .

Similarly, there was divided opinion regarding the choice of TKA technique; surgeons prefer the enhanced wound healing that Gritti-Stokes offers while physiotherapists and prosthetists prefer the prosthetic advantages that KDA provides. Both groups felt their preferred variation offered the best chance of end-weight bearing. As end-weight bearing was identified as one of the most important reasons for performing a TKA it stands to reason that the chance of successful end-weight bearing depending on surgery technique should be better understood. Rehabilitation clinicians disagreeing with surgeons on this point is a cause for concern and means potentially patients are at risk of poor outcomes. While Gritti-Stokes has been shown to have statistically superior wound healing over KDA ($p = 0.04$) by Campbell and Morris (1987), this paper has been criticized by physiotherapists stating that wound healing should not be the only factor on which to base a decision that has a lifelong impact on the patient (Buttenshaw & Riglin, 1987). Furthermore, the trial by Campbell and Morris (1987) included only 22 participants suggesting there may have been confounding factors that affect wound healing. The group also had previous experience performing Gritti-Stokes but not KDA, which might be another reason healing rates were better in the Gritti-Stokes group.

Participants across the professional groups made the case for TKA for patients with good rehabilitation potential and poor rehabilitation potential. Benefits of TKA for both patient groups are supported in the literature (Siev-Ner, 2000; Morse et al., 2008). Proportion of patients achieving prosthetic mobility after TKA was examined by Morse et al. (2008) by reviewing 50 cases of TKA at one centre over an eight-year period. Morse concluded that TKA is a good option for people who are expected to mobilise with a prosthesis with 81% of patients achieving successful wound healing and 56% of patients still mobilising at three years. However, no comparisons were made to other levels of amputation in this study. In contrast, Siev-Ner (2000) recommends TKA for people who are predicted not to limb wear, due to the biomechanical advantages over AKA, however, this conclusion does not seem to be drawn from the findings of the study. Siev-Ner (2000) reviewed medical notes at one centre and identified 49 TKAs over a ten-year period. He identified that only 14 people mobilise after a TKA from the data, and all recommendations of the benefits of TKA for non-ambulatory patients are drawn from theory from pre-existing literature.

Clinicians satisfaction with TKA has been previously studied by MacKenzie et al. (2004). MacKenzie et al. (2004) explored clinicians' satisfaction of clinical, cosmetic and functional outcomes of TKA compared to AKA and BKA in the trauma population. They found that clinicians were less satisfied with TKA than the other levels, which is different to the results of the current study. This might be because the trauma population are very different to the vascular population. Mackenzie reported that 96% of people with AKA were mobilising with a prosthesis two years post operatively; this figure is significantly higher than the vascular and diabetic population, where up to 39% of people with AKA abandon their prosthesis (Hagberg, 1992; Davies & Datta, 2003; Morse et al., 2008).

Recently, Parry and Neufeld (2022) conducted a short survey to prosthetists working in the USA investigating their preferences between TKA and AKA and why, and opinions of their patients preference between TKA and AKA and why. They received response from 102 prosthetists and found no preference between TKA or AKA, and equal opinion on which amputation is favoured by their patients. The current survey had fewer responses but asked more probing questions to generate theory as to why some clinicians prefer one over the other.

The perceived poor healing rates reported by the clinicians in the survey could be explained by the unclear understanding of patient selection for TKA and the lack of training in surgical technique. Murakami and Murray (2016) highlighted a lack of physiological methods for determining amputation level in current TKA studies leading to high reamputation rates; they hypothesized that many patients may have been unsuitable for TKA in the first place. They also found that lack of surgeon experience contributes to high reamputation rates. Only clinicians working in the acute setting reported wound healing problems. No prosthetists complained about a TKA wound, in fact some prosthetists and outpatient physiotherapists reported better wound healing for TKA than AKA. This might mean that while TKA can have poor initial healing rates, and possibly undergo multiple surgeries, which outpatient physiotherapists and prosthetists would not be exposed to, in the long run there are minimal problems.

5.6 Strengths and Limitations

Response rates were low as expected. Surveying clinicians is important but problematic as they are known for low response rates (Cho et al., 2013) and the population of UK vascular and amputee clinicians is small. More than half the responses were from physiotherapists, so they are over-represented in this study. Strengths are that responses came from across the UK, so all regions were represented. The responses from physiotherapists and prosthetists are consistent making the drawing of conclusions straightforward. There was a greater spread in the surgical responses with limited concordance, however opinions both for and against TKA were sufficiently articulated in the responses given, resulting in a balanced reflection of clinician’s views.

Little is known about the views of clinicians regarding levels of proximal lower limb amputation, so this fills an important knowledge gap. So far, research regarding the clinicians view of TKA versus AKA has previously been limited to traumatic amputations. This study specifically targeted vascular surgeons to understand how decisions of level of amputation are considered in the vascular population, the largest population of patients undergoing amputation. As already discussed, vascular patients are more likely to encounter wound healing problems than traumatic amputation patients, and therefore considerations of level need to be considered separately to the trauma population. Also, by allowing open-ended questions, important questions about the use of TKA around the UK were raised that may not have previously been considered.

5.7 Conclusion

TKA is an uncommon choice of amputation level with diverse opinions held by clinicians regarding its place. Surgeons recognise how the longer TKA residuum assists early-stage rehab but were relatively unaware of the prosthetic implications of TKA. They were more concerned about the rates of primary wound healing; overall rates were considered inferior to AKA, which some linked to the perception of TKA as a more challenging surgical procedure than AKA. They were aware of some of the advantages that a long residuum can offer at early-stage rehabilitation, but very few surgeons mentioned the prosthetic implications of TKA. In comparison, physiotherapists and prosthetists made multiple comments about the surgical implications of TKA and provided multiple suggestions as to why the surgical technique means TKA is uncommon.

Physiotherapists and prosthetists’ main concern is the poor cosmetic appearance of TKA, but many reported that this is not a concern shared by their patients who prioritise the functional advantages.

There is no consensus regarding whether TKA is more suitable for someone with good or poor rehab potential with good arguments to support TKA for both. There is a lack of agreement between clinical teams and lack of awareness of each group’s clinical priorities.

This study raises important questions concerning TKA including what are the functional and surgical outcome differences between Gritti-Stokes and KDA? Which patients should have a TKA and how this is determined? It is also clear that all clinicians lacked understanding of the TKA patient journey as a whole.

Chapter 6 Clinicians Perceptions of TKA Compared to AKA: A Qualitative Interview Study

6.1 Introduction

This chapter includes the methods, results and discussion of study 3: a qualitative cross-sectional interview study involving clinicians. Six physiotherapists, five prosthetist, and ten vascular surgeons were interviewed resulting in themes as presented in Figure 6.5. The analysis is supported by direct quotes (in italics) and profession of speaker provided as context using subject IDs (e.g., PHYS001).

6.2 Aims

The qualitative study involved clinicians working directly with those with limb loss. The aim of this study was to compare and contrast experiences and perceptions of TKA and AKA from the point of view of specialist clinicians.

The objectives of the clinician study were:

1) To explore experiences and perceptions of specialist clinicians working with patients pre- and post-amputation regarding TKA

2) To explore the advantages and disadvantages of TKA compared to AKA as reported by specialist clinicians

3) Compare and contrast the data gathered between the different groups of health professionals

6.3 Methods

This was a cross-sectional comparative qualitative interview study of clinicians who work with patients pre- and post- amputation. Table 6.1 outlines the criteria of included participants and the rationale behind these criteria. Participants were recruited from Hull University Teaching Hospitals NHS Trust (HUTH) initially and recruitment was later expanded (see 6.3.3). Participants were not excluded for having a previous relationship with the researcher. Data collection and analysis was completed simultaneously (Braun and Clarke, 2013).

Table 6.1 – rationale for inclusion and exclusion criteria

Inclusion Criteria	**Rationale**
Surgeons, prosthetists, specialist physiotherapists	These clinical roles have been identified as key clinical decision makers along the amputation pathway (Gough et al., 2014) .
More than three years clinical experience working in vascular surgery and/or amputee rehabilitation*	Specialists in their field were sought therefore clinicians needed sufficient time working in this area to have enough first-hand experience to draw on to be able to answer the research questions
Exclusion Criteria	Rationale
Language barriers	Non-English-speaking individuals were not recruited due to financial reasons related to translation. Additionally, it was considered unlikely to find many non-English speaking potential participants in the recruiting areas. All clinicians were assumed to speak English to a good enough standard to participate as they all work as qualified health clinicians in the UK.
No first-hand experience with TKA	The aim was to explore first-hand experiences, therefore clinical experience with this patient group was essential.

*This inclusion criterion was added after recruitment was opened to other trusts.

6.3.1 Sample size

Previous qualitative studies exploring clinician's perspectives of post-amputation prosthetic rehabilitation stated that they reached data saturation between six and 11 interviews with rehabilitation doctors, physiotherapists and prosthetists (Van der Linde, 2004; Schaffalitzky, 2011; Sansam et al., 2014). The additional view of surgeons is essential to this study therefore target sample range was set as 15 to 20 participants in order to gain insight from all key clinical roles along the entire amputation pathway (Gough et al., 2014). Clinicians with diverse opinions of TKA were targeted to achieve a balanced view.

6.3.2 Sampling approach

Stratified sampling was used to ensure a similar number of prosthetists, physiotherapists, and surgeons, with flexibility to recruit more participants of any group if they held more diverse views (Braun and Clarke, 2013). Clinical experience indicates that clinicians often have strong feelings for or against the use of TKA, therefore cases with extreme views were targeted to explore both opinions (Palinkas et al., 2015).

6.3.3 Recruitment

Clinician participants were recruited from HUTH, but more diverse views were needed to fully explore all topics. Therefore, ethical approval was gained from the HYMS ethics committee on 17th December 2020 (Appendix 5) to recruit via professional networks and appropriate closed social media groups. A snowballing tactic (Hesse-Biber & Leavy, 2006) was also used to reach the recruitment target. Snowballing was considered an appropriate method as the number of clinicians in the UK who work with people with TKA is small, therefore they are a difficult group to identify. It was expected that clinicians would be aware of other suitable participants through their colleagues, for example, a prosthetist would be able to recommend a surgeon who performs a lot of the TKAs, or a surgeon be aware of a colleague who dislikes TKA (King, 2019). There was no financial reward given to clinician participants on completion of the study; participants were informed during consent that there was no reward or personal benefits for their participation. Recruitment was stopped when the quality of the data was considered adequate to answer the research question (Braun & Clarke, 2019).

6.3.4 The interview procedure

The first clinician interviews were conducted face to face with clinicians at HUTH. After the decision to expand recruitment to other centres, COVID-19 restrictions were in place, so all subsequent interviews were conducted over telephone or video call. Participants were allowed to choose which method they preferred. Participant information sheet (PIS) and consent form were emailed to participants and electronic signatures were accepted. All interviews were audio recorded.

6.3.5 Topic guide

Topic guides were used to structure the interviews (appendix 4). The clinician topic guide was created using the results from the clinician survey (section 5.4). The topic guide was piloted prior to use with fellow researchers and a rehabilitation consultant. No changes were made to the questions in the topic guide, but the layout of the questions was improved, and prompts were shortened to make it easier for the interviewer to use. The topic guides were flexible to allow exploration of issues raised by the participants. The researcher probed pertinent issues with participants and, when relevant, explored issues raised by previous interviews. There were different versions of the clinician topic guide for each clinical group.

6.3.6 Interview

All interviews were completed by the researcher. They were audio recorded with participants consent. Interviews were planned to last 30 minutes to allow for the participants busy schedules. Some participants had less than 30 minutes, so questions were prioritised in order of importance, whereas others allowed for more than 30 minutes and were allowed to continue until the participant felt they had said everything they wanted to say. Clinicians are used to answering questions directly and concisely and therefore all questions were normally answered easily within the allocated time.

6.3.7 Field notes/diary

Immediately after each interview the researcher wrote a reflection on how the interview went and any initial thoughts about the interviewee’s perspectives. This interview diary was also used to record any changes made to the interview procedure. Regular reflections were also written by the researcher about their thoughts and approaches to the research (Braun and Clarke, 2013). The diary was used to help with the reflexive process, in supervision to discuss challenges, in analysis to resituate the researcher in the interviews, and to improve the quality of interviews.

6.3.8 Transcription

All interviews were transcribed verbatim. Thirteen interviews were transcribed by the researcher to increase familiarisation with the data (King, 2019). The remaining eight were transcribed by an administrate member of the HUTH academic vascular surgery unit research team. Transcripts were checked by the researcher for accuracy by comparing the transcripts with the audio recordings, which again increased familiarisation with the data. Any names used in the interviews were replaced with pseudonyms, while any place names were replaced with generic terms for example “the limb centre” or “the hospital” to anonymise the transcripts before analysis. Only pauses or nonverbal communication, such as gesturing about a residual or prosthetic limb, which would aid the interpretation of the text were included in the transcript.

6.3.9 Security

Collected data was anonymised by giving participants a study code, and all data was stored securely at the Hull Royal Infirmary site. Electronic data was stored on a password protected computer that was part of the trust network. Hard copies were stored in a locked office in the Vascular Lab. Only members of the research team had access to the data. Data was stored in accordance with HUTH policies.

6.3.10 Ethics

Ethical approval was granted by the HYMS ethics committee on 17th December 2020 (appendix 5).

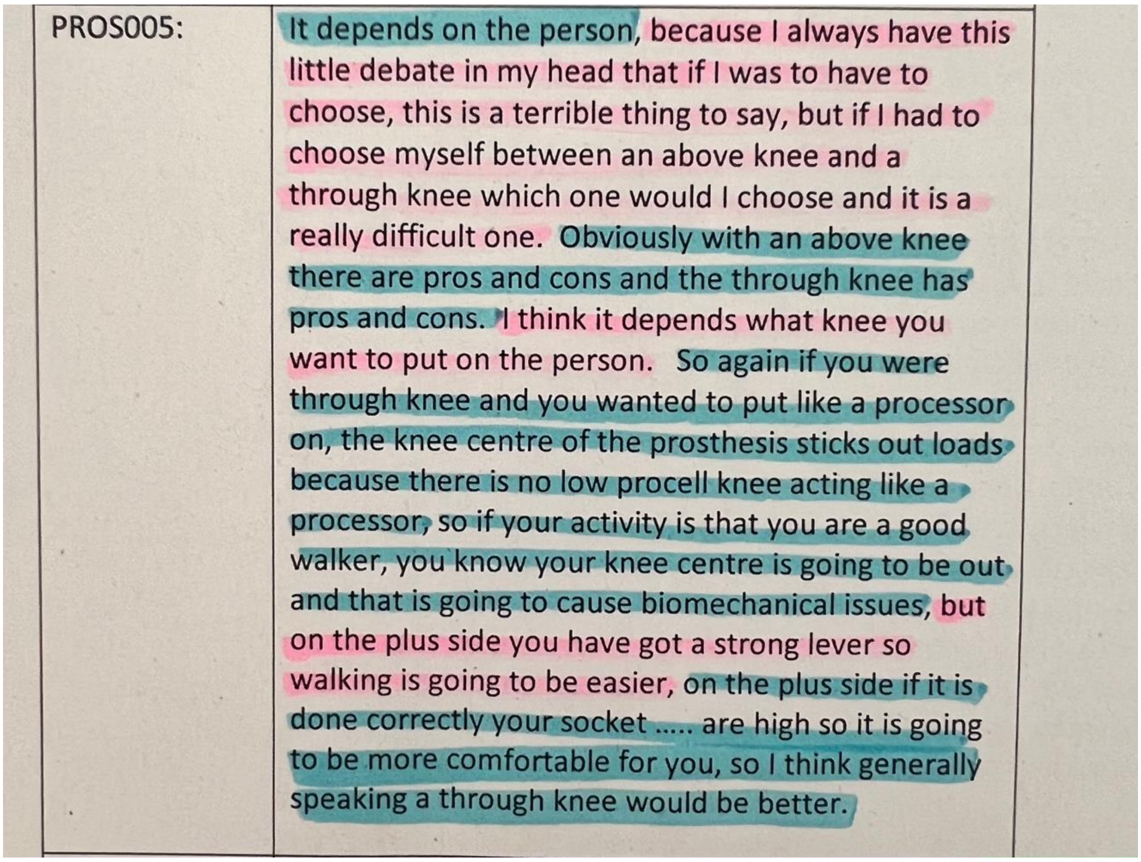
6.4 Analysis

Data analysis started during the data collection phase using a staged data collection process, whereby two or three interviews were completed, and the first stages of analysis started, so that subsequent data collection could be refined based on the early findings (Braun and Clarke, 2013).

The reflexive TA analytic process consists of the following steps: familiarisation, generating initial codes, theme development, reviewing and defining themes, and writing the analysis (Braun and Clarke 2006). Each stage is described in detail to demonstrate how the researcher interpreted TA.

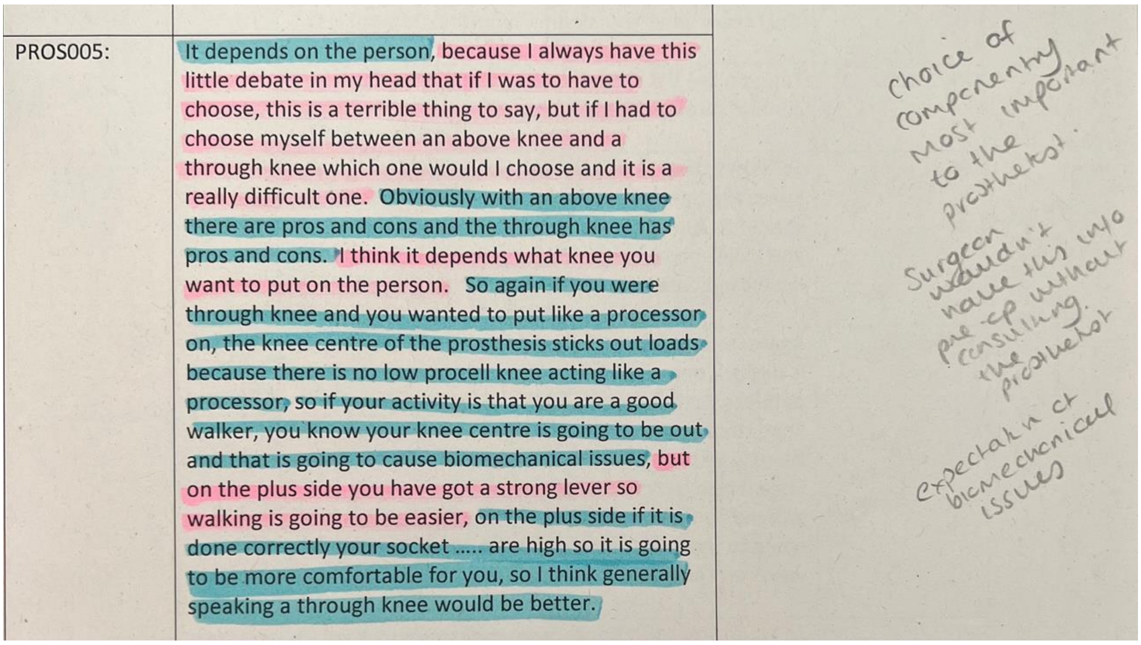
Familiarisation

Transcripts were read through by the researcher to become intimately familiar with the data (Braun and Clarke 2013). Then, they were read through again and all data that was or might be relevant to the research question highlighted. Different colours were used to separate different items. Initial thoughts were noted in the margins of the transcript. Clinician analysis was to be compared to patient analysis so additional notes were made in the margins for potential findings that went across both studies.



PROS005:	It depends on the person, because I always have this little debate in my head that if I was to have to choose, this is a terrible thing to say, but if I had to choose myself between an above knee and a through knee which one would I choose and it is a really difficult one. Obviously with an above knee there are pros and cons and the through knee has pros and cons. I think it depends what knee you want to put on the person. So again if you were through knee and you wanted to put like a processor on, the knee centre of the prosthesis sticks out loads because there is no low procell knee acting like a processor, so if your activity is that you are a good walker, you know your knee centre is going to be out and that is going to cause biomechanical issues, but on the plus side you have got a strong lever so walking is going to be easier, on the plus side if it is done correctly your socket ….. are high so it is going to be more comfortable for you, so I think generally speaking a through knee would be better.

Figure 6.1 – familiarisation stage



PROS005:	It depends on the person, because I always have this little debate in my head that if I was to have to choose, this is a terrible thing to say, but if I had to choose myself between an above knee and a through knee which one would I choose and it is a really difficult one. Obviously with an above knee there are pros and cons and the through knee has pros and cons. I think it depends what knee you want to put on the person. So again if you were through knee and you wanted to put like a processor on, the knee centre of the prosthesis sticks out loads because there is no low procell knee acting like a processor, so if your activity is that you are a good walker, you know your knee centre is going to be out and that is going to cause biomechanical issues, but on the plus side you have got a strong lever so walking is going to be easier, on the plus side if it is done correctly your socket ….. are high so it is going to be more comfortable for you, so I think generally speaking a through knee would be better.

Choice of componentry most important to the prosthetist.

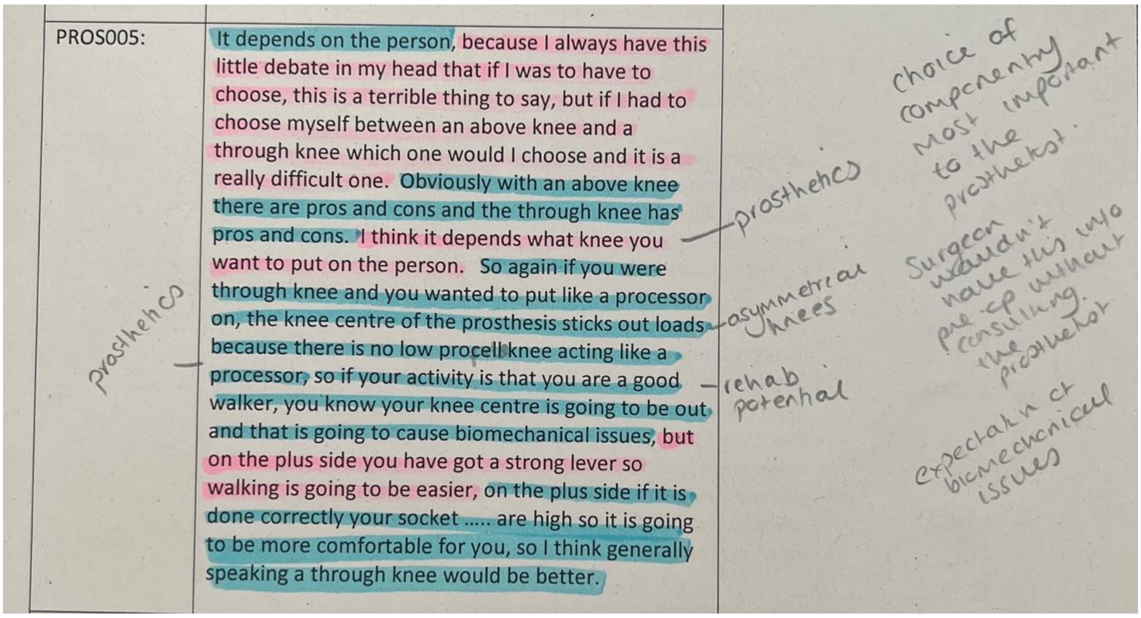
Surgeon wouldn't have this info pre-op without consulting the prosthetist

expectation of biomechanical issues

Figure 6.2 – notes of initial thoughts

Generating Initial Codes

Existing concepts from the survey results (5.4) acted as a starting point to help make sense of the interview data in a prior-research-driven approach (Boyatzis, 1998), and to allow the interview data to further explore the conceptual ideas from the survey using deductive coding (Braun and Clarke, 2022). The remaining data was then inductively coded, whereby the data itself was driving the analysis and new codes were formed based on the contents of the dataset (Braun and Clarke, 2022). NVivo software was used for coding the transcripts.



PROS005:

It depends on the person, because I always have this little debate in my head that if I was to have to choose, this is a terrible thing to say, but if I had to choose myself between an above knee and a through knee which one would I choose and it is a really difficult one. Obviously with an above knee there are pros and cons and the through knee has pros and cons. I think it depends what knee you want to put on the person. So again if you were through knee and you wanted to put like a processor on, the knee centre of the prosthesis sticks out loads because there is no low procell knee acting like a processor, so if your activity is that you are a good walker, you know your knee centre is going to be out and that is going to cause biomechanical issues, but on the plus side you have got a strong lever so walking is going to be easier, on the plus side if it is done correctly your socket ….. are high so it is going to be more comfortable for you, so I think generally speaking a through knee would be better.

prosthetics

prosthetics

asymmetrical knees

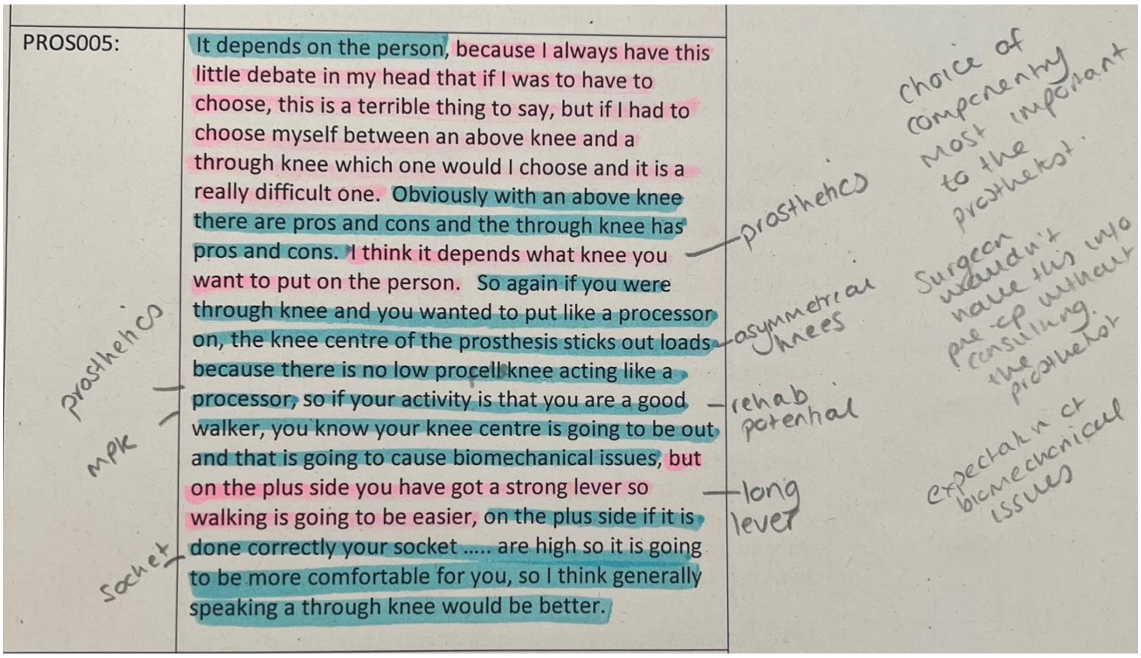
rehab potential

Choice of components most important to the prosthetist.

Surgeon wouldn't have this info pre-op without consulting the prosthetist

expectation of biomechanical issues

Figure 6.3- coding using deductive codes



PROS005:

It depends on the person, because I always have this little debate in my head that if I was to have to choose, this is a terrible thing to say, but if I had to choose myself between an above knee and a through knee which one would I choose and it is a really difficult one. Obviously with an above knee there are pros and cons and the through knee has pros and cons. I think it depends what knee you want to put on the person. So again if you were through knee and you wanted to put like a processor on, the knee centre of the prosthesis sticks out loads because there is no low procell knee acting like a processor, so if your activity is that you are a good walker, you know your knee centre is going to be out and that is going to cause biomechanical issues, but on the plus side you have got a strong lever so walking is going to be easier, on the plus side if it is done correctly your socket ….. are high so it is going to be more comfortable for you, so I think generally speaking a through knee would be better.

prosthetics

MPK

socket

prosthetics

asymmetrical knees

rehab potential

long lever

Choice of components most important to the prosthetist.

Surgeon wouldn't have this info pre-op without consulting the prosthetist

expectation of biomechanical issues

Figure 6.4 – development of inductive codes

Theme Development

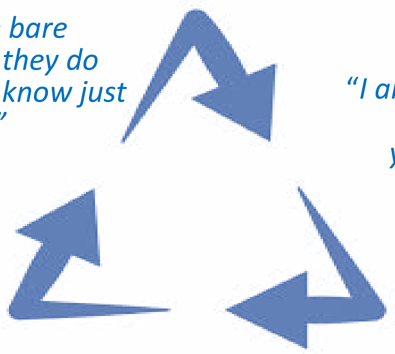
Codes were reviewed and grouped together and then themes developed using mind mapping and discussions with a supervisor (MT). Then comparisons were made between groups (physiotherapist, surgeon, prosthetist) to look for any similarities or differences in experiences and perceptions. Each sub-theme was summarised with quotes in a table and similarities and differences observed between the two groups were noted and summarised.

Reviewing and Defining Themes

Revisions were made to candidate themes by reviewing the data. All the codes were reviewed, and revisions made to ensure the codes worked within the themes. Then a full dataset review was completed with a mindset of ensuring the final themes answered the original research question represented the corpus of the data (Braun and Clarke, 2013). For example, professional priorities in the early stages of the theme development was called “the marmite amputation” because the clinicians were discussing the reasons why they did or did not like amputation and which factors were important to decision making. This then developed after some comparison between groups where it became apparent that each clinician group had their own distinct set of factors that influence their opinion and decision making regarding TKA or AKA. Themes, codes, and quotes are presented in Table 6.3.

6.5 Results

“*No, we never really speak to the surgeons*” (prosthetist)



“So, we haven’t got down to the bare bones of being picky about how they do their through-knees yet but you know just that they’re doing them is good” (physiotherapist)

“I am sure I would hear otherwise if it was bad, the physio would tell me if it was bad, you would be left in no doubt” (surgeon)

“We don’t know, when we go to other conferences it’s not something that’s brought up a lot” (physiotherapist)

“(knee disarticulations) do have slight benefits for wheelchair patients because it does give a little bit more stability in the wheelchair but not enough to warrant wound healing problems I think.” (surgeon)

“their surgery does not necessarily reflect what would be best for their rehabilitation but what would be nicest surgically” (prosthetist)

Figure 6.5 – relationship between themes

6.6 Participants

Twenty-seven clinicians expressed an interest in participating in the study and 21 met the inclusion criteria, agreed to take part and completed an interview. The other six did not complete an interview for the following reasons: one could not find the time to complete the interview, two did not meet the inclusion criteria as one was a specialist vascular nurse and the other a rehabilitation consultant, three volunteered but saturation had already been met from their clinical group or vascular centre.

Key participant details are summarised in Table 6.2. As all surgeons interviewed were consultant vascular surgeons, they therefore had a minimum of 6 years working in vascular surgery. The physiotherapists were all senior specialists in vascular inpatients or prosthetic outpatients. The prosthetists ranged from junior prosthetists with 18 months experience at time of interviewing, to others with decades of experience. One prosthetist also had a TKA from childhood.

Subject ID	Profession	Region	Practice
PHYS001	Physiotherapist	Yorkshire	Sees small numbers of all types of TKA
PHYS002	Physiotherapist	Yorkshire	See small numbers of all types of TKA
PHYS003	Physiotherapist	South East	Sees small numbers of all types of TKA
PHYS004	Physiotherapist	Yorkshire	Sees moderate numbers of all types of TKA
PHYS005	Physiotherapist	South East	Sees large numbers knee disarticulation only
PHYS006	Physiotherapist	West Midlands	Sees large numbers Gritti-Stokes only
PROS001	Prosthetist	Yorkshire	Sees small numbers of all types of TKA
PROS002	Prosthetist	Yorkshire	Saw large numbers in previous trust but small numbers currently
PROS003	Prosthetist	South East	Sees moderate numbers knee disarticulation only
PROS004	Prosthetist	South East	Sees small number knee disarticulation only
PROS005	Prosthetist	West Midlands	Sees moderate numbers Gritti-Stokes only
SURG001	Vascular Surgeon	Yorkshire	Performs 3-6 Gritti-Stokes per year
SURG002	Vascular Surgeon	Yorkshire	Performed approximately 300 Gritti-Stokes in career
SURG003	Vascular Surgeon	Yorkshire	Performs Gritti-Stokes once in every three proximal amputations
SURG004	Vascular Surgeon	Scotland	Does not do any TKA
SURG005	Vascular Surgeon	West Midlands	Performs large numbers of Gritti-Stokes only
SURG006	Vascular Surgeon	Wales	Performs small numbers of knee disarticulation
SURG007	Vascular Surgeon	London	Always does knee disarticulation instead of AKA

Subject ID	Profession	Region	Practice
Subject ID	Profession	Region	Practice
SURG008	Vascular Surgeon	South East	Does not do any TKA
SURG009	Vascular Surgeon	South East	Performs large numbers of knee disarticulation
SURG010	Vascular Surgeon	North East	Does not do any TKA but would like to

Table 6.2- participant demographics

6.7 Codes

As described above (section 6.4) a deductive analysis approach was used first using the categories identified from the clinician survey. Then inductive coding was applied to the transcripts, and the deductive and inductive codes used together to develop themes one and three. The second theme, communication and power differential, was derived solely from inductively developed codes. The deductive codes, inductive codes, themes and example quotes are presented in Table 6.3.

Table 6.3 – codes and example quotes of themes

<table>
<tr><td>**Theme**</td><td>**Deductive codes**</td><td>**Inductively developed codes**</td></tr>
<tr><td>**Professional priorities**</td><td>Asymmetrical knees
Cosmetic appearance
End-weight bearing
Patient outcomes
Prosthetics
Rehabilitation potential
Rehabilitation
Surgical</td><td>Aetiology
Healing and revisions
Long lever
Prosthetics sub nodes: components, socket, suspension, MPK
Residuum</td></tr>
<tr><td colspan="3">**Example quotes**
“*the cosmetic thing, for surgeons isn’t really important. Would healing and poster-operative stuff is their kind of key goals*” (PROS001)
“*it [through knee] does give a little bit more stability in the wheelchair but not enough to warrant wound healing problems*” (SURG008)
“*I like working with the through knee patients because I think pain is less of an issue… so I guess we can just do a little bit more with them perhaps in the early days*” (PHYS005)</td></tr>
<tr><td>**Theme**</td><td>**Deductive codes**</td><td>**Inductively developed codes**</td></tr>
<tr><td>**Communication and power differential**</td><td></td><td>MDT involvement
MDT opinion
Outdated information</td></tr>
<tr><td colspan="3">**Example quotes**
*“Generally, we don’t have any discussions with the surgeons, the rehab consultant has a bit more contact with them than we do but were never personally consulted on our opinions or anything” (*PROS001*)*
“…no reason why the physiotherapist should not be involved in the level of the amputation. The culture needs to change” (SURG001)
“*are you happy for me to say this, or have you already decided you’re going above or through? As obviously we don’t want to upset the patient, I don’t want to step on anyone’s toes*” (PHYS002)</td></tr>
<tr><td>**Theme**</td><td>**Deductive codes**</td><td>**Inductively developed codes**</td></tr>
<tr><td>**Unchallenged practice**</td><td>All or none
No clear guidance
Surgical expertise
Patient opinions</td><td>Gritti-Stokes
Knee Disarticulation
Surgeon preference
Guidance/training
Patient involvement</td></tr>
<tr><td colspan="3">**Example quotes**
*“…it is what it is, we just have to go with it” (*PROS002*)*
*“I think that reflects the position that amputation as a subject sort of figures in our world, we regard it as the end of the line, a failure” (*SURG002*)*
“we very rarely get any vascular disartic, so I would question, it might be something I need to do really, but question maybe why, is it actually considered in the process or not” (PHYS004)</td></tr>
</table>

6.8 Themes

The three themes, while distinct, are connected with linking concepts, as demonstrated in Figure 6.5.

6.8.1 Theme I: Professional Priorities

This theme focuses on the priorities of the different professional groups; some priorities are shared, and others are exclusive to a professional group. Priorities were grounded in the belief that they provided the best outcome for the patient. This theme explores how the clinician’s job role influences their priorities and to what extent they are aware of the priorities of the other professions, and how this awareness influences their own practice.

The surgeons’ priorities included primary wound healing, performing an atraumatic surgery, creating a residuum whereby the sharp end of the transected femur is unable to damage the frail soft tissue, and functional ability gained from a longer residuum to aid in early post-operative recovery i.e., sitting balance and bed mobility. Many of these priorities influenced the surgeons to perform a TKA. However, primary wound healing was an important consideration for surgeons and the dominant narrative was that TKA is associated with poor healing which biased some surgeons against TKA. A small number of non-healing wounds was enough to convince surgeons that TKA should be discontinued from their practice. Primary wound healing was a priority that outweighed any other advantage the surgeons were aware of for TKA.

“*it does give a little bit more stability in the wheelchair but not enough to warrant wound healing problems*” (SURG008)

“*it’s a rubbish amputation. Because the reason is because of the skin incision, that is the problem. It leaves you with a posterior scar with just skin and the wound healing is dreadful*” (SURG004).

Very few surgeons mentioned considerations of prosthetic limbs for TKA. When asked about prostheses for TKA the surgeons were either not aware of the differences between TKA and AKA, thought prostheses for TKA does not exist, or choose not to consider prosthetic implications.

"*you need to ask your prosthetist; do you speak to any? You ask them if they have any prosthesis on the shelf for a Gritti and they will say no*" (SURG004)

"*they [patients] are more likely to achieve ambulation from an above-knee prosthesis rather than a Gritti prosthesis, which I don't think we even keep*" (SURG004)

"the problem with some of the psychology of surgeons is around, you are focused on people ambulating, whereas actually when you look at the numbers, the reality is we treat a lot of people who will be wheelchair users and we are not very focused on that" (SURG005)

The prosthetists and physiotherapists were aware of the surgeon's lack of understanding around prostheses for TKA, and while recognising the different professional perspectives, were dissatisfied that surgeons did not consider long term prosthetic outcomes for patients.

"once that amputation's done and the patient's kind of off the ward and been signed off fine they don't deal with the consequences afterwards so its whether they're aware of how their decision impacts the patient ultimately. I guess their goal is to do a nice amputation that heals well, it's not, the rest of the patient's life isn't their, like that's not what they've striving to achieve the best at" (PROS001).

The prosthetists, despite lack of exposure to and communication with the surgeons, demonstrated further unreciprocated insight into the professional priorities of the surgeons, demonstrating a one-sided awareness.

"*the cosmetic thing, for surgeons isn't really important. Would healing and poster-operative stuff is their kind of key goals*" (PROS001).

Unsurprisingly, the prosthetists had several priorities relating to the prosthesis, such as creating a comfortable prosthetic socket, prosthetic weight bearing through the end of the residual limb, and prosthetic self-suspension using the condyles, all of which are made possible by TKA. The prosthetists described how finding the right component to get knees as level as possible for a TKA prosthesis can be a challenge, and this was considered fundamental to achieving an acceptable gait pattern and satisfactory cosmetic finish. Prosthetists felt that a good-looking prosthesis is viewed as an important priority by their patients, that could improve patient satisfaction and use of the prosthesis

"*people want to have optimal cosmesis and that is one of the big drawbacks of a through-knee*" (PROS002).

The physiotherapists shared several priorities with the prosthetists including end-weight bearing and self-suspension. They also shared priorities with the surgeons including the atraumatic surgery and better early rehabilitation. In contrast to the prosthetists, for whom cosmetic finish was always priority, the physiotherapists approached this as a factor that should be considered on a person-by-person basis, considering the likelihood that the person would walk again. This means the poorer cosmetic finish needs to be balanced against the functional advantages offered by TKA. In contrast, the surgeons felt cosmetic factors should not be considered at all, though the cosmetic drawbacks of a long residual limb were acknowledged by two surgeons, though they felt this was not an important factor to be considered in decision making and does not influence their practice

"*if that gentleman had been an above-knee limb wearer, yes, we would have done a better job of the cosmesis, I'm sure, but I don't think he would have walked as an above-knee limb wearer so, you know. What's more important*?" (PHYS006)

"*I think the ugly thing was overplayed, and I think probably it come from a dissatisfaction with their healing or something*" (SURG009).

Additional priorities from the physiotherapists included time to complete rehabilitation, the energy required to move and walk, and gait pattern, all of which were considered superior with TKA. When it came to post amputation rehabilitation some said they offer the same rehabilitation programme to people with TKA as they would with someone with an AKA, and some said they also include end-weight tolerance exercises. The dominant narrative was that patients with TKA find rehabilitation easier due to having better muscle control, better balance, and are in less pain which means that can start their rehabilitation earlier and progress quicker. However, one physiotherapist said that although they could see how, in theory, TKA had rehabilitation advantages over AKA, they have not actually observed this in practice. They described one patient in particular who influenced their personal opinion of TKA, which was largely negative;

"*every time we would put the prosthesis on the skin would break down and then we'd be back a step each time, which the patient then became frustrated with*" (PHYS001).

Professional priorities influenced the type of preferred TKA, which differed between the professional groups. Prosthetists and physiotherapists almost exclusively preferred KDA;

"*it is rare that a Gritt-Stokes works well enough for them to end-weight bear and it provides no suspension, so you end up having a very, very long transfemoral socket, so I think it has got no advantages*" (PROS003).

Criticism of Gritti-Stokes was common across the physiotherapists and prosthetists. Most of the prosthetists and physiotherapists reported seeing very small numbers of Gritti-Stokes, for which they were pleased as it was considered to give the patient poor outcomes. The most common criticism of Gritt-Stokes is how the patella can move from its fixed position on the end of the femur which makes it impossible for the patient to use a prosthesis, the worst possible outcome for a prosthetist or prosthetic rehabilitation physiotherapist. However, one physiotherapist had extensive experience treating patients with Gritti-Stokes and viewed it positively. Many surgeons like Gritti-Stokes because it aligns with their priorities such as primary wound healing, creating an aesthetic looking stump, and protecting the skin of the residuum

"*I mean the femur is like one of those pastry cutters… it just cuts straight through the muscle and if you put the patella over the end of that's its much less likely to happen I think so that's why I quite like the Gritti*" (SURG002).

To summarise, each professional group described the factors they consider to be a priority when considering successful patient outcome after surgery. These priorities clearly have an influence on the clinician's opinions and decision making when considering TKA. Unsurprisingly the priorities reflect the part of the patient journey that that professional group is involved with. Surgeons prioritise surgical procedures and early post-operative outcomes, prosthetists prioritise the best prosthetic outcomes, while physiotherapists who work in acute and prosthetic rehabilitation share priorities with both groups

"*I would suspect it is to do with the disconnect between the surgeon and the prosthetic service, so the surgeons very rarely get involved at all in the rehabilitation of the patient and, therefore, their surgery does not necessarily reflect what would be best for their rehabilitation but what would be nicest surgically, and I am sure it is a very aesthetically pleasing amputation for the surgeon, it is just rubbish for the patients' rehabilitation."* (PROS003).

The fact that most participants did not show awareness of one another's priorities, shows there must be some sort of partition between surgical and rehabilitation services. This is explored in theme II.

6.8.2 Theme II: Communication and power differential

This theme explores the relationship between professional groups, how they communicate, and how this is influenced by the power differential between AHP and surgeon.

Many participants described barriers to communication between professional groups. Some prosthetists and surgeons describe how the lack of visibility of the other profession acts as a barrier to communication. They work in separate parts of the hospital, often in different buildings, and do not have time to visit each other's setting, which means they never physically see each other, unless someone makes the conscious effort to arrange a meeting. This distance and physical separation cause a physical barrier to communication. Even though communication is obviously possible by other means, such as telephone or email, the physical barrier prevents relationships from forming and initial communication ever being initiated

"*No, we never really speak to the surgeons… we're never personally consulted on our opinion or anything*." (PROS001)

"*These people [surgeons] are very busy people, and that's not being condescending its, it is what it is, and have they got time to spend five minutes with the prosthetist? Probably not*" (PROS002).

While physiotherapists who work on the vascular ward are not affected by this physical barrier, the expertise of the physiotherapist as perceived by the surgeon, influences whether they are invited to give their opinion, rather than just if they are visible. The surgeon feels they need to trust the opinion of their physiotherapist and would not ask a physiotherapist just because they are there. These relationships take time to build, physiotherapists seem to wait to be invited to form a working relationship with the surgeons, and possibly as the surgeon starts to recognise the same physiotherapist on their ward these relationships start to form. This could be because while surgeons remain working in their specialist areas, physiotherapists often rotate round departments, which may not leave enough time for these bonds to form

"the physio where I worked [before] I knew well and I could phone her up and ask her advice… she was somebody who's opinion I valued… I haven't quite got that relationship with people here and that may be a reflection that I just haven't been here long enough" (SURG002).

Prosthetists and physiotherapists describe their desire to be invited by the surgeon to give their opinion, suggesting they do not feel they can share their opinions unless specifically asked. The surgeons, however, are interested in their opinions, some even criticized the physiotherapists for not providing their opinions, not realizing that the physiotherapist is waiting to be asked. This indicates a power dynamic that acts as a barrier to effective MDT working. The hierarchical culture in the NHS leads the physiotherapists to feel they can only speak when spoken to by the senior consultants, even if the consultants do not think this way

"*…no reason why the physiotherapist should not be involved in the level of the amputation. The culture needs to change*" (SURG001).

Sometimes, the physiotherapists and prosthetists are consulted, but they feel they are only being asked to tick a box and suspect their input does not change the surgeon's mind. This suggests that even though they are technically involved it is not a true collaboration. The physiotherapists feel their input is not valued, and are therefore disincentivised to offer their opinion in future *“and they do sometimes ask us to assess and see what we think, but often the decision has kind of already been made”* (PHYS005).

While the prosthetists and physiotherapists are keen to give their opinion, they are also aware that the final decision is not theirs to make, and possibly do not wish to disagree with the surgeon in front of the patient, and break the illusion of collaborative working. They pre-empt the chance that their input won’t be taken into consideration by the surgeon

“are you happy for me to say this, or have you already decided you’re going above or through? As obviously we don’t want to upset the patient, I don’t want to step on anyone’s toes.” (PHYS002).

This desire to not disagree with the surgeon continues along the pathway. Once the patient is under the care of the prosthetics service one barrier to providing feedback to the surgeon is that the prosthetists are worried they may offend the surgeon

“perhaps traditionally surgeons won’t be questioned or criticised” (PROS005).

As well as worrying about causing offence one prosthetist felt that a surgeon’s time was too valuable to spend talking to the prosthetist. The prosthetists themselves described the surgeons as being ‘above’ them, and therefore do not seek to challenge the power differential between doctor and AHP, and therefore reinforce this invisible barrier between surgeon and AHP

“These people are very busy people, and that’s not being condescending its, it is what it is, and have they got time to spend five minutes with the prosthetist, probably not.” (PROS002).

Some of the surgeons describe a one-off discussion with a prosthetist or physiotherapist about TKA which still influences their practice. This one entrenched opinion is enough to dictate their daily practice, removing the possibility of individualised care. This evidences the contrast in the way the different clinical groups think amputation level should be decided. This blanket approach taken by some of the surgeons disregards the individual needs of the whole patient, instead focusing on the body part. Whereas the physiotherapists and prosthetists take a holistic approach and think about the specific needs and goals of each patient

"as I say that time before I went to the fitting centre and talked to the prosthetists and they were very keen [for TKA] and that was enough for me" (SURG007).

One surgeon asked a prosthetist about TKA 30 years ago and this has influenced their clinical practice since, but a lack of ongoing dialog and a reluctance by physiotherapists and prosthetists to speak up means that their outdated views continue to influence care. Sometimes this information is out of date as prosthetic technology has changed considerably, and this opinion has not been updated.

In summary, two main barriers to communication between professional groups were explored in this theme. The first being a physical barrier; professional groups often work in separate parts of the hospital and work with their patients on different parts of the amputation pathway. The second is around the power differential between surgeon and AHP. Often the AHP will only offer an opinion if they are asked by the surgeon as they are worried about offending the surgeon, or threatening the chance of collaboration, if they have a different opinion.

If communication is poor between professional groups, then the surgeon's awareness of the implications of their surgery on the rehabilitation of the patient will never improve, if they do not have that information, they cannot use it to influence their practice - this is discussed in theme III.

6.8.3 Theme III: Unchallenged practice

This theme encompasses the feelings the participants have about lack of evolution of their practice and whether this is acceptable or not. There was a general sense of defeatism from the clinicians concerning how they perceive that current practice is the way it is, and that they must perpetuate this approach rather than try and change it. The rehabilitation team seemed to simply accept the fact that they are not referred many patients with TKA. Most have not questioned whether the numbers they see are reasonable for this patient group. This theme also identifies some of the barriers to implementing change *"we very rarely get any vascular disartic, so I would question, it might be something I need to do really, but question maybe why, is it actually considered in the process or not."* (PHYS004).

This lack of exposure caused the physiotherapists to have a level of uncertainty and a lack of confidence in their knowledge when treating patients with TKA. Even the physiotherapists who strongly like TKA still want better guidance, quality evidence and more confidence in their knowledge of TKA. Without complete confidence from the physiotherapists that they are right to encourage use of TKA they are less likely to try and challenge practice. There is a sense of fear that they might get this wrong, but blame the lack of experience and evidence at the fault of others for their lack of action

"*I would love to have more experience of it you know so that I can be more definitive*" (PHYS003).

The physiotherapists largely attributed the small numbers of TKAs performed to preference of the surgeon; surgeons either do not like them or are real enthusiasts. In contrast, many surgeons themselves dispute this argument by stating it is not preference but actually they have not been trained how to do a TKA. They were not trained as a junior surgeon and now as a consultant surgeon are unlikely to learn a new amputation technique

"*…we seem to have a problem with learning to do things as consultants*." (SURG007).

Those that have been trained were most likely only trained in one technique, so that is the technique they choose to do because they feel comfortable using that technique, they therefore would not consider using a different technique

"*I guess it is probably more experience and comfort with the technique rather than evidence based*." (SURG005).

Another reason the consultant surgeons are unlikely to learn how to do TKA is because amputation surgery is not considered an important surgery by some vascular surgeons, and therefore it is not considered important to develop new skills in this area. They describe a reluctance to talk with other surgeons about amputation techniques, which is very different to the prosthetists and physiotherapists

“*I think that reflects the position that amputation as a subject sort of figures in our world, we regard it as the end of the line, a failure*” (SURG002).

This low position of amputation surgery as viewed by vascular surgeons was evidenced by one surgeon being surprised to hear that TKA is being performed in the UK at all, and another surgeon who wants to raise the profile of TKA who feels he is struggling to connect with surgeons nationally to change current practice. The responsibility of who should drive this change often considered to sit with one of the other professional groups, or even with the patient. Surgeons felt the physiotherapists and prosthetists should be driving any changes since the advantages of TKA are mainly seen in rehabilitation. However, the rehabilitation team are used to the surgeons making the decisions and feel the responsibility is with the surgeons to make the change to doing more TKAs. The absence of established communication channels between surgeon and rehabilitation teams also removes the opportunity for change. The lack of change is driven by no-one having or taking ownership of this, and attitude within the surgical community that this is not an ‘important’ surgery, so clinical practice is not being challenged, or championed loudly by anyone. Patients do not have the power to influence this change, and they are not given the opportunity or the encouragement to discover any other options for themselves

“So, I think, what you’ve got to work out, or what the surgeon has to work out is, what is their reticence for not doing them. That’s the big question isn’t it to say, well why don’t we don’t them? If we can?” (PROS002)

“no patient’s empowered to say well actually I’ve heard through-knees are pretty good what about a through-knee? (SURG010).

Many surgeons do not feel there is a reason for their practice to change. Whether they perform TKAs or not, they are satisfied with their patient outcomes and confident in their own decision making. They do not receive any complaints from the physiotherapists or prosthetists so there is no reason for them to question the prosthetic outcomes of their patients

“*I think on the whole, and I am sure I would hear otherwise if it was bad, the physio would tell me if it was bad, you would be left in no doubt*.” (SURG005)

“*I take that to mean there’s no particular problem, if they were having lots of problems I’m sure they would feed back to us, no news is good news*” (SURG003).

All clinicians complained of the lack of guidelines and quality evidence to inform their practice and many reported that practice will not change until that evidence is available. Current practice regarding TKA is that it is not a routinely performed operation nationally. This practice is likely to remain unchallenged without high quality evidence and agreement from surgeons, physiotherapists and prosthetists regarding the place of TKA and an understanding and recognition of who it benefits.

One of the big drivers that could potentially influence change, or challenge current practice, are the advantages observed in prosthetic rehabilitation. For these factors to become driving factors for a change the surgeons need to be made aware of the prosthetic differences between TKA and AKA. If the physiotherapists and prosthetists are not able or willing to get this information to the surgeons, and the surgeons either do not want to, or do not realise to look for it, they will never become factors that surgeons consider when deciding on level of amputation. If practice goes on unchallenged patients are potentially missing out on an operation that could offer them superior rehabilitation outcomes.

6.9 Discussion

6.9.1 Main findings

Different professional groups in amputation surgery and rehabilitation have different professional priorities. Communication pathways between groups are often inadequate which means the groups are not aware of each other’s priorities. Decision making is often based on experience and preference of the surgeon rather than knowledge of the full implications the surgical decision will have on the rehabilitation of individual patients. The lack of clear guidance and evidence perpetuates the behaviour that TKA can be overlooked.

One possible factor as to why the priorities are different between professional groups is likely down to the structure of amputation care in the NHS. Rehabilitation centres are normally based away from the main hospital (Gough et al., 2014) meaning that surgeons have little exposure to the patient care that is provided there. Surgeons routinely follow their patients up in the early post-operative stage and if there are no problems with the surgical site then the patient will be discharged. Therefore, the surgeon may be unaware of any long-term prosthetic outcomes for this patient unless they receive updates from their rehabilitation team. Whereas they do witness the early stages of rehabilitation while the patient is still directly under their care. As the majority of patients postamputation do not mobilise the surgeons may be more concerned with non-mobility outcomes and efficient discharge from hospital, as evidenced by the surgeon responses to the survey in chapter 5 (5.4) where the most common answers were around early rehabilitation and wound healing. Prosthetists and some physiotherapists only work with patients who are prosthetic limb wearers so their views on outcomes reflect their caseload, and they therefore might not consider any difference in TKA and AKA for non-limb wearers. Similarly, prosthetists are unlikely to visit the surgical ward and may be unaware of the wound healing problems and further surgeries that take place before the patient is discharged. Physiotherapists however can work on the surgical ward and in the outpatient rehabilitation centre so this could explain why they shared some priorities with both surgeons and prosthetists.

A review of the care received by patients who underwent major lower limb amputation due to vascular disease or diabetes (Gough et al., 2014) found that even though amputation is perceived as a straightforward surgery, the pathway of care before and after amputation is complex. Many established care pathways in the NHS are designed to suit the convenience of the care provider and when multiple care providers are involved the design of the pathway itself can act as a barrier to shared decision making and patient centred care (Jabbour, 2018; Grocott, 2019). Better co-ordination between surgical and rehabilitation services are required to deliver good care (Gough et al., 2014).

Challenging current practice and implementing change within the NHS is often met with multiple barriers including feeling comfortable with current practice, and clinicians feeling their opinion is not important (NHS England, 2021). The current study increased our understanding of these barriers within vascular surgery and rehabilitation by highlighting the way this clinical group consider each other's roles in implementing change and the impact of the hierarchy.

Professional priorities

Recent work has identified the research priorities to improve outcomes in vascular surgery from the clinician and patient point of view (Smith et al., 2021) but little has been explored around the different outcome priorities between professionals working in amputation rehabilitation and how this might impact patient care. The three different professional groups were included for interview because it was hypothesised that their opinions would differ and wanted to explore the reasons for these discrepancies. It is the lack of awareness of each other's priorities that runs the risk of affecting quality of patient care. The current study has shown a lack of collaborative working between surgical and rehabilitation teams caused by physical barriers and poor communication. Guidelines recommend all members of the MDT be involved for decision making regarding level of amputation (Gough et al., 2014; Smith, 2016), but the interviews in this study demonstrate that that is not always possible. This means the lifelong differences for the patient between TKA and AKA may not be considered for every patient at the point of amputation.

Communication and power differential

Communication and power dynamics within healthcare teams have been extensively studied (e.g.,(Okpala, 2020; Schot, 2020; Kearns, 2021)). While these studies found some similar results regarding the negative impact of hierarchy on communication and patient safety (Okpala, 2020; Kearns, 2021) and how differences in professional perspectives means different clinical groups have difference ideas on how to treat a patient (Schot, 2020) they focused on medics and nurses so the perspective of the rehabilitation teams, and considerations of non-rehabilitation clinicians on rehabilitation outcomes is missing. The current study adds to the little evidence exploring communication and power differentials specifically within amputation surgery and rehabilitation teams.

Spyrou (2021) explored clinicians experiences of and beliefs regarding inpatient rehabilitation pathways for people post amputation. She reported that obvious accessibility of different clinical groups through physical closeness was considered to lead to better MDT working and therefore superior patient care. Participants for the current study worked in centres which used an outpatient rehabilitation model, where they felt physical distance was a key barrier to good MDT working and communication. However, even when members of the MDT are visible this does not necessarily ensure team discussions. Rogers (2020) describes how AHPs have traditionally assumed subordinate positions within healthcare teams and found this leads to a “chain of forgotten voices” when it comes to decision making. This power differential embedded in healthcare teams was apparent in the current study where the physiotherapists and prosthetists described waiting for an invitation to share their opinion with the surgeons, which the surgeons were unaware of.

Some surgeons seemed aware of the power relationship between surgeon ad physiotherapist and others did not. Those that were aware that they were gatekeepers to collaborative decision making would invite the physiotherapists opinion if they knew them well and therefore valued their clinical opinion. On the one hand some surgeons were unaware of the power differential and said they want physiotherapists to voice their opinions and are unsure why they do not, possibly assuming the physiotherapist must agree with the surgeons’ plan if they do not object. Whereas the physiotherapist, if they do have a different opinion to the surgeon, may be unsure how their opposing viewpoint will be met by the surgeon. Kim (2019) explored clinicians’ opinions of what makes effective communication within healthcare teams and found that mutual respect between clinicians and sharing knowledge across professions were considered important factors. Sanders (2021) explored experiential knowledge within specialist prosthetic clinicians and found that not sharing knowledge acted as a barrier to managing patient expectations, specifically, surgeons lack of awareness of prosthetics leads to unrealistic patient expectations. Effective communication is only likely to happen if there is a forum within which the three professions can mix. The split site approach is a physical barrier to MDT collaboration in many NHS trusts.

Unchallenged practice

The physiotherapists and prosthetists in this study described their lack of confidence around TKA due to lack of experience working with this patient group. Sanders (2021) states that due to lack of evidence in prosthetic rehabilitation clinicians are used to making decisions, recommendations and treatment plans based primarily on their clinical experience. Sanders made comparisons to experienced clinicians working in prosthetic rehabilitation and junior staff; the experienced staff were more confident to give advice, set goals with patients and predict patient outcomes. Similarly, clinicians in the current study with limited experience with TKA described their dissatisfaction with their own practice when treating patients with TKA.

Lack of guidance and evidence was given as a reason not to change practice; however, some acknowledged the fact that their current practice in not backed up by evidence. However, there is a level of comfort expressed by the surgeons that their current practice works. A qualitative study by Pearsall et al (2015) investigated surgeons views of barriers and enablers to implementing change. The surgeons were well aware that they often work within their personally preferences and are resistant to change. The findings of the current study that surgeons do not feel responsible for driving change in amputation surgery, joint with the fact that amputation surgery is not viewed as important by many vascular surgeons, leads to a lack of innovation and change in this area. The physiotherapists, prosthetists, and some surgeons expressed frustrations regarding the lack of importance placed on amputation surgery by vascular surgeons. Despite vascular surgeons performing a large majority of the approximately five thousand major lower limb amputations in the UK each year (NHS Digital, 2020; Waton, 2021) their experiences and perceptions of amputation is severely lacking in the qualitative literature. This is important to explore to understand why such little importance is placed on such a common surgery. Patient outcomes are potentially at risk if less care and enthusiasm is placed on their surgery than others which may be deemed more important.

In the present study, the different clinical groups passed off the responsibility of who should be driving change to each other. Surgeons felt without the drive from the prosthetists and physiotherapists they could not create change in isolation, but many had not tried to communicate with the physiotherapists and prosthetists about this change, possibly due to identified communication barriers. The physiotherapists and prosthetists reported feeling incapable or powerless to implement change and may be feeling the impact of political power structures acting as barriers to change from AHPs as described by Rogers (2020). Driving and implementing change within healthcare is challenging and failure to introduce new research findings and guideline recommendations into everyday practice is a common occurrence (Nilsen, 2015). Numerous frameworks and strategies have been suggested to improve implementation of evidence-based practice (e.g., (Kitson et al., 1998; Grol & Grimshaw, 1999; Rycroft-Malone, 2004)). Introducing new surgical techniques has been claimed to be even more challenging than implementing change in medical specialties (Williams, 2019). There is a history of new surgeries being recommended but not used and the Royal College of Surgeons recommend introduction of new surgeries should be accompanied by national training, incentives, support from senior managers, and a workforce culture that is open to change (Williams, 2019).

6.9.2 What this study adds

This study adds some important findings to the existing literature around amputation surgery and rehabilitation pathways, practice, and clinical decision making. The qualitative literature from the point of view of amputation rehabilitation clinicians is sparse with very little from the point of view of vascular surgeons regarding amputation surgery, an important and complex topic. By improving our understanding of the whole patient pathway from surgery to rehabilitation it is possible to identify ways to make change. It specifically highlights the need for an established communication method between rehabilitation team and surgeon to ensure the best patient outcomes. This study also highlights the fact that recommendations in national and international guidelines regarding clinical decision making for amputation surgery are not always being followed i.e., physiotherapists and prosthetists are not involved in decision of amputation level due to physical distance between clinicians, lack of confidence in physiotherapists role from surgeons, and hierarchy preventing rehabilitation clinicians from offering their input.

This study also adds previously unexplored information regarding the outcomes of TKA and will help to challenge pre-defined opinions based on hearsay. Several advantages of TKA compared to AKA were identified by the rehabilitation clinicians in this study with reasons explaining why vascular surgeons may not be aware of such advantages.

By highlighting these advantages and contributing to more research around TKA vascular surgeons may be prompted to revaluate their clinical decision-making regarding level of amputation for patients.

6.9.3 Reflection on methods

I had to remain aware of my background as a clinician throughout the whole process and reflect on how this may influence each stage of the interviews and analysis. My awareness of the NHS pathways and procedures, and established links with other professionals, assisted with recruitment. As a physiotherapist I had an insider position when interviewing the clinicians, as I shared some group identity with the participants. To make sure I was not assuming meaning within the clinician interviews I read back through the first transcripts looking for vague comments and incomplete sentences (McDermid et al., 2014). Clinicians were direct and concise with their responses, which was good when we had limited time but sometimes, I had to work hard to get the level of detail I needed, with staff more likely to provide descriptive, professional responses. They were also confident in what they were saying, and often did not disclose any emotion or feeling, unless prompted, which is likely how they would speak to a junior colleague or patient about different procedures. This was recognised in a physiotherapist interview where at first, I felt there was little new knowledge gained from the interview, but on reflection realised that this interviewee actually shared a lot of my personal feelings around the topic and therefore I had not asked enough probing question or asked for clarity. This was corrected in the following interviews.

During analysis I used diagrams and descriptions to map how the different codes, subthemes and themes link together to help orient the reader to my analysis which demonstrates both transparency and rigour in my analysis process. Finally, throughout the analysis I have discussed my findings with my supervisor and shared the findings at conferences to gain feedback on the emerging analytical framework.

Face-to-face versus phone interviews

The first seven interviews were conducted face to face, these were all completed in Hull, and before the COVID-19 pandemic this was the dominant accepted method. When COVID restrictions were put in place the obvious option was to convert to phone or video call interviews, especially as by this point clinicians had better access to video call software or were set up to work from home which made it more convenient for the participants. Video calls also allowed the interviewer to see hand gestures which was not possible in the telephone interviews. By using telephone and virtual interviews clinicians working in any area of the UK could be included, this improved the quality of the study as participants were recruited from across Britain and the findings are not isolated to a few geographical areas but are much more generalisable. While face-to face interviews have been considered the superior method of data collection this has not been formally proven (Block & Erskine, 2012). It is claimed face-to-face is superior because the physical meeting can make the participant feel comfortable and help to quickly build a rapport between interviewer and interviewee (Saarijarvi & Bratt, 2021). However, telephone and video call interviews have several advantages, such as added convenience for the participant, which is a great advantage to busy clinicians and suitable for shorter interviews as it removes the need to travel. Additionally, these interviews were not with patients, and were not sensitive, so there was no need to be physically present to address any emotional distress.

Impacts from the COVID-19 pandemic

Recruitment halted in March 2020 as it was deemed inappropriate to recruit healthcare staff due to significant strain on their clinical time due to the pandemic and the pressures on the NHS. However, by January 2021 many clinicians were accessible as they had protected office based or working from home time. Many vascular surgeries were cancelled but surgeons were no longer redeployed elsewhere, and prosthetic centres were reducing services meaning prosthetists or physiotherapists were available. One physiotherapist was redeployed to an intensive care unit and completed their interview on a working from home day.

Recruitment strategy strengths

The recruitment strategy meant that most areas of the UK were represented. The snowballing method (Frey, 2018) worked well with clinicians and increased the speed of recruitment. There is a risk with a snowballing strategy of recruiting similar people, however this did not happen as purposive maximum variation sampling was used

(Creswell & Plano Clark, 2011) to target clinicians with opposing views of TKA to avoid getting a one-sided view. At the end of each interview the researcher would describe the characteristics of the participants that were needed for recruitment (i.e., a surgeon who does not perform TKA, or a prosthetist who likes TKA) and ask the participant to pass the researchers details on to their colleagues who met that description.

Using the survey codes to form a deductive coding framework

A deductive approach to coding (Fereday & Muir-Cochrane, 2006) was used initially, using the results of the survey to inform the analysis to try to understand and explain the survey findings. A second level of inductive coding (Braun and Clarke, 2022) was then used to identify new ideas and issues, not mapped to the survey. These codes were then used to develop the thematic structure and themes presented. The theme communication and power differentials from the interviews did not map to the survey data and was developed purely from the inductive coding. This method can be used using theoretical frameworks as deductive codes have been described to improve rigour within the coding process (Fereday & Muir-Cochrane, 2006).

6.10 Limitations

There are several different health professionals that should be involved in the care of someone having an amputation (Gough et al., 2014). It would not be possible to include all the different professions therefore surgeons, physiotherapists and prosthetists were carefully chosen due to the decisions they have to make about patients having an amputation and the time they spend face to face working with the patient. However, other interesting viewpoints would have been from vascular specialist nurses, occupational therapists and rehabilitation consultants. By focusing on three clinical groups, however, this allowed a richer understanding of their views, and opposing views to be studied in greater depth.

During analysis it became apparent that some of the early interviews were not probing enough to fully explore all the issues raised. This might be because the researcher was a physiotherapist. Making assumptions based on a clinicians “insider” knowledge is a documented problem to be aware of as a clinician interviewer (McNair et al., 2008). This was identified by the interviewer and supervisor early on using critical reflections of the quality of interview post every interview and discussions with supervisor. Once identified an effort was made to follow up points with open questions during subsequent interviews. The researchers background as a clinician working in this area influences the understanding of the participants role and the clinical environment in which they work. This insight may result in a greater depth of understanding of the participants responses. In addition, by being a specialist clinician in this field this could place the researcher in a position of trust by the participant and encourage them to further explore the topic (McNair et al., 2008).

6.10.1 Study Quality

Several steps were taken to ensure study quality. An audit trial of the analysis was kept by exporting the coding book at each stage of coding and summarising the contents of each code. This provides transparency with the analysis process. Analysis was completed by the researcher but with support from a supervisor at each stage. Full details of each stage and evidence from the audit trail is provided in section 6.4. By including the details of the participants, and the questions from the interviews this allows the reader to interpret their transferability to other populations. Also, similar themes to other qualitative papers where found which suggests good transferability and a broader relevance. Quality of the thematic analysis was assessed using the Braun and Clarke (2006) quality checklist to ensure all points had been followed.

6.11 Conclusion

There is a compartmentalised approach to amputation surgery and rehabilitation and different professional groups in amputation surgery and rehabilitation have different professional priorities. Several barriers exist in the NHS which prevent effective communication between surgical and rehabilitation teams. Some are physical, like the fact that prosthetic limb centres are often away from the surgical wards, whereas some are down to the hierarchy that is well established in the NHS which prevents the rehabilitation teams giving feedback to surgeons in case it comes across as criticism. Current practice is based on clinical experience and clinicians like to work within their comfort zone, there is little appetite to change practice when it comes to amputation surgery, either because it is not considered a priority surgery to surgeons or because rehabilitation teams are too accepting of the way things are to challenge it.

Surgeons, prosthetists and physiotherapists have different priorities regarding what comprises a good or bad outcome after amputation. Communication is often difficult between these professional groups, so this information is not shared along the pathway. As a result, information about the final outcomes of patients is not shared with those making decisions at the start of the pathway, and ultimately practice is unlikely to change.

Chapter 7 The Similiarities and Differences in the Lived Experience of TKA and AKA: A Patient Qualitative Interview Study

7.1 Introduction

This chapter includes the methods, results and discussion of study 4: a qualitative cross-sectional comparative study interviewing people living with amputation. The aims of this study were to compare and contrast the experience of living with TKA or AKA, specifically prosthetic satisfaction, perceived body image, and overall quality of life.

7.2 Aims

This qualitative study involved individuals with limb loss. The aim of this study was to compare and contrast experiences and perceptions of TKA and AKA from the point of view of people living with TKA and AKA.

The objectives of the study were:

1) To explore lived experience post amputation including perceptions of body image and prosthetic satisfaction of both groups

2) To assess the similarities and differences surrounding quality of life of people with TKA and AKA

7.3 Methods

This was a cross-sectional comparative qualitative interview study of patients with TKA or AKA. Table 7.1 outlines the criteria of included participants and the rationale behind these criteria for each study. Participants were recruited from two NHS sites: Hull University Teaching Hospitals NHS Trust and Portsmouth Hospitals University NHS Trust. Participants were not excluded for having a previous relationship with the researcher. Analysis started while still conducting interviews (Braun and Clarke, 2013).

Table 7.1 - rationale for inclusion and exclusion criteria

Inclusion Criteria	Rationale
People with any type of TKA (including Gritti-Stokes)	All types of TKA are suitable for inclusion as it is expected that the variation of TKA will have little influence on lived experience, but if there is, by including all types it may be possible to compare the experiences of sub-groups. Secondly, TKA is extremely rare so including variations creates a bigger population to recruit from.
People with any type of AKA	People with AKA are a suitable comparator as AKA is the current standard UK practice over TKA. Also, both groups have lost their knee joint but retain their hip joint. AKA has previously used as a comparator for TKA in quantitative studies (Houghton et al., 1989; Tennent et al., 2018; Polfer et al., 2019)

Exclusion Criteria	Rationale
People with other levels of amputation more distal than TKA or more proximal than AKA	Other amputations levels are not an appropriate comparator due to the number of joints removed by the amputation. As a result, the prosthetic limbs are vastly different and therefore, lived experience would differ based on that alone. Other studies have compared AKA and BKA and found that the increased difficulty of using an AKA prosthesis had a negative impact on quality of life (Davie-Smith et al., 2017).
People with another health condition that has a greater impact on their quality of life than their amputation	To reduce the risk of creating wasted data, potential participants were excluded in they declared a health condition that impacted their quality of life greater than their amputation, therefore risking the focus of the interview not being how their amputation effects their life.
Younger than 18	Several factors that influences a child's quality of life post amputation have been shown to be different to the adult population (McQuerry et al., 2019) therefore unsuitable to include.
People who are not cognitively able to provide informed consent or take part in an interview	Must be able to provide informed consent to meet ethical criteria for participation.
Main language other than English	There were restrictions on the availability and costs of a translator for this study.

7.3.1 Sample Size

The target sample size was set at a provisional range of between 12 and 16 participants with TKA and 12 to 16 participants with AKA, making two groups for comparison. This was to allow for enough participants with each characteristic of the sampling frame (Table 7.2). Braun and Clarke (2019) suggest to use a provisional range for sample size and base the decision to stop recruiting once collected data is sufficient in depth and quality to address the research question. The AKA interviews were adapted to explore the points raised by the TKA participants, and each interview was assessed for quality to allow for comparisons between groups to be made. Quality of the interview could be determined by reflection of the experience of the interview, as the interviewer had over three years of experience of working with people post amputation and was therefore comfortable and skilled at building rapport this assists with greater quality of interviews (Malterud et al., 2016). A good quality interview creates a free flowing but concise and relevant dialogue, and good quality interviews mean a smaller number of participants are required (Malterud et al., 2016).

7.3.2 Sampling approach

A purposive sampling approach was used to identify participants using a predetermined sampling frame (Table 7.2)

Table 7.2 - sampling frame

	Male	Female
SIGAM A, B, C	3 - 4	3 - 4
SIGAM D, E, F	3 - 4	3 - 4

The purpose of the sampling frame is to capture the important variations within the sample and gather rich data efficiently (Suri, 2011). The sample consisted of two groups: one with people with TKA, and the other people with AKA. The groups were specified further by gender and mobility level, as per the sampling frame. Clinical experience informed the need to sample males and females with TKA due to the belief amongst health professionals that females with amputations are more likely to be dissatisfied with the cosmetic appearance of a TKA prosthesis. However, a systematic review (Davie-Smith 2017) described “being male” as one of the most significant factors to negatively affect QoL after amputation. This review concluded that the greatest factor that affects QoL post amputation is mobility level therefore a range of ambulatory status, specified by SIGAM level was included.

SIGAM levels are routinely used by rehabilitation consultants and prosthetists to classify a person's mobility level post-amputation (Table 7.3) (Ryall et al., 2003). The groups were divided into high and low mobility level. Individuals with SIGAM levels A, B, and C are unable to mobilise or are limited to mobilising in the house only. Those with SIGAM levels D, E, and F can mobilise outdoors managing curbs and stairs safely, with or without a walking aid.

Table 7.3 – Description of SIGAM Grades

SIGAM Grade	Description
A	Not using limb/for cosmesis only
B	Uses limb for transfers or short distances
C	Walks indoors only and uses a walking aid
D	Walks indoors and outdoors with a walking aid
E	Walks indoors and outdoors and occasionally uses a walking aid
F	Can walk anywhere in any weather without using a walking aid

7.3.3 Recruitment

Participants were recruited from two NHS sites. Clinicians from each site identified potential participants from their databases and spoke to them face to face or over the phone about the study. Once verbal consent was gained the name and contact details of potential participants were passed securely to the research team and they were sent a PIS in the post (appendix 6). Approximately 48 hours after the expected arrival of the PIS the potential participants were contacted via telephone call to discuss the study and answer any questions. To check eligibility, they were asked about their level of amputation and if they had any other health conditions that effected their QoL more than their amputation. If they were eligible and interested to take part a date, time, and venue or telephone contact for the interview was arranged. A £10 shopping voucher was given to all participants on completion of the study. All travel costs were also reimbursed so there was no financial cost to the participant for taking part. The funding for this was awarded from a BACPAR research bursary.

7.3.4 The interview procedure

A small patient and public involvement (PPI) discussion was conducted in October 2018 to design the interview process to ensure ease of participation. The interviews took place between July 2019 and June 2021, after April 2020 all interviews were conducted over the phone due to COVID-19 restrictions. Participants chose the location for the interview. This was an essential recommendation from the PPI group to be considerate towards the different mobility needs of each participant, but also to allow the participant the option to choose the location where they felt most comfortable (Braun and Clarke, 2013; King, 2019). Pre-COVID-19 restrictions, most chose to have the interview in their own home and two came to their local artificial limb centre. When visiting a participant's house, the lone working policy for HUTH was followed.

After the introduction of COVID-19 restrictions telephone interviews were used exclusively to maintain safety of participants. All face-to-face data collection was suspended by HUTH for most of the data collection time, and the participants in this study were a high-risk group for severe illness from COVID-19. Evidence has shown face-to-face and telephone interviews in the same study does not impact on trustworthiness of findings (Holt, 2010). Video calls were deemed inappropriate at the risk of excluding people who did not have access to the technology (King, 2019); it was not possible to lend equipment to participants due to the COVID-19 restrictions at the time. Telephone interviews had the added advantage of being easier for participants with very restricted mobility, particularly those who found it difficult to leave the house (Braun and Clarke, 2013).

Before commencing the interview, the PIS was explained to the participant to check understanding and provide the opportunity for questions. Consent forms were then explained, and participants given the opportunity to agree or not agree with each point on the consent form (appendix 7). One participant had great difficulty initialling the boxes on the consent form, she gave the researcher verbal consent to initial on her behalf and she signed the bottom of the form. This was recorded on a file note. For telephone interviews, signed consent forms were returned to the researcher by email or post prior to the interview.

Demographics were collected at the start of the interview after the consent form was signed. If participants were unable to answer questions about their prosthetic components, past medical history or surgery type the medical notes were requested with the participants consent to obtain this information. Interviews were audio recorded.

7.3.5 Topic guide

Topic guides were used to structure the interviews (appendix 8). The topic guide was created using available literature, relevant questionnaires, and clinical experience. The topic guide was piloted prior to use, by conducting interviews with colleagues. The topic guides were flexible to allow exploration of issues raised by the participants. The researcher probed pertinent issues with participants and, when relevant, explored issues raised by previous interviews. The topic guide was amended before interviews with the AKA group to explore issues raised by the TKA group.

7.3.6 Interview

All interviews were completed by the researcher. They were audio recorded with participant's consent. All interviews started by asking the participant why they had their amputation then questions were asked from initial reaction, to getting home, going through rehabilitation and accepting their amputation, to how they feel now. The topic guide was used as a prompt to go through these themes and exact questions were tailored to the conversation. Photographs of TKA and AKA residual limbs and prostheses were used as a prompt to aid comparative discussion, however they added little to the interview as participants felt unable to make comparisons based on photographs, and when face-to-face interviews were stopped due to COVID-19 restrictions, the photographs were no longer used. The interview was not expected to cause any distress, participants were warned that questions may be considered personal and they had the right to decline to answer any questions without giving a reason, in fact interviews have been shown to provide therapeutic effect when talking about past experiences (Ryan, 2009). All participants were told after the interview they may feel emotional and offered the researchers office number to call if they wanted to discuss further. Only one participant did call to say on reflection he felt he had been negative during the interview, and he wanted to let the researcher know he was grateful he has had his amputation because it meant he was still alive.

7.3.7 Field notes/diary

Immediately after each interview the researcher wrote a reflection on how the interview went and any initial thoughts about what the interviewee had said. This interview diary was also used to record any changes made to the interview procedure. Regular reflections were also written by the researcher about their thoughts and approaches to the research (Braun and Clarke, 2013). The diary was used to help with the reflexive process, in supervision to discuss challenges, in analysis to resituate the researcher in the interviews, and to improve the quality of interviews.

7.3.8 Transcription

All interviews were transcribed verbatim. Ten interviews were transcribed by the researcher to increase familiarisation with the data (King, 2019). The remaining ten were transcribed by an external transcription company which has a confidentiality agreement with the University of Hull. Transcripts were checked by the researcher for accuracy by comparing the transcripts with the audio recordings, which again increased familiarisation with the data. Any names used in the interviews were replaced with pseudonyms, while any place names were replaced with generic terms for example “the limb centre” or “the hospital” to anonymise the transcripts before analysis. Only pauses or nonverbal communication, such as gesturing to their residual or prosthetic limb, which would aid the interpretation of the text were included in the transcript.

7.3.9 Security

Collected data was anonymised by giving participants a study code, and all data was stored securely at the Hull Royal Infirmary site. Electronic data was stored on a password protected computer that was part of the trust network. Hard copies were stored in a locked office in the Vascular Lab. Only members of the research team had access to the data. Data was be stored in accordance with HUTH policies.

7.3.10 Ethics

Ethical approval was granted from the Health Research Authority and Heath and Care Research Wales on 30th May 2019 (reference: 19/WA/0124).

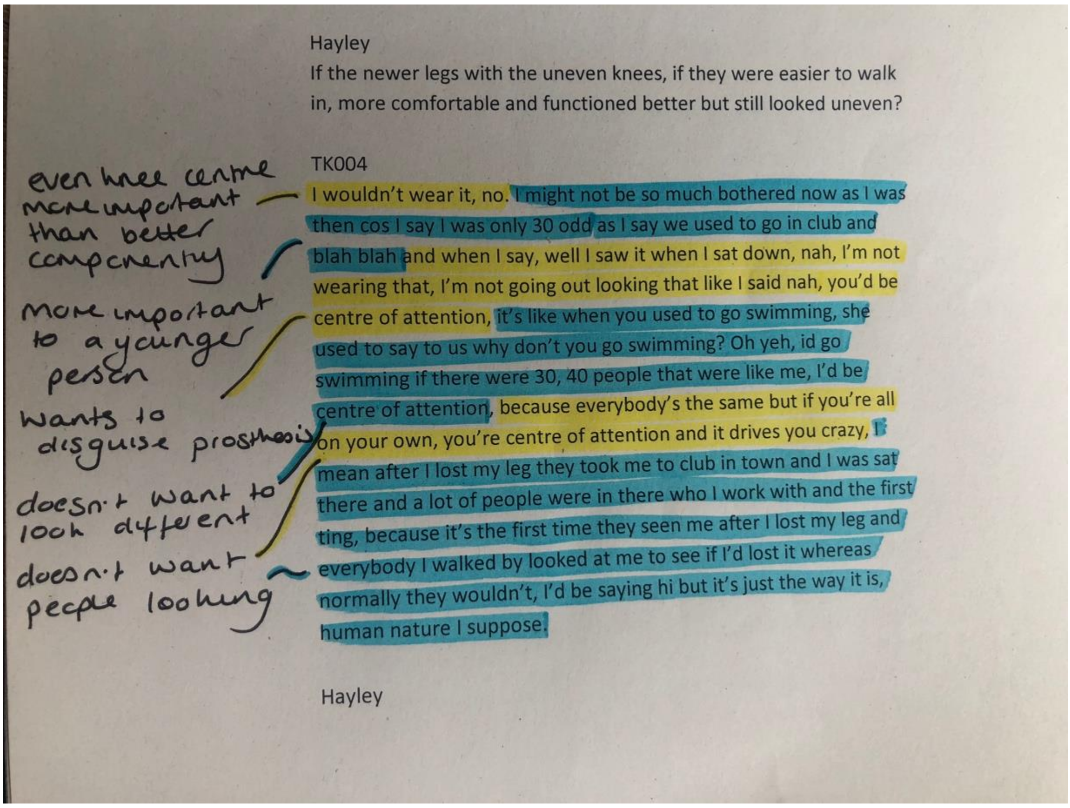
7.4 Analysis

Data analysis started during the data collection phase using a staged data collection process, whereby two or three interviews were completed, and the first stages of analysis started, so that subsequent data collection could be refined based on the early findings (Braun and Clarke, 2013).

The reflexive TA analytic process consists of the following steps: familiarisation, generating initial codes, theme development, reviewing and defining themes, writing the analysis (Braun and Clarke 2006). Each stage is described in detail to demonstrate how the researcher interpreted TA.

Familiarisation

Each transcript was read through to become intimately familiar with the data (Braun and Clarke 2013). Then, it was read through again and all data that was or might be relevant to the research question was highlighted. Different colours were used to separate different items. Thoughts were noted in the margins of the transcript, including where cross over with themes arising from clinician interviews were identified.



Hayley

If the newer legs with the uneven knees, if they were easier to walk in, more comfortable and functioned better but still looked uneven?

TK004

I wouldn't wear it, no. I might not be so much bothered now as I was then cos I say I was only 30 odd as I say we used to go in club and blah blah and when I say, well I saw it when I sat down, nah, I'm not wearing that, I'm not going out looking that like I said nah, you'd be centre of attention, it's like when you used to go swimming, she used to say to us why don't you go swimming? Oh yeh, id go swimming if there were 30, 40 people that were like me, I'd be centre of attention, because everybody's the same but if you're all on your own, you're centre of attention and it drives you crazy, I mean after I lost my leg they took me to club in town and I was sat there and a lot of people were in there who I work with and the first ting, because it's the first time they seen me after I lost my leg and everybody I walked by looked at me to see if I'd lost it whereas normally they wouldn't, I'd be saying hi but it's just the way it is, human nature I suppose.

Hayley

even knee centre more important than better componentry

more important to a younger person

wants to disguise prosthesis

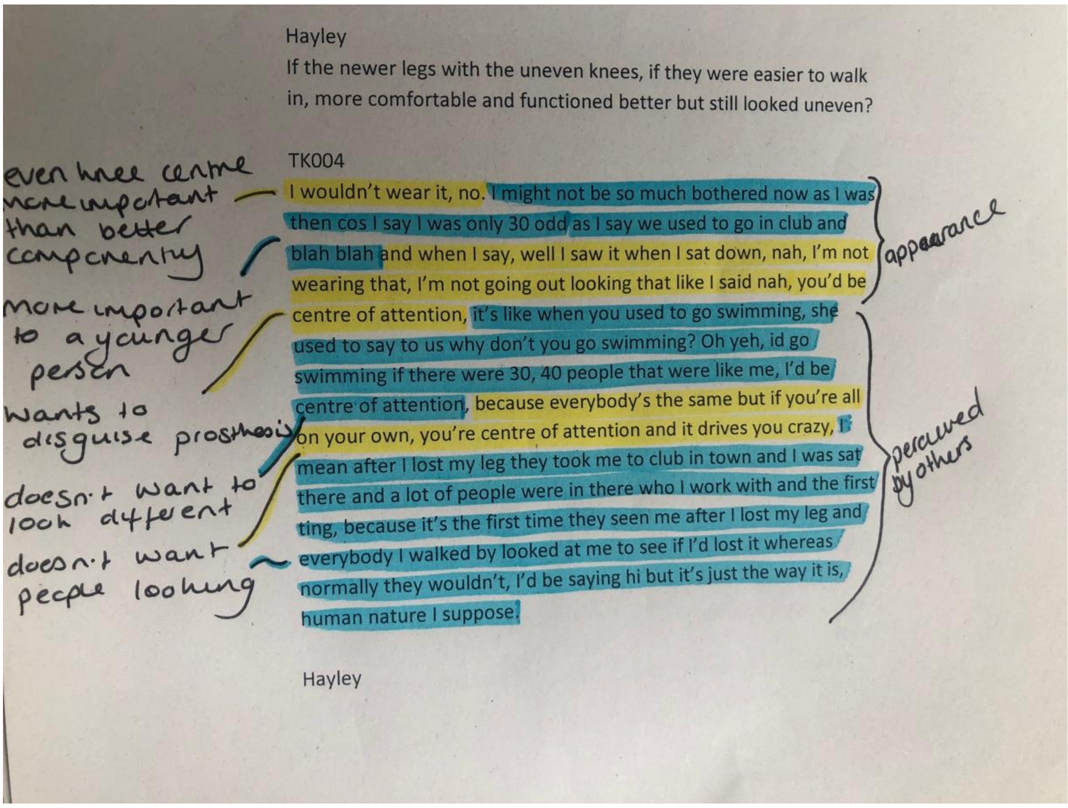
doesn't want to look different

doesn't want people looking

Figure 7.1 - familiarisation and initial thoughts

Generating Initial Codes

Items were considered relevant to be coded if they were in any way relevant to the research question, this method is called complete coding (Braun and Clarke 2013). The transcript was read through again and notes made about potential codes and any patterns or links with other transcripts. NVivo was then used to code the transcripts. A single coder was used, and enough time was allocated to coding to allow engagement with the data and for reflection during and after coding (Braun & Clarke, 2019). Coding was supervised by an experienced researcher (MT) by discussing examples of codes throughout the coding process. All TKA transcripts were coded first and then all codes reviewed and notes made before conducting the AKA interviews.



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Hayley

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more important to a younger person

wants to disguise prosthesis

doesn't want to look different

doesn't want people looking

appearance

perceived by others

Figure 7.2 - initial codes

Theme Development

All codes were summarised in an initial look at potential themes and the topic guide was adapted to further explore these working themes with the AKA patients (appendix 9). Codes were reviewed to look for similarities and overlap between codes and grouped together and then themes were developed using mind mapping (Figure 7.3) and discussions with a supervisor (MT) to focus and organise the sub-themes. Then within each sub-theme comparisons were made between groups (AKA and TKA) to look for any similarities or differences in experiences and perceptions. Each sub-theme was summarised with quotes in a table and similarities and differences observed between the two groups studied and summarised.

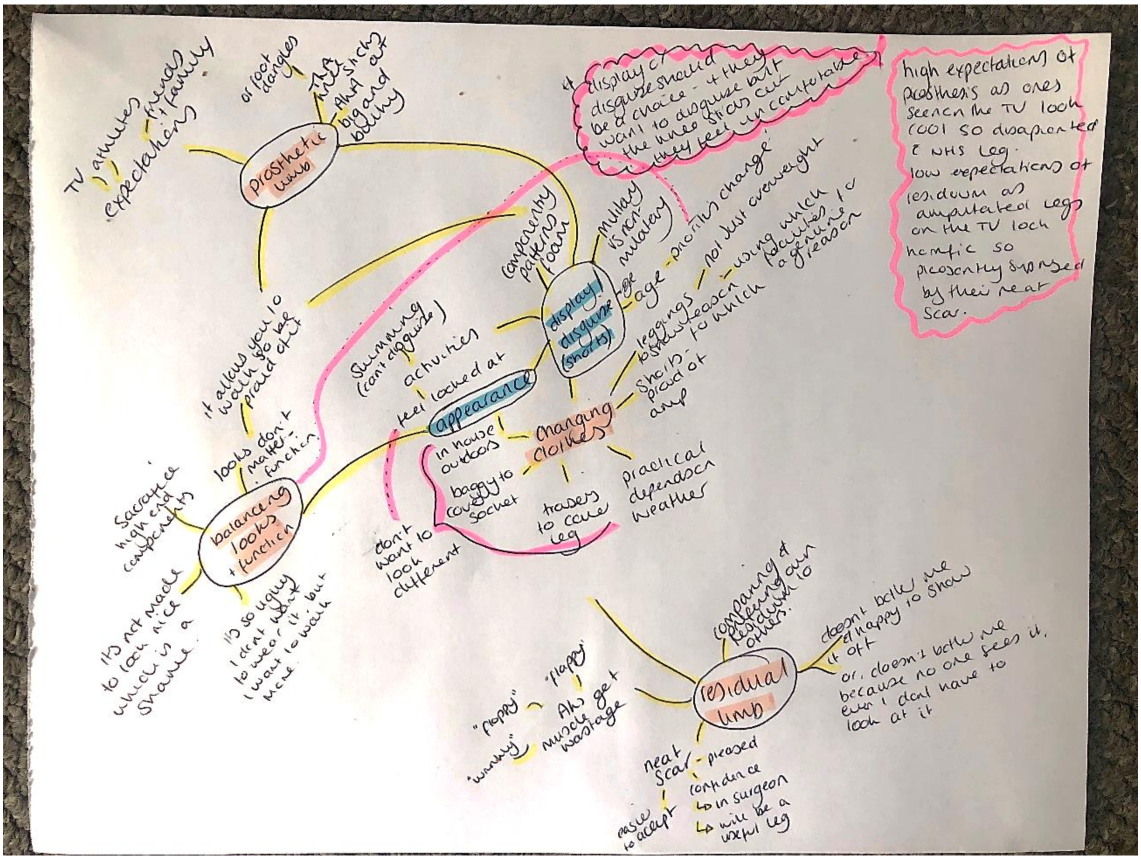
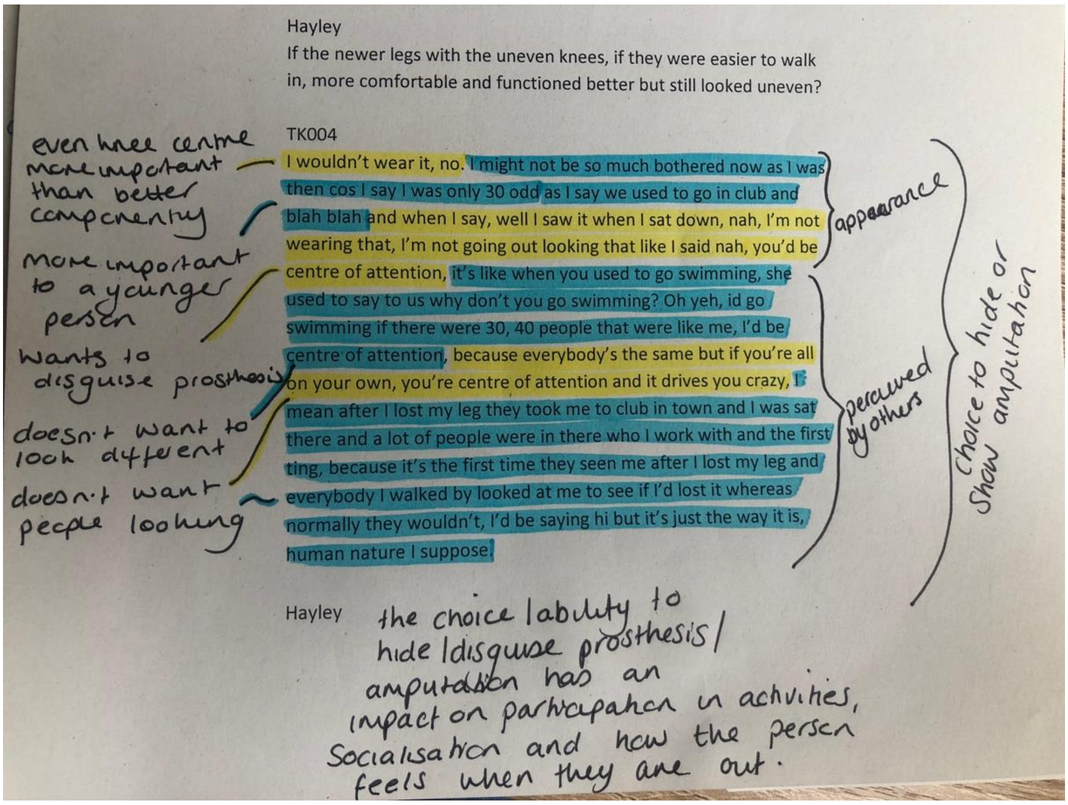


Figure 7.3- Mindmap of theme development for ‘Hide or Pride’

Reviewing and Defining Themes

Revisions were made to candidate themes by reviewing the data. All the codes were reviewed, and revisions made to ensure the codes worked within the themes. Then a full dataset review was completed with a mindset of ensuring the final themes answered the original research question represented the corpus of the data (Braun and Clarke, 2013). One change was made to one of the theme labels based on the re-reading of the data; the theme Staying Positive was initially called “living as a disabled person” and talked about all the things participants had to face now that they were disabled, but when re-reading the transcripts, it was apparent that none of the interviewees referred to themselves as disabled, or if they did it any reference was infrequent. It was more apparent that, nearly all, saw themselves as positive people, who had had this major event happen to them but were reflecting on how they feel and how they can move forward. As such, the theme label was changed to Staying Positive.



Hayley
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Hayley the choice /ability to hide /disguise prosthesis/ amputation has an impact on participation in activities, socialisation and how the person feels when they are out.

even knee centre more important than better componentry

more important to a younger person

wants to disguise prosthesis

doesn't want to look different

doesn't want people looking

appearance

perceived by others

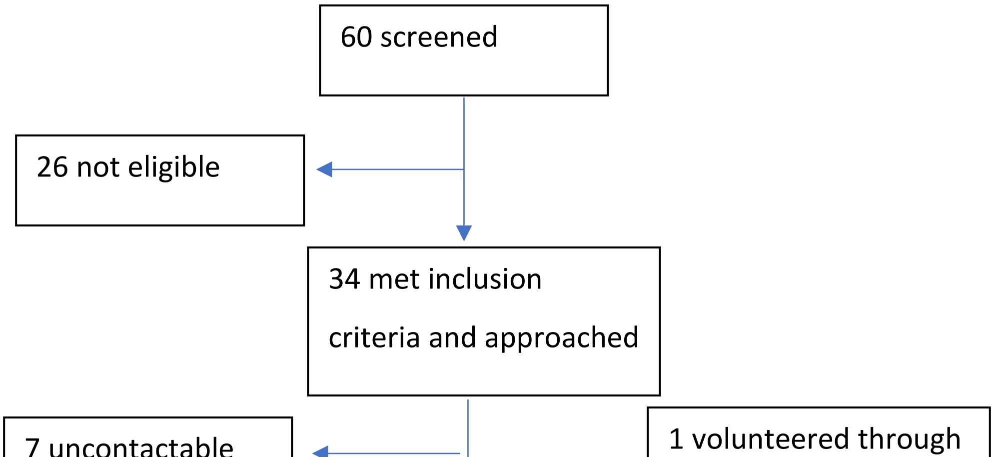
Choice to hide or show amputation

Figure 7.4 - theme development

7.5 Results

7.5.1 Description of participants

Thirteen people with TKA and seven people with AKA completed the study. The below participant recruitment flowchart demonstrates the screening and consent process.



Participant characteristics are displayed in Table 7.4. There were an even number of male and female participants. The mean age was 64(±13) years with an average length of time since amputation of 11(±18) years. The most common reason for amputation was vascular disease and 30% of the group had diabetes. Fifteen participants had a prosthesis. Six participants had microprocessor knees (MPK) (computer assisted knees for mid to high activity levels). Four had mechanical free knees, which stabilise on weight bearing, and require momentum from the user to flex the knee, also for mid to high activity users. Four participants had knees that automatically locked, or had a hand operated lock, on weight bearing for low activity users. One participant had side steels; a traditional type of knee joint used with leather corset suspension. The group had a wide range of activity levels from A – does not use a prosthesis, through to F – can mobilise with a prosthesis in any weather without a walking aid, as defined by the SIGAM mobility grades (Table 7.3) (Ryall et al., 2003).

7.5.2 Recruitment

The recruitment method relied on NHS clinicians identifying and contacting potential participants. In March 2020 many clinicians at the recruiting limb centres were redeployed to other areas for several months and were therefore unable to assist with recruitment. However, once they returned to the limb centre, the reduced patient numbers due to COVID restrictions give them more time to help with recruitment.

Potential participants who had been identified in the weeks leading up to the pandemic were all keen to take part in telephone interviews. This is likely due to the fact they were having to stay at home and therefore had more free time. It could also be because there was a huge sense of wanting to help the NHS and the participants were all keen to share their stories.

Six participants were recruited from Portsmouth Hospitals NHS Trust and 12 from Hull University Teaching Hospitals NHS Trust. One participant from the clinician study also met the criteria for the patient study and consented to her data being used for both. One TKA participant contacted BACPAR looking to take part in a research study. Recruitment was stopped after 13 TKA and seven AKA because it was decided that the data was rich enough to answer the research question (Braun and Clarke, 2022). The term data saturation is not applicable to this research as this research is conducted in the constructivist pragmatic paradigm, meaning that knowledge is co-constructed therefore data saturation can never truly be met as each interview will construct new data (Braun & Clarke, 2019). Instead, a pragmatic approach was taken and interviews stopped when enough quality data was collected to answer the research question (Braun & Clarke, 2019).

Table 7.4 – participant characteristics

Subject ID	**Recruitment site**	**Gender**	**Age**	**Diabetic**	**Level**	**Years since amputation**	**Aetiology**	**Componentry**	**SIGAM**
TK001	Hull	male	65	yes	TKA	1	vascular	mechanical locked knee	C
TK002	Hull	male	68	no	TKA	53	congenital	mechanical free polycentric knee	D
TK003	Hull	male	65	yes	TKA	2	diabetes	none	A
TK004	Hull	male	70	no	TKA	38	cancer	side steels	C
TK005	Hull	male	67	yes	TKA	49	trauma	mechanical free polycentric knee	F
TK006	Other	male	58	no	TKA	2	cancer	MPK	F
TK007	Hull	female	90	yes	TKA	3	infection	none	A
TK008	Hull	female	82	no	TKA	2	vascular	none	A
TK009	Portsmouth	female	86	no	TKA	1	cancer	mechanical locked knee	C
TK010	Portsmouth	female	57	no	TKA	1	sepsis	MPK	E
TK011	Portsmouth	female	53	no	TKA	2	ortho	MPK	F
TK015	Hull	female	69	no	TKA	1.5	vascular	mechanical free polycentric knee	C
TK016	Other	female	44	no	TKA	42	congenital	mechanical free polycentric knee	F
AK001	Portsmouth	male	64	no	AKA	1.5	trauma	MPK	F
AK002	Portsmouth	female	64	no	AKA	3	ortho	MPK	D

Subject ID	Recruitment site	Gender	Age	Diabetic	Level	Years since amputation	Aetiology	Componentry	SIGAM
AK003	Portsmouth	female	43	no	AKA	3	sepsis	none	A
AK004	Hull	male	67	no	AKA	5	vascular	mechanical locked knee	F
AK005	Hull	male	66	yes	AKA	3	trauma	mechanical locked knee	A
AK006	Hull	male	56	yes	AKA	5	vascular	MPK	E
AK007	Hull	female	45	no	AKA	4	sepsis	none	A

7.6 Themes

Three themes were developed from the data. The first theme “Hide or Pride” illustrates the spectrum on which participants choose to display their amputation with pride, or to hide it, in two sub-themes “prosthesis” and “residuum”. The second theme is “Staying Positive” and describes the participants initial feeling of “Relief”, and then how they demonstrate “Resilience”. The final theme is called “Getting on with it” which explores the adaptions to life after amputation in the sub-themes “Slow down”, “Falls and phantoms”, and “Prosthetic grievances”.

7.6.1 Theme I: Hide or Pride

This theme explores the spectrum of feelings around the choice to hide one’s amputation or show it off with pride. At the hide end of the spectrum the priority is to have the ability to disguise the amputated limb, avoid unwanted stares, or even deceive strangers to think there has been no amputation of a limb. At the other end of the spectrum, pride, is the willingness to proudly display the amputated limb by wearing shorts all year round and get brightly coloured patterns printed on the prosthesis. Some people stay at one end of the spectrum, but others choose when they want to disguise and when they want to display their amputation based on the situation they are in. The level of amputation did not influence which end of the spectrum the participant is on. The first sub-theme, “the prosthesis”, includes how participants disguise or display their prosthetic limb, and the second sub-theme, “the residuum” describes how participants disguise or display their residual limb.

Table 7.5 - sub-themes and example quotes for theme I

Theme	Sub-theme	Codes	Quotes
Hide or pride	The prosthesis	Appearance Identity Perceived by others	"*because I like tight, tight, tight-ish clothes, which is another thing that upset me cos I can't wear 'em anymore cos your, your prosthesis shows through*" (AK002) "*I wear shorts a lot; I'm not one of them that tries to hide it… because I found if I'm in public or in the supermarket or whatever or it's a bit crowded people will get out of your way*" (AK006) "*but at the end of the day, you know, once you've got you trousers on and you're sat like this and you sit cross legged like this no one knows, nobody*" (TK005)
	The residual limb	Appearance Identity Perceived by others	"*in the summer months I wouldn't want to wear a pair of shorts so that people can look at it. I want people to know that it, like its gone but I don't want people to stare*" (AK003) "*I don't feel like a woman anymore, and, I don't feel as though I'm attractive anymore*" (AK002) "*Well, I think it looks pretty good. I don't mind showing it to anybody. Like I say the below knees I've seen with the little bit of lower leg it looks awful to me it really does*" (TK001)

The prosthesis

Being able to walk with a prosthesis is considered as a significant achievement which participants were proud to discuss in the interviews. The prosthesis is the only alternative to using the wheelchair, something that the participants who were active pre-amputation, wanted to avoid. However, the expectations of the prosthesis were often high, as they were based on athletes seen on the television, and when presented with the prosthesis for the first time many expressed their disappointment with its appearance. However, as soon as they were able to walk with the prosthesis, the relationship with the prosthesis improved

"*I disliked it so much that I thought this is a waste… a waste of the physio's time because I'm never gonna wear this leg because it's hideous*" (AK003)

"*I'm Arnie Schwarzenegger, me, I'm The Terminator. Yeah, seriously it doesn't bother me at all. It's a prosthetic leg; you know that if, if, if I didn't have it I wouldn't be able to walk down the road so be proud of it*" (AK001).

As well as providing opportunity to escape the wheelchair and walk, the prosthesis makes it possible to hide the disability from others. Cosmetic options can be tailored to optimise the disguise so that other people cannot tell it is an artificial leg; a cosmetic foam with flesh-coloured stockings can be added to give the prosthesis the shape and colour of a leg. This choice is influenced by the desire to disguise or display the prosthesis; the foam cosmesis makes it easier to disguise under trousers or long skirts, whereas without the foam covering a bright pattern can be applied to the socket and the knee componentry displayed

"*I chose not to have the cover because it just reminded me of old lady's tights so I literally just have the socket and then the metalwork*" (AK003)

"*I don't want to show all that lot off, I want this to be as perfect looking as a leg basically*" (TK005).

Even with a cosmetic foam, disguising the prosthesis can still be challenging. The long residuum of the TKA causes the prosthetic knee to stick out beyond the remaining knee. For people on the "hide" end of the spectrum this is an unacceptable outcome which is resolved by opting for a smaller, more basic, prosthetic knee;

"*they made it [an MPK] and I tried it on, I was walking about the thing and I thought, well, this is alright but when I sat down that knee was there and the other was there… so I thought, well I ain't wearing that, I'm not going out like that*" (TK004).

Those with TKA towards the middle of the spectrum accepted this cosmetic limitation for the functional advantages gained from the long residuum;

"*I have the ability to stand on it for quite a period, long periods of time which I know I wouldn't be able to do quite the same, and I would rather have that than, as I say, be bothered about how it looks*" (TK006).

The shorter length of the AKA residuum means it is possible to get the prosthetic knee level with the remaining knee. While the participants in the AKA group did not have issues with the knee components, they still face challenges hiding their prosthetic leg because their socket is larger than a TKA socket;

"If I've got trousers on or whatever, you can see that I'm wearing a leg, there's, there's no way of getting away from that, because that side is always bigger" (AK003).

Clothing choices are influenced by the desire to disguise or display the prosthesis. Finding the right clothing to achieve the desired look can be problematic due to the protruding knee or bulky socket, but finding a clothing solution is rewarding and participants enjoyed being able to share their clothing solutions with others;

"*my twin sister, she's a very good seamstress, she doesn't do it as a job now but she does it for other people and she helps out other amputees as well, is I get her to cut the right-side leg off [my trousers]" (TK015).*

For the female participants, finding clothes that achieved their desire to hide or disguise, and represent their clothing style pre-amputation was important. For some, they felt their preferred clothing was no longer an option;

"*I used to like, like, like tight jeans, you know, your, your skinny jeans or; I've, I've had to go to wide jeans now, wide trouser. I used to like those skinny dresses and now I've, I've had to change, ooh, well the whole wardrobe really has had to change because you can't wear anything tight because you can see it; at the back you can see the, there's a lip that goes out and so it's, it's a bit upsetting when you, you, when you like the clothes, you look at the clothes, you saw, oh I can't have that cos it'd show up"* (AK002).

However, each individual position on the hide or pride spectrum is not necessarily fixed. Sometimes their position can change depending on the scenario. There are some scenarios where having the disability visible is advantageous;

"*I'll just wear long shorts, because I found if I'm in public or in supermarkets or whatever or it's a bit crowded people will get out yer way, whereas if you've just got a stick they tend not to*" (AK006)

Or if the participants feel they need to make their disability more obvious, they may choose to remove their prosthesis and use the wheelchair to display their amputation, justifying their disability. This avoids being questioned for using accessible facilities;

"*when I go to the football… I have to sit in my wheelchair to get in to the ground because I'm in a wheelchair bay" (TK015).*

The residuum

Those that use a prosthesis have the option to disguise their disability, whereas those who do not have a prosthesis, non-prosthetic users, who rely on their wheelchair to mobilise, have the option to hide their residual limb, but cannot hide their disability as the wheelchair is always visible. Choosing to display or disguise the residuum came down to whether the person wanted other people to know the reason they are using the wheelchair;

"*I don't like the thought that people might sense that I'm in a wheelchair because I'm overweight so I always might, make it look obvious. So I, if I've got leggings on or whatever I tuck the, the leg underneath me* [or if she has a blanket in the cold] *I always tuck the blanket under so you can see that I've only got one leg*" (AK003).

However, not everyone feels comfortable displaying their residual limb. For some this means they would change their activities rather than do something where their residuum would be on show, such as swimming;

"*I'd go swimming if there were 30, 40 people that were like me. I'd be centre of attention, because everybody's the same but if you're all on your own, you're centre of attention and it drives you crazy*" (TK004).

The dominant narrative was that the appearance of the residual limb is less important than the appearance of the prosthetic limb. This is partly because the residual limb is so easy to hide from others, and even the person themselves can choose to avoid looking at the residual limb easily if they do not wish to see it. Most participants expected their residual limb to have an unpleasant appearance immediately after surgery and were pleasantly surprised by how neat and tidy the scar looked;

“*I just thought it’d be horrendous looking you know, so it’d be like, you know, a bit like the movies where it looks horrible, but it actually doesn’t*” (TK015).

The appearance of the residual limb influenced their expectations of its functionality, with a neat residuum being perceived as more functional than a less attractive one. A neat residuum gave the participants confidence that their surgery had been performed well and they felt optimistic that the residuum would function well

“it just looks so neat it looks so tidy, like, yeah, I’ve got a chance” (AK006)

whereas a less appealing residuum reduced confidence in the future prospects of walking

“*the first year it really looked horrible and I thought well I’m never gonna walk on that*” (AK004).

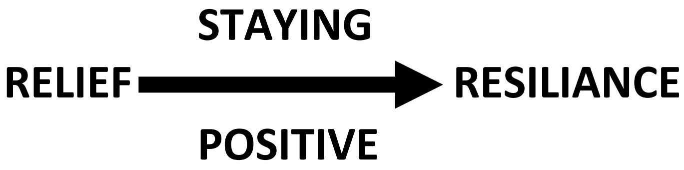
The AKA group described how their residual limb became less toned over time as the muscles in the thigh are no longer attached to anything, leading to muscle wastage and wrinkled skin. They were no longer happy with the appearance of their residual limb, describing the limb as looking older than it should do for their age, and some would avoid looking at their residual limb. However, despite this, there was no mention from any participants that they felt the way it looked influenced the function of their residual limb at this later stage

“*well I don’t like my stump now at all cos it’s getting floppy and horrible cos there’s no muscle in it*” (AK002).

By comparison the TKA group mostly reported positive feelings regarding their residual limb, regardless of how much time has passed. The muscles are still intact, so it is not prone to the same muscle wastage as an AKA residuum, and therefore the appearance changes less over time. One participant said that when she is sitting, and she looks down at her legs they look the same

“well I’ve still got, you know from the top it’s like an ordinary knee if you know what I mean” (TK009).

7.6.2 Theme II: Staying positive



The importance of staying positive after amputation was evident through most of the interviews with strong similarities across both the TKA and AKA group. Many described the ability to quickly accept your new circumstances without dwelling on the loss of the leg and felt that maintaining a positive outlook was the key to living a successful life after amputation. This theme explores the emotions immediately post amputation in the first sub-theme "relief", and the attitude that participants described as essential for succeeding post amputation, which is a lifelong inner strength and optimism in the second sub-theme "resilience".

Table 7.6 - sub-themes and example quotes for theme II

Theme	**Sub-theme**	**Codes**	**Quotes**
Staying positive	Relief	Acceptance Decisions made by self	*"I'm a through the knee amputation, I know there's less of them, I much prefer that to above the knee, just the fact that I can stand longer, go further distances when I'm walking"* (TK006) *"I mean it was wonderful to, to actually wake up and not have any pain, it was absolutely amazing"* (AK002) *"but I never, I can't remember it bothering me at all. The, the fact was while it, while I had my leg it was, the pain was horrendous, it really was, I, I was crying out in pain, and the fact that all that had gone was a relief really; I, I wasn't in pain anymore, you know"* (TK007)
	Resilience	Acceptance Life could have been different	*"People's attitudes towards, well any disability really, not just amputees but any disability, is very bad"* (AK001) *"I try not to be negative, if that's possible, I try not to think like that, I only think of the good things that could come out of these things"* (TK015)

Relief

Most participants described feeling an enormous sense of the relief immediately after their amputation. They described pre-amputation symptoms including intolerable pain, restricted mobility, and loss of independence. The affected limb was seen as the cause for these symptoms and amputating the limb was the solution. All participants who described suffering with high levels of pre-amputation pain described a feeling of instant relief post TKA or AKA

"*when I came round I, I, I felt nothing and I just thought, oh peace at last*" (TK008)

"*it was a relief, it was, don't get me wrong, I was terrified because obviously you don't know what's gonna happen afterwards, but it was, more than anything it was a relief*" (AK003).

Many participants took ownership of the decision to have the amputation which removed a lot of the emotions they had towards their leg. They had distanced themselves from the limb prior to amputation, and welcomed its removal, so it may well be that for these participants the grieving stages, that are natural post amputation, had already taken place

"*I got sepsis and then developed CRPS so, I begged basically for my amputation*" (AK003)

"*it was just a useless appendage that I no longer wanted in place*" (AK005).

All the participants who requested their amputation experienced initial relief after their surgery. As already mentioned for many this was relief to be rid of pain, for others it was relief to have the dreaded surgery over with, and to have survived the surgery. Some felt relieved that a surgeon had finally agreed to do their amputation, they felt validated by a medical professional, and satisfied that they were right in asking for an amputation. These initial stages were supplemented with optimistic thoughts of getting their life back, using a prosthesis which won't cause pain, and allowing them to return to normal life. These optimistic feelings were enhanced for those that found the early stages of rehabilitation effortless, as the removal of the affected limb meant it was easier to move around

“*I think I was quite confident because I’d lived so long with the dead limb that it was, the limb was in, in, in effect just like dragging behind me constantly so I felt a bit freer*” (AK003).

Despite these positive emotions some still experienced stages of grief; demonstrating a confusing assortment of emotions a person losing their leg can experience when they finally have their amputation. They are relieved to have had the surgery, but still upset over the loss of their leg, sometimes with additional guilt for feeling upset; experiences of how individuals process this loss were diverse across the sample

“*I went through a, a real period of grieving, I guess, grieving the loss of the leg, and then, but then I felt, always felt guilty for feeling that, that was because I’d chosen, you know, it was my option to have the amputation, I’d, I’d chosen, so I shouldn’t, I felt guilty that I shouldn’t be grieving the loss of it, if that makes sense*? (AK004).

While most experienced an initial feeling of relief, whether this feeling of relief lasted or dissipated was reliant on the success of their rehabilitation compared to their abilities pre-amputation, and whether their level of function post amputation was better or worse than they had expected. Most of the participants in this study struggled to mobilise pre-amputation due to pain and lack of function of the affected leg. For those participants, they were able to perform tasks post amputation that they had previously been unable to do. If levels of independence improved post amputation it was easier for the participants to accept that the amputation had been the right choice;

“*I can walk down the shops now without crutches, I can, and, and no pain, you know, I can get in and out the care easier, funnily enough”* (AK001).

Some participants however, felt immediate relief due to loss of pain but struggled with rehabilitation and therefore did not experience this feeling of relief for long. A lack of expected progress could result in declining acceptability of the amputation and negative perceptions of the prosthesis, as the expected and anticipated gains were not realised. This was the case for participant AK002, the amputation went well, and they felt optimistic about learning to walk with their prosthesis. They described managing well with the early walking aids “*I mean at first it was good, the pain had gone, I was* *up on, on that leg thing [the early walking aid] and I was walking"* but then they go on to say how difficult it was to master using a prosthetic leg at home *"[I] got my leg and started to do that and then started to fall and things like that and it just goes downhill*". The expected gains were not achieved with the prosthesis despite managing well with rehabilitation initially, but they reached their rehabilitation potential sooner than they anticipated which felt frustrating and disappointing "*it was, yes! You're up! You're up and about and now I can get on and I'll be fine and I'll be running around soon, and as time goes on and nothing changes*". When they realised their mobility was no longer improving, they had to reassess their goals and priorities. Mobilising unaided for example became a lower priority, "*Ok, I can't let go of these sticks, I can't do, and, but never mind (laughs) that's what I try to say to myself anyway, just to try and keep myself up*".

The participants who were not expecting an amputation, or were hoping their leg could be saved, did not experience feelings of relief. Their contrasting reactions to amputation included initial feelings of shock, followed by devastation when they realised how the loss of the leg was going to affect their lives. This groups experience was more closely related to the stages of grief as they suffered the unexpected, and sometimes traumatic, loss of their lower limb. Some participants had no previous problems with their limb prior to amputation and the resulting loss of mobility came as an unwanted shock. The loss of the leg was associated with immediate loss of independence and social life which was understandably devastating

"and when I came round I just wanted to be dead; that was how I, how I felt, you know, cos I was quite active" (AK007).

However, some denied any feelings of devastation;

"*but I woke up and me leg was gone, but I weren't traumatised or anything I just got on with it and, well I just got on with it and that, that's all there was to it… after about three weeks it started to sink in that me leg had gone and I got a li-, I did, when I got home, after the amputation and I got home and I was sat in a wheelchair, until I got me prosthetic leg, you know, I was a bit depressed*" (AK004).

It is possible that in order to protect themselves from feeling emotional, and to focus on rehabilitation, which starts on the first day after amputation, these participants did not allow themselves to feel their true emotions. It is likely they protected themselves from any feelings, rather than just not having feelings. These participants therefore moved straight into the resilience phase. Time spent not accepting the amputation, and being sad was considered time wasted when the goal was to regain independence

"*you don't want to sit and dwell on your amputation, you need to be up and about as soon as you can*" (TK011).

While participants in both TKA and AKA groups experienced feelings of relief, suggesting that this is not influenced by the level of amputation, the TKA group voiced additional factors they were relieved about specific to their TKA. They had an awareness that TKA was not the standard amputation method performed by every amputation surgeon, and were also aware they had specific functional advantages that people with AKA did not have, such as the ability to end-weight bear

"*yeh because that would be very painful wouldn't it, weight bearing on the end of that [an AKA residuum] because which is why when they did mine and which is why mine is so much better because I've still got the big knuckle there to weight bear on*" (TK005)

"*so obviously with a through-knee you've got the whole of that femur and I don't get as much pain at the end of it as an above knee should, like if I go, to put weight through it because people with above-knee and below-knee can't put weight through the end of that stump because it's a sharp bone whereas I can*" (TK011).

They also expressed relief at keeping more of their residual limb by keeping the whole thigh, rather than having their amputation mid-thigh like an AKA. They also felt that additional reassurance of knowing if their surgery had any problems, they had the safety net of going to an AKA if they had to, but saw no option after an AKA

"*I'm a through-knee amputation, I know there's less of them, I much prefer that to above the knee, just the fact that I can stand longer, go further distances when I'm walking*" (TK006) “*when he came and said they couldn’t get any blood flow to it so the best thing to do it have the bottom of the leg off and we’ll do it through the knee because that’s probably the easiest way and I’m very pleased he did*” (TK001).

Resilience

Psychological resilience and mental toughness were considered essential traits to coping after amputation by participants in both groups. Some participants felt they bounced back mentally immediately after their amputation, some took a short while, and one participant reported they have not achieved this yet. The participants described daily obstacles and challenges they must overcome, which is why attributes like having a strong mental attitude, being a positive person, and feeling good about yourself, were described as essential to cope with everyday life. Many described already having the mental toughness and determination required to cope, while others described developing this mental toughness over time. Some achieved resilience, or developed this mental toughness, while others put on a display, they had achieved this, by being stoic

“*as long as you’re strong mentally and the people around you are strong mentally you’ll, you’ll get through it*” (AK001).

Participants of working age with dependents talked about having to be resilient for the sake of their family. They described resilience as something they needed to develop internally, so they could return to work and provide for their children. Those who had their amputation later in life described developing resilience together with their long-term partner in a shared process

“*I just had to get on with it, I still had to go to work, I still had three lads and a missus and you’ve just got to do it ain’t you, just get on with it*” (TK004).

Resilience is not only important to get over feelings of loss for the leg itself, but also for loss of what could have been had the leg been saved, or even amputated earlier

“*if that hadn’t have come off I’d still be at home looking after meself* [not in a care home]” (TK007)

"*I wish I'd have had the amputation the year before…instead of waiting… but I suppose I had to go through the process*" (AK001).

Whenever participants mentioned unresolved feelings of anger or sadness regarding their situation, they immediately followed with feels of gratitude for having the mental toughness to cope with these feelings

"*if I'm on my own then I start thinking about it and you start getting a bit down or wondering why the hell it happened to you or, or whatever, you know. But, but again it's just a case of buck up, get on with it, it's happened, just move on*" (TK006).

Those that had their amputation several years ago reflected on the fact they had to adjust without any psychological support, assuming that if they had their amputation now, they would have received professional support and potentially processed the loss of their leg better

"*I'm kind of a generation that was you just, just have to, you know, buck up and get on with it to a great degree*" (TK006)

"*I had to get on with it and it would be like, mind you things are different now aren't they, I say I'm talking nearly 40 years ago and it's a bit different now people will get talked to nowadays won't they?"* (TK004).

However, most participants reported that they did not receive any sort of formal counselling. The participants described having to find their own ways of coping without professional support. They described their coping strategies as simply choosing to stay positive and just getting on with it, without the support of any structured acceptance methods. They also suggested that the reason they managed was because they had a pre-existing strong mental attitude which helped them to adjust, and felt that if others were not strong mentally, without professional help they would not cope. Some described being stoic and used avoidance behaviour as a way of coping; they did not allow themselves to process their true feelings about the amputation, possibly because they did not have the right support or tools to do this. If they did feel any anguish, they did not disclose it to others or discuss their feelings with anyone. They were surprised by this lack of psychological support and felt abandoned

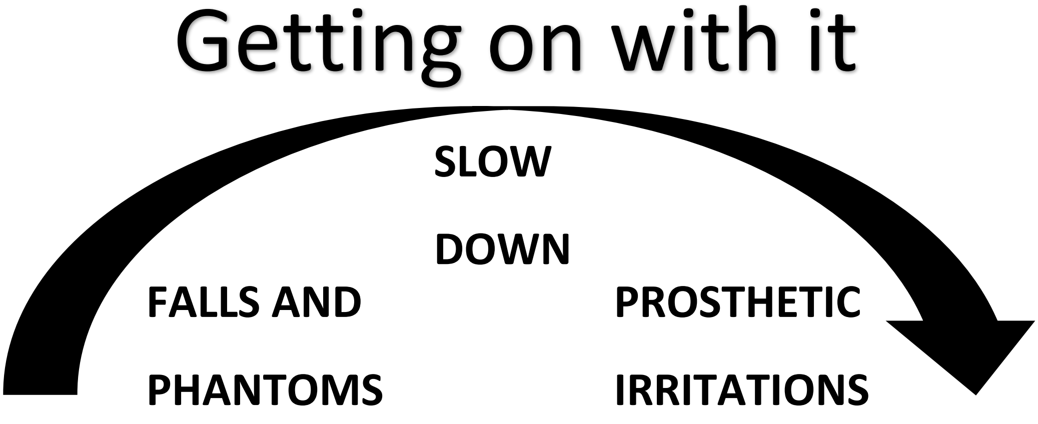
“*There’s nothing, there’s nothing following it up, particularly mentally, I found that well disappointing really, cos I hadn’t really got anybody to speak to, you didn’t even get offered any, no telephone numbers or, you know, that sorta thing, it’s like no follow-up over telephone, how are you getting on, that sorta thing. I’m like really*?” (AK006).

Another challenge the participants described was poor treatment received from strangers when they were out in their wheelchair. These poor societal attitudes were considered exclusive to using the wheelchair, where attitudes from strangers were considered so bad that participants needed to mentally prepare before they go out. However, they had a different experience when using the prosthesis when they feel they are treated with greater respect

“*I get more abuse in my wheelchair than what I do on my prosthetic; on my prosthetic I very rarely get any abuse at all. I think most people just look at you and think well, you know, good on you, mate, but when you’re in your wheelchair people tend to, you know, they’ll, they’ll push past you, they, they’ll walk in front of you… people’s attitude towards people in wheelchairs is very poor*” (AK001).

Mental toughness is required in these situations to cope with the unfair judgements of others.

7.6.3 Theme III: Getting on with it



This theme describes the process of finding new ways to do things with the inevitable burdens of amputation, the practicalities of daily life, and the worked involved with navigating daily tasks as someone with a missing limb. The first sub-theme "slow down" describes how life as a whole post amputation must be taken at a slower pace, and how the participants make their world smaller in order to feel safe. The second sub-theme "falls and phantoms" includes the exclusive problems that people with limb loss experience on a daily basis. The third sub-theme "prosthetic irritations" describes the issues caused by the prosthetic limb.

Table 7.7 - sub-themes and example quotes for theme III

Theme	**Sub-theme**	**Codes**	**Quotes**
Getting on with it	Slow down	Ability Environment Expectations of amputation Life goals, priorities and achievements Social factors	"*I can do most things but it's just certain things like hoovering, cos I've got two sticks I can't hoover when I'm standing, I can hoover in the chair but I can't hoover when I'm standing*" (AK002) "*I don't do a lot, I don't do a lot of walking, to be honest with you, cos it, it's still quite a struggle to get around, but at least I can potter about*" (AK006) "*So you just set yourself different things, different targets and be realistic about it*" (TK006)
	Falls and phantoms	Day to day impact of amputation Expectations of amputation or prosthesis	"*I think my biggest thing is that I'm terrified I'm going to fall over but I don't really know what I'm terrified of falling over*" (AK003) "*I did ask a doctor; how come we get these phantom pains then? "it's all in the mind" he said, no it isn't, it's in my leg*!" (TK003)
	Prosthetic grievances	Expectations of prosthesis Living with a prosthesis	When the prosthesis becomes misaligned: "*you've then got to stop somewhere and get into somewhere where you can sort of remove it and then put it back on again properly kinda thing, and it, it, it can be an embarrassment*". (AK005) "*…even with the seat fully back can be a problem getting into a car without smacking the knee off, you know, the, the, the lower part of the dashboard*" (TK006)

Slow down

Participants described their reluctant acceptance of having to slow down post amputation. Whether they were using their prosthesis or in the wheelchair many everyday activities now took more time than they did pre-amputation. Slowing down did not only refer to time taken to compete a task or activity, but also the activity itself had to change, and life as a whole must be taken at a slower pace

"*I've become more pragmatic, what happens happens, what I can do, I do it, for however long it takes me to do it as opposed to rushing*" (TK003).

"*I've always been an active person, you know, and I've had to take life, you know leisurely, slowly. I can't, there's, there's no way, you know, like I used to rush about and do things and get a lot done and stuff, but now it's, everything takes time but I've got used to it so it's not a problem*" (AK004).

Adjustments to everyday life are made to accommodate new levels of ability. Those who had their amputation many years ago have accepted these changes in activities. For prosthetic limb users, activities are bound by the limitations of having a prosthesis, or by the limitations of the prosthetic componentry. For example, one participant (TK006) is aiming to return to playing golf and needed an additional rotation adaptor on his prosthesis to make rotation during golf swing easier. However, due to the length of his through-knee socket there was no space to fit the adaptor. He still plays golf however but wonders if this would be easier had he been able to add the specialist parts to his prosthesis. Other participants describe changing their hobbies to suit their new abilities

"*I'm quite happy pottering about in the shed or the garage; I know that sounds a very old person thing to do, doing different types of things rather than the stuff I used to do*" (TK006).

Those who had their amputations more recently recall the way they felt they had to push themselves in the early stages of rehabilitation. These participants then learned that this level of activity is not sustainable in the long run, and they settle into a new activity level which is sustainable

"cos initially you've got, you're focusing on, right, I'm gonna get back to driving, I'm gonna get back to work, I'm gonna get back to going, going out and about and getting in the pub, and you, and you make the special effort to do that and then you get home and you're knackered and what have you but you've done it, and that's what it really

focuses on, doing that, but later on when you're capable of doing them things you don't want 'em, you feel more isolated" (AK006).

Without internal motivation to reach a goal, or motivation and encouragement from others, it is hard to continue to take part in activities regularly due to amount of effort required. Motivation in the first year comes from having a focus and working towards a goal but once that is achieved the motivation is lost as AK006 described. He had difficulty finding internal motivation, as he lives on his own, but when friends invite him somewhere he is more likely to do it.

Once they have achieved that sustainable level it become apparent which activities won't ever be possible again. For some, they grieve for the activities that they are not able to do anymore. Some participants also described the inability to perform essential everyday tasks like driving, or taking care of themselves, which leads to decreased levels of independence

"*me and my husband, before it all started, before my knee went and everything else, used to go down and walk for ten miles on a Sunday. There's no way on earth I'd be able to do that now; a mile I think would be, I'd, I'd be pushing is. It's, it's just heart breaking that you have to stop things that you liked*" (AK002).

However, due to how challenging activities can be after having an amputation, when a goal is achieved, or a new skill learned this comes with a huge a sense of pride and achievement

"*I can kick a ball, you know, I can't kick it very hard but I can kick a ball…so, you know, if one of the grandkids comes round I can side-kick the ball to them, I can play in the back-garden football with them and they think it's great, you know, I'm the bionic man*" (AK001).

One coping mechanism to achieving goals and becoming socially active is thorough planning. By planning ahead, you reduce the risk of being faced unexpectedly with an obstacle that cannot be overcome. While good planning means the task is now possible, it does take longer. Not only must planning time be taken into consideration but it also reduces the number of new places people are likely to go. Once an easily accessible route is established, they are more likely to repeat this route and return to the same place. Therefore, they lose that spontaneity that non-disabled people take for granted

"*we like to go out for dinner, saves on cooking and washing up, so we try to do that a couple of time a week if we can, depending on where were going its either the wheelchair, the rollator or the sticks, we check out what it's like first, if its wheelchair friendly, stick friendly whatever if they've got big steps here there and everywhere just do a bit of research then you know what's coming and you can plan for it*" (TK001).

The prosthesis or the wheelchair places physical restrictions on the person meaning that nearly all tasks now take longer. In addition, prosthetic limb users must purposefully slow themselves down to avoid having a fall.

Some of the participants with TKA described specific movements, abilities, and tasks they could do because of their end-weight bearing residuum. When the prosthesis is removed, they have a residual limb that is functional and can be used to kneel to do the gardening, or used as a lever for tricky transfers

"*I don't so much kneel but I do tend to, when I've got the leg off I'll, I'll weight bear, I'll almost walk down the bed if that makes sense with my good leg on the floor and weight bearing on the end of the stump to get to the end of the bed to get my crutches*" (TK010).

Falls and phantoms

Participants were not asked about falls or phantoms unless they brought it up. Falls and phantom pain was described as an expected part of life post amputation. The participants all expected to have falls and experience phantom pain, and when they did, they could often accept this as normal life as an amputee; it is not seen as a failure, but something to learn to live with.

Falls were considered an inevitable part of life post amputation by participants in both groups. They live their lives with the expectations of having a fall constantly in the back of their minds, having to constantly think about avoiding falls at all times. Most participants in both groups describe a history of falls and feeling afraid of having further falls. Participants who have never fallen, or only fallen once, still feel like they are constantly at risk of falling

“*to be honest with you with amputees I don’t think it’s a matter of if, it’s a matter of when you’re gonna fall over and how bad*” (TK011).

Some participants have anxiety caused by frequent falls which deters them from trying some activities. By restricting how far they go they make their life smaller, but safer;

“*never really recovered from falling, I think. I mean I do get, I have got the confidence to get out and about more than I used to but I don’t go very far*” (AK002).

Some participants had found greater confidence due to a change in prosthetic componentry. Those with MPKs, whether they had TKA or AKA, were more confident because their prosthetic knee is designed to prevent falls. Those who did not meet the criteria for an MPK and were afraid of falling chose to have a locked knee which increased their confidence enough to increase their mobility. The knee function made the difference here, not the amputation level

“*I wouldn’t have gone abroad on my old, this knee, its, the stumble recovery and whatever is brilliant so it gives you confidence that you can walk about on your own and not make a tit of yourself, basically*” (AK006)

“*I had five bad falls and I had about nineteen near misses; so that’s, as I say, that’s why they gave me the C, C-leg, and touch wood and everything else I don’t fall, I haven’t fallen now so since they gave me the C-leg. I’ve had the C-leg about, I suppose just under eighteen months I think, something like that, so it’s, that, in that respect I’m starting to get more confident on it*” (AK002).

The AKA group reported being more afraid of falling than the TKA group. One participant with an AKA, despite their small number of falls, described being terrified of falling, especially at the thought of falling somewhere they cannot get up, and are particularly worried about feeling embarrassed should this happen in a public place. The TKA group were more concerned about harm minimisation and described previous falls whilst doing high level actives like fishing or hiking. This may suggest this group of people with TKA had greater confidence in mobility, possibly due to the greater stability offered by a TKA compared to an AKA.

Phantom pain was described as normal, something that everyone gets after amputation and therefore is another thing to contend with in everyday life. It is also something that is exclusive to people after amputation and therefore considered that people who had not had an amputation would struggle to ever understand what it is like. There was a range of levels of phantom pain experienced by the participants. Those that experience only low levels of phantom pain described themselves as being lucky, whereas others experienced high levels of phantom pain, which severely impacts their day-to-day experiences and requires management strategies. Frequency and severity of phantom pain was similar between the two groups

"*it's hard to describe the type, the types of pain you get for people that haven't had their leg off you know, the, the sort of when it, when it proper starts and it feels like somebody's took a hammer to your ankle but you haven't got an ankle, you know, or, or, or, or, or your shin is on fire, you haven't, you haven't got a shin, or your toes are, are wrapped in barbed wire but you haven't got any toes*" (AK006).

Prosthetic Grievances

Having to live with the ongoing irritants caused by the prosthetic limb was also accepted as an unavoidable element unique to living with an amputation. The task of learning to walk with the prosthesis is the first challenge, and one that requires not only physical but mental engagement to visualise and activate the muscles needed to make each step

"*it's not only a physical exercise it's a mental exercise as well, cos it, almost each step you're trying to think of what muscles you need to use to make that step*" (AK003).

Over time a personal relationship is formed with the prosthesis which involves understanding the quirks of their prosthesis and learning how to correct any problems on an ongoing basis. Problems tended to develop as the residual limb changes shape causing issues with the fit and comfort of the prosthesis

“*I’ve been back to the limb centre and had it adjusted and all sorts of things it, it doesn’t take into account that your stump changes all the time, or it can change on a daily basis and the, the limb itself just doesn’t, it isn’t an adaptive limb*” (AK005).

When the prosthesis is not fitting correctly it can make unwanted noises, become dislodged, or even fall off. Leading not only to discomfort but also embarrassment;

“*it’s the rubber sock really that causes me a little bit of grief, you know, and its, you know, you’re walking down the street, if it’s not fitting aright and you go out and its, it’s like, you know, like you’re blowing wind all day*” (AK004).

Sometimes these problems become so serious that the prosthesis can no longer be worn and must be adjusted. Replacing the prosthesis is something that is avoided for as long as possible because there is a fear that the newly adjusted prosthesis will be worse than the current one, leaving the prosthesis wearer in the position or re-learning how to manage their limb, and leaving them without a limb for a period of time, which risks further muscle wastage

“*then my leg got too big and started falling off and not being, being very good; so, I was actually out of, out of my leg for about two or three weeks and you, you don’t under, you don’t realise how your muscle wastes so quick*” (AK002).

Participants in both groups talked about their residuum changing shape resulting in poor fit of the prosthesis. For some this causes discomfort or even pressure damage to the skin. For those in the AKA group, when their socket becomes too large it can become dislodged when walking, requiring the person to stop and adjust their prosthesis, sometimes even needing to find somewhere to remove it and put it on again. The TKA group are less likely to have this problem due to the shape of their residuum which holds the socket in place better. The shape of the AKA socket, even when fitting correctly can cause discomfort when sitting down or kneeling

“*it’s so uncomfortable to sit in because it’s so high up in your crutch and up into your bottom*” (AK003)

“*when you go to kneel down that socket can nip certain parts of your anatomy so, so you’ve kinda got to be careful. So I try not to kneel down as much*” (AK006).

This was a particular problem for participants who were less active and needed to spend time sitting down

"*it's very uncomfortable to sit and if you, I'm alright when I'm walking but you can't walk all the time cos I'm, I'm not that good at walking*" (AK002).

This limits this participant from wearing her leg all day, which is what she would like to do, but she describes if she has had a busy day and is tired, she feels her only option is to take the leg off while she rests.

Interviewees with AKA also talked about their dislike of the total elastic suspension (TES) belts commonly used to hold the prosthesis in place. They are usually used for people with an AKA, as a TKA residuum has the potential for self-suspension. TES belts were disliked because of their appearance, and they were uncomfortable to wear, often causing chaffing and soreness:

"*dirty great big harness*" (AK001)

"*bulky horrible old lady's tights looking kind of contraption*" (AK003)

"*the strap used to chaff round me waist and cause me sores*" (AK004).

In contrast, the biggest concern raised by the TKA group was the protruding prosthetic knee can cause problems when sitting somewhere with limited leg room.

"*I paid for extra leg, extra, extra leg room seats. I wouldn't have, on a normal economy short haul flight I just couldn't fit into, into the, the normal seats*" (TK006)

"*when I first started to drive I found it [the prosthesis] really got in the way because it was basically straight up against the dash whereas my other knee was a lot further back, so what I did was I took my leg off put it on the passenger seat and drove that way*" (TK011).

7.7 Discussion

7.7.1 Main findings

This study investigated the experiences of 13 people with TKA and compared their lived experience to seven people with AKA. At the time of writing this is the largest sample of people with TKA in a qualitative study. The ten papers included in the qualitative evidence synthesis in Chapter 2 had a total of 11 participants with TKA across all ten studies. This study found that level of amputation did not influence whether a person chooses to hide or display their prosthesis; the theme hide or pride portrays the participant's relationship with their prosthesis, and how they want to portray themselves to the outside world. People with TKA find it hard to disguise their knee, but are grateful for the functional advantages, while people with AKA find it hard to disguise their bulky socket. Both groups experience initial relief post amputation; the TKA group were grateful they had kept more of their leg. Both groups also draw from their inner mental toughness as a way of coping with their change in circumstances and to learn to live with their amputation. Finally, both groups had to learn to live with the daily challenges all people post amputation face including falls and phantoms, changing pace, and annoyances with their prosthesis. The TKA group complained their knee sticks out when there is limited leg room, while the AKA group dislike that their socket rotates, digs in and nips their skin.

Hide or pride

For some, the desire to hide or reveal their prosthesis would depend on the scenario; their disability is always there and whether they choose to disguise their prosthesis in the background or display their prosthesis in the foreground was due to what benefitted them most in whichever situation they were in at the time. In some scenarios, they wanted to be recognised and treated as a disabled person, be entitled to accessible services without being questioned, and for this they made sure their disability was clearly visible. Participants who do not use a prosthesis do not have the option to hide their disability as they rely on the wheelchair to move around. However, at times they still felt the need to justify their reason for using a wheelchair. They had the choice to show or hide their amputation and this was related to demonstrating their need for their wheelchair. While there is a large body of qualitative evidence exploring experiences of wheelchair users, most amputation specific research, similar to amputation rehabilitation services in the UK, is mostly focused on prosthetic limb users. Lopez (2017) explored the experiences of wheelchair users after amputation but did not explore body image or how people in wheelchairs choose to portray themselves to others.

While showing the disability was often used to the participants advantage, if someone's disability is visible, the participants in this study felt vulnerable to being judged by strangers based solely on their visible symptoms. Goffman (1963) has written extensively on the concept of stigma "the situation of the individual who is disqualified from full social acceptance" specific to individual social encounters, rather than other theories which focus on socio-economic structures. The participants in the current study felt that their degree of social acceptance could change depending on how they chose to portray their disability. They felt they were placed into categories by strangers depending on their physical appearance; being in their wheelchair meant they felt categorised as disabled, whereas when they were wearing their prosthetic leg, they were seen as someone to be respected. This fits in to the individual-idealist model of disability (Priestley, 1998) whereby an individual's disability is determined by the attitudes of non-disabled people towards them, but also, from the individuals own attitudes, beliefs and experiences (Budd, 2016). This would suggest these experiences from the participants of the current study also reflect how they feel about themselves when in the wheelchair compared to using their prosthesis. Those participants who can use a prosthesis and sometimes use a wheelchair therefore have dual identity and can further choose which identity they wish to portray depending in the situation.

Similar themes were found by Heavey (2013), who explored what disability means to people with limb loss; the participants in that study defined disability as "a measure of (in)ability", how they appeared to others "a stigmatizing mask", and as a label which granted certain privileges "an official status".

In the current study the social interactions experienced by participants displaying their prosthesis were mostly positive. For those who display their prosthesis, there was a feeling that they were treated with more respect by strangers when they can see their prosthesis. Murray (2009) interviewed 35 people with upper or lower limb loss about their thoughts on their cosmesis. Some participants described the psychological advantages a convincing cosmetic limb provided and the importance of looking bodily complete. Whereas other participants in Murray's study felt this was not important, in fact they felt they should not be made to feel like they should conform to pressures to hide their amputation to please others. Writing in 1994, Radley (1994) argued that members of society tend to have a positive response to people who look more bodily-complete, because the prosthesis is more “human” looking, it is easier to look at, understand, and therefore accept. By walking around, the person with the disability “fits in” with the rest of society, and by showing the prosthesis the public perceive them as being strong. However, sometimes it is important for the participants to display their differences or disabled characteristics to manage the expectations put on them by society. There is a tension felt by the participants in this current study between passing as normal and hiding disability and feeling the need to demonstrate disability to access support or manage expectations of others. This “playing the disabled role” has been previously explored by Porter (2000). Porter defines playing the disabled role as “accepting and conforming to the definition of ‘disabled’ as imposed by others, in return for certain privileges”. To play this role the individual must actively express their disability, and then let themselves be labelled as such by others. The social model of disability, first defined by Oliver (1983) refers more to the limitations the structural world, institutions, and cultural society place on people with impairments. Therefore, the degree to which the individual is impaired is based on how much they are able to do based on their environment and what they want to be able to achieve. For example, someone who wants to mobilise around the house safely might not feel disabled, but someone who can mobilise unaided, but used to climb ladders for work and now cannot do that, feels disabled. This extends to attitudes from others in that a lay person might see a person walking unaided with a prosthesis and are unlikely to understand the difficulties that person faces by using a prosthesis, for example the increased energy expenditure needed to mobilise, the additional attention to the environment, and socket discomfort, so they do not necessarily see the person as being impaired. Whereas in a wheelchair, their impairment is obvious to a lay person.

Decision to display the prosthesis was also associated to the identity the person wants to portray to the world. With advancements in prosthetic technology there are now more options for how someone choose to express their identity through their body (Barnes & Mercer, 2003). In the current study clothing was used as the method to either confidently display ones' prosthesis, for example by wearing shorts, or disguise by wearing long baggy trousers, which was distressing for some female participants who would not have worn baggy trousers pre-amputation. Similar themes have been identified by Ward Khan et al. (2019) who explored women's body image and sexuality following BKA, AKA and pelvic amputation. In their study, the loss of wearing their preferred clothing and shoes led to the women in that study feeling like they had lost their identity, and was described as "frustrating" and a "tragic loss". Roberts et al. (2021) interviewed ten people with lower limb loss, including one person with TKA about the daily experience of using a prosthesis. Similar to some participants in the current study, Roberts found that people prioritise function over appearance of the prosthesis, but some did voice a desire for their prosthesis to look like their other leg. The participants in the current study described having to choose between the larger circuitry in the more advanced prosthetic limbs, which provided greater functionality, but pay the price of increase bulk and being obvious to others. For some this was not viewed as an issue, but for some it was significantly stigmatising to make their prosthesis so obvious to others and give themselves a less than "normal" general appearance. In our society disability and impairment have negative connotations (Hughes, 2012) and clothes can be used to either kick against the norm, or to hide disability (Kaiser et al., 2010).

The results of the current study suggest that an individual's preference to disguise or display their amputation is not influenced by the level of their amputation. People with TKA who wish to hide their prosthesis face challenges caused by the long residuum and the prosthetic knee sticking out, whereas people with AKA find it difficult to disguise their bulky prosthetic socket under their trousers. However, for those that like to display their prosthesis they mostly like the cosmetic look, enjoy getting patterns printed on the socket, and feel a sense of pride for mobilising with their prosthesis. It is important for clinicians to open dialog with their patients about their preferences and counsel them on the different cosmetic options. We also need to know more about body image and identity expression in people with different levels of amputation and at different mobility levels to better support people post amputation.

Staying positive

Staying positive was presented by the participants in the current study as an essential trait needed to cope after a major amputation. This appeared to be easiest in the initial stages of amputation where feelings of relief and optimism are strongest. Pain caused by the affected foot or knee is resolved which has an instant improvement in QoL. Before rehabilitation starts, or in the early stages of rehabilitation, as the effected body part has been taken away movements are easier, and the thought of getting a prosthetic leg and moving forward with life enhances this huge feeling of relief. Those with TKA have additional feelings of relief to have kept more of their own leg than if they had had an AKA.

The finding that some people feel relieved after amputation is contradictory to most qualitative studies exploring experiences of amputation. A meta-synthesis by Murray and Forshaw (2013) described how having an amputation and facing prosthesis use provoked negative feelings including shock, loss of independence, sadness, anger, and disappointment, with no positive feelings associated with this initial post amputation phase. A theory presented by Madsen et al. (2016) is that of a “pendulating” pattern of experiences post amputation where people described swinging between emotions of losing control and regaining control, but again all initial feelings were described as “losing control”, “being overwhelmed”, and “facing dependency”. Day et al. (2019) presented similar findings of daily fluctuations of physical, social, and psychological functioning. One explanation for the different experiences described by the participants in the present study is the effect of recall bias. Many qualitative studies interview the participants at the time of amputation, whereas the participants in the present study ranged from amputation between one and 49 years. However, this is not to say that this makes the findings of the present study of relief post-amputation any less accurate but reflects the passage of time on how participants feel about the time of their amputation. The lens through which people look at the events of their amputation several years, or even decades later is quite different to the lens through which people currently going through an amputation may see things.

Sanders et al. (2020) used interviews, observations, and diaries, to map people’s recovery trajectories over the first year after amputation. One of the five identified narrative typologies was called the “illusive cure” trajectory which maps the well-being of people struggling with pain and disability pre-amputation, and how these patients experience an increase in well-being immediately after amputation. However, this narrative describes an inevitable decrease in well-being over time. This mapped trajectory only covers the first few months after amputation while people were attending rehabilitation. Participants in the current study reflected on how they experienced this decrease in well-being when they realised rehabilitation was going to be harder than they thought, but also recognised the potential to increase in well-being if rehabilitation was successful; some were happy with their current mobility several years post amputation, some felt it was acceptable, and some had declined, which suggests when looking at longer term outcomes the trajectory can be different not just decline.

Following the early post-operative stage, psychological resilience is essential to returning to normal life. Resilience is the ability to adapt, move on, and bounce back after a traumatic event, injury, or stress (Charney, 2018). External stresses continue not only with the physical demands post amputation but also when out and about, the way people with disabilities are perceived or treated in the community can be demoralising. Resilience is required to maintain motivation to keep socially active and to ignore negative looks and comments from the public. There is a large body of evidence exploring societies negative attitudes towards people in wheelchairs (Furnham & Thompson, 1994; Taleporos, 2002; Bailey et al., 2016). The daily prejudice experienced by people in wheelchairs by non-disabled people feeds into the ongoing oppression and segregation that society places on disabled people (Riddell & Watson, 2003).

Barnes (2003) describes rehabilitation as a “second chance”, or an opportunity to “rebuild” oneself. This was particularly true for the participants in this study who had poor mobility and function before their amputation. Barnes also describes how traditionally, for someone to be seen as successfully rehabilitated, they are expected to regain “normal” function; in the case of the present study population walking with a prosthesis. However, Barnes goes on to argue that this should not be the case as some people achieve high levels of function using a wheelchair. Some of the participants in the present study described how the use of walking aids with their prosthesis were more disabling than the wheelchair, and they were able to achieve more tasks in the wheelchair. Other qualitative studies have also evidenced that people find some daily tasks easier to do in the wheelchair (Roberts et al., 2021).

Getting on with it

The participants in the current study felt that falling and phantom pain are a normal part of life after amputation. Those who have not experienced falls or phantoms consider themselves lucky, but are aware this is something they may yet encounter.

It must be accepted that many activities, either enjoyable or essential, are more difficult following an amputation and a new way to achieve the task must be found - accepting this will take longer than previously - or in some cases admitting this is no longer possible. The participants described that they adapted and reduced the size of their world to accommodate their disability. Time spent being annoyed at this before acceptance was felt by many to be time wasted and the best thing to do was just get on with it. Daily life will continue to be a challenge but one that must be faced day in day out. Some things that cannot be changed and therefore must be accepted and tolerated are the irritations caused by the prosthesis. The prosthesis is uncomfortable to wear and does not fit effortlessly within the participants' world. People with TKA must get used to the long knee unit, and people with AKA must get used to the uncomfortable socket. Participants learned to be stoical about their prosthetic discomfort in order to continue mobilising. Acceptance of their situation allows them to move on and to lead enriching lives. Norlyk et al. (2016) labelled this time period as "the in-between" where the previous life of the individual is over, but they have not yet integrated into their new life. Time spent focussed on what they have lost is viewed as time wasted, and to push beyond this requires adjustment, organisation and planning.

Adjusting goals and planning ahead were coping strategies found in the current study and have been previously studied in the amputation population. Day et al. (2019) conducted focus groups with people who had had amputations to explore their everyday experiences. She developed a theme called "organization and planning" which describes the sense of joy the participants felt when they overcame obstacles, but that in order to do this involves a lot of planning. Similarly, Dunne et al. (2014) evidenced the importance of adjusting goals and accepting limitations, as well as accepting help from family and friends to achieve certain goals. Roberts et al. (2021) interviewed ten people with amputations including one person with a TKA. One theme from that study was called “New routines and challenges: performing activities of daily living” where participants described which tasks they use their prosthesis for, and which were easier done in the wheelchair. There were clear similarities between the findings of the current study and those of Roberts’, with participants adapting how they undertook daily activities to accomplish basic tasks.

Radley (1994) discussed the ways people adapt to living with chronic illness and how people use coping strategies. These different strategies of coping as described by Radley come into play by the participants in the current study. Problem-based coping is their way of finding new ways to do things. Emotion-based coping is the attempt to minimise their emotional impact through adopting a particular attitude.

It has been argued that the prosthetic socket is more important to functional use of the prostheses than the knee component (Lee et al., 1997; Turner & McGregor, 2020). Without a comfortable socket the person is less likely to utilise their prosthesis regardless of knee component (Lee et al., 1997). While lack of prosthetic components for TKA was given as a reason not to perform TKA by some surgeons, the patients with TKA reported greater socket comfort which should potentially have a greater influence over decision making of level of amputation and future ambulation potential.

7.7.2 What this study adds

This is the first study, to the authors knowledge, to focus on the lived experience of people with TKA, giving people with TKA a represented voice in the body of qualitative amputation literature. This study adds a unique perspective regarding life post major lower limb amputation and will help to debunk the myths held by clinicians that people do not like TKA. This study supports the option of TKA for people needing amputation and demonstrates the need for future prospective studies.

People with TKA, when included in samples of qualitative studies, are commonly grouped together with people with AKA; this is the first time a study has compared the differences between living with each type of amputation. The main differences found were:

- People with TKA have difficulty disguising their long prosthetic knee, whereas people with AKA have knees at the same level
- People with AKA struggle to disguise their bulky sockets under trousers
- People with TKA feel relief post amputation for keeping more of their own leg than if they had had AKA
- People with TKA can use their residual limb to assist with transfers
- People with TKA find that when their knee sticks out it can get in the way when there is little leg room
- People with AKA have more problems with socket comfort; their socket nips their skin, or rotates when walking requiring it to be adjusted

The main similarities between the groups were:

- People with TKA and AKA consider positive mental attitude after amputation an important trait
- Many people after TKA and AKA are relieved to have had their amputation, especially those who were in pain pre-operatively
- Increased function after amputation leads to sustained feelings of relief
- People with TKA and AKA consider falling and phantom pain to be a normal part of life after amputation; prosthetic componentry seems to play a bigger role in falls confidence than level of amputation

This study found that feeling relieved after having a major amputation was more common in interviewed participants than the existing literature suggests. Amputation surgery is not the end of the road, but the start of a new one, and several participants described their optimism for the future immediately post amputation. Lower limb amputation can improve QoL if the person is suffering with pain or reduced independence due to a non-functioning limb.

This study also adds an incredibly important viewpoint of non-prosthetic users who are often neglected from studies involving people after amputation. Often the focus of the study is the prosthesis, which excludes the majority of people after amputation as less than half the people who have amputations are fitted with a prosthesis (Davie-Smith et al., 2020). This study explored, how people feel about the appearance of their residual limb, and how they feel displaying or disguising the reason for being in their wheelchair.

The findings of the current study were compared to the findings of the qualitative evidence synthesis (QES) in Chapter 2. Similar themes were found across the two studies. Firstly, the QES supports the finding that choice to display or disguise is not based on amputation level but rather the personality traits of the individual combined with the situation they are in. Secondly, the results of the QES suggested that people with TKA prefer the look of their residual limb which is also suggested in the findings of this study. Thirdly, the QES suggested that people with TKA may have a more comfortable prosthesis than people with AKA which is reinforced in the current study where more people with AKA had complaints about the discomfort of their prosthesis. Finally, the QES had uncertain conclusions about possible differences in falls between TKA and AKA, where the findings of the current study suggest that people with TKA may have more confidence and walking but suggests that componentry makes a bigger difference on falls confidence than level of amputation.

7.7.3 Reflection on methods

I had to remain aware of my background as a clinician throughout the whole process and reflect on how this may influence each stage of the interviews and analysis. As a clinician, and non-disabled person, I had an outsider position (Braun and Clarke, 2013). During analysis I had to make sure I was listening to the participants stories and not applying clinical rationale. The technique I used for this was making a note of my thoughts and feelings and then physically putting that to one side, I would write these clinical thoughts in a notebook to get them out of my head and close the notebook so I could focus on what the participant was telling me. I did not disclose that I am physiotherapist unless asked by the participants due to the risk of creating a power dynamic. However, interviews themselves have been criticised for forming a power dynamic, as the researcher asking questions takes on the dominant role, thus reducing the likelihood of uncovering deep feelings from the participants, and encouraging a more conversation style interview as superior for reducing power dynamics (Russell, 1999). Though power dynamics exist in all human interactions (Nunkoosing, 2005) therefore cannot be removed completely from the research interview (Glesne, 2010), an awareness of the threat to quality is important and interviewees must be made to feel as comfortable as possible.

I was aware that I am a new researcher and had limited qualitative interviewing experience. I could draw on experiences of clinical interviewing but had to make sure I was applying practices of qualitative interviewing. While the purpose of clinician interviews and research interviews differ, i.e., when I would complete a clinical interview with a patient, I was aiming to uncover how often they were doing their exercises and using their prosthesis, any problems they were having with their prosthesis, and any outstanding goals whereas these research interviews with patients were aiming to explore what the participants felt is important about living with their amputation. Skills such as using non-leading open-ended questions and knowing when to probe for more detail could be transferred from clinician to research interview (Hunt, 2011).

I have also reflected on how my findings resonate with my clinical practice. The sub-theme of relief after amputation was not a surprise to me as this is something I often see in clinical practice. I had to be careful when analysing the data that I was not at risk of biasing the results because I had found something I was familiar with. I looked at how I asked the questions to make sure I had not been leading with my wording; I did not ask any participants if they felt relieved, only how they felt after amputation, and the words relief and relived were often used by the participants.

I also reflected on the differences between the two qualitative studies and the differences between the interviews with the clinicians and the patients, and I had to adapt my interview style accordingly. It took longer to build a rapport with the patients, and they often wanted to talk about other subjects, so I had to learn to manage the time we had for the interview to make sure I covered all the topics, but also let them speak to not ruin the rapport. When reflecting on the different methods of data collection, i.e., face-to-face versus telephone, by listening back to the audio recordings and critically reflecting on my interview style, I identified times where I had interrupted the participant by not allowing for long pauses, so I started leaving more time after participant responses. I also realised that I was not allowing enough time for the participant to relax in to the interview, with face-to-face interviews the small talk pre-interview happened naturally, discussing the weather or travel to the interview for example, whereas with the first telephone interviews I immediately started asking the topic guide questions, however after the first couple I started to ask how their day had been so far, or about the weather, and found this improved the interview quality. Once I had refined my telephone interview technique, I found them to be just as good as face to face. I reflected on each telephone interview and spoke with my supervisor and the quality improved quickly and I actually found the participants opened up over the telephone interviews, possibly because of the additional feeling of anonymity, a finding also reported by Novick (2008). I also could not use the photos I used in the first interviews, but on reflection they added little to the interview, so this was not considered to be a limitation.

The biggest risk to completing this study was the introduction of COVID-19 restrictions in March 2020. Changes had to be made to the methods retrospectively to meet the new requirements and minimise unnecessary risks to participants. Recruitment time was extended and approved by IRAS and while many study recruitments within the Hull University Teaching Hospitals NHS Trust were suspended, as this study was able to be completed remotely, recruitment was allowed to continue. With these new challenges a pragmatic approach was taken to target numbers for recruitment and satisfactory numbers of people with TKA, the target subset, were mostly recruited already. Sufficient interviews were finished after the seventh AKA interview (Malterud et al., 2016). All the interviews were of good enough quality to contribute to the findings. I also had good connections for recruitment, a good understanding of the patient population, so therefore recruitment, despite COVID-19, went relatively smoothly. It was however decided in the early stages of the project that focus groups were no longer appropriate as at the time of recruitment it was deemed unlikely that groups of potentially vulnerable people would be allowed to meet in a hospital setting for non-essential visits. Virtual focus groups were also considered, but based on the technology skills, and ownership of devices of the participants that had already taken part, it was obvious that choosing to do this would remove the opportunity for a large portion of people to participate, increasing the social disadvantage already experienced by many people with amputations and potentially introducing selection bias.

The use of shopping vouchers helped with recruitment, participants were keen to take part and felt valued for receiving a thank you voucher. Some were grateful to get a voucher that you could spend at shops that sell essential items, and others said they were going to donate their voucher to a charity.

No participants expressed any distress during the interview. One participant said it had been a therapeutic experience and even said it was the first time since his amputation that someone from the hospital had been to talk to him about his feelings.

7.7.4 Limitations

The focus groups would have provided the opportunity for people with TKA to talk to people with AKA and vice versa. This was expected to produce more information about the differences in their experiences and abilities, as it is known from clinical experience that people with amputation like talking to other people with amputation, this was even stated by several participants in this study, and so the interviews mean that the comparative aspect of the analysis is drawn from my analysis, rather than direct participant quotes. All participants were white British. Recruitment took place where the majority of the population are white British which means it is possible we missed out on unique views held by people from other ethnic backgrounds. The youngest person in the sample is 43. Three female participants under the age of 40 were identified as potentially meeting the criteria but all three declined to take part. No young males were identified at screening but three of the men that took part had their amputation when they were young and could reflect back on those times. The mean age of this sample was 64(±13) years which is similar to the SPARG study where the mean population age was 69(±13) years.

The theme staying positive may have been a reflection on the sample that agreed to participate in my study. It is possible they were keen to share their success stories;

however, some opposing views were also found within the sample, so this was not the case for every participant.

Few conclusions could be drawn regarding how type of TKA influenced the lived experience of the patient, partly because this data was not collected from the second site, a limitation to the study, or because there were several inconsistencies in the reporting of the available medical notes of the participants from the first site regarding type of surgery, lack of detailed surgery notes, and conflicting responses between patients and their medical notes regarding the type of surgery they had had. The number of participants with accurate data regarding exact surgical procedure was too small to allow any attempt to compare and contrast different TKA techniques in terms of patient experience. Even if this information had been available for all participants, the patients were mostly not well informed about the type of TKA they had, one participant thought he had an AKA, not a TKA, and this may have impacted the findings.

7.7.5 Study quality

Several steps were taken to ensure study quality. An audit trial of the analysis was kept by exporting the coding book at each stage of coding and summarising the contents of each code. This provides transparency with the analysis process (Connelly & Peltzer, 2016; Nowell et al., 2017). Analysis was completed by the researcher but with support from a supervisor (MT) at each stage. Full details of each stage and evidence from the audit trail is provided in section 7.4. By including the details of the participants (Table 7.4), and the questions from the interviews (appendix 8) this allows the reader to interpret transferability to other populations. Also, similar themes to other qualitative papers were found which suggests good transferability and a broader relevance. Quality of the thematic analysis was assessed using the Braun and Clarke (2006) quality checklist to ensure all points have been followed.

7.8 Conclusion

This study examined the experiences of those living with TKA and AKA and how they have adapted to life post amputation. The prosthetic knee of a TKA prosthesis sticks out further than patients would like, but they are prepared to accept this cosmetic drawback to keep the functional advantages. Whereas people with AKA dislike their bulky socket as it is difficult to disguise under trousers, and also causes discomfort by nipping into the skin and rotating when walking. Prosthetic irritations are to be expected post amputation, as are falls and phantom pains. As a result, people in this study adapted to their new situation by slowing down and adjust their life goals post amputation.

Many people feel a sense of relief immediately post amputation, and then draw on resilient processes which helps them to get on with life post amputation. In contrast to the belief expressed by many UK clinicians (Siev-Ner, 2000; Smith, 2004), people with TKA are not unhappy with their amputation, in fact people with TKA expressed additional relief to those with AKA for having kept their entire thigh and for having a weight bearing end to their residual limb.

Chapter 8 Discussion

8.1 Introduction

This mixed methods study aimed to compare and contrast the outcomes, experiences, and perceptions of TKA and AKA through the completion of four studies. The mixed methods approach allowed for comparison of quantitative clinical outcome data, supported by in-depth qualitative exploration of perceptions of health care clinicians and people living with TKA and AKA. This chapter will discuss the key findings across the four studies of this thesis, any confirmation or contradiction of findings between the four studies, and the clinical implications of the findings.

This mixed methods study comprised of the following four studies:

Study 1) The SPARG study - quantitative retrospective cohort study (Chapter 4)
Study 2) The survey – a descriptive cross-sectional online survey for clinicians (Chapter 5)
Study 3) The clinician study – a cross-sectional comparative qualitative interview study of specialist clinicians (Chapter 6)
Study 4) The patient study – a cross-sectional comparative qualitative interview study of people with TKA and AKA (Chapter 7)

8.2 Integration of findings

This mixed methods research has, for the first time, explored clinician and patient voices regarding TKA and used these voices to give meaning to and help interpret the quantitative clinical outcomes observed in this surgery. The integration of findings will generate greater understanding of the research topic.

The discussion will use a weaving approach to present the integration of the data through narrative by describing the findings of all four studies on a concept-by-concept basis (Fetters et al., 2013). The findings will be organised by the four research questions and a table of findings will be presented for each research question to demonstrate which studies contributed findings for that question. The research questions of this thesis were:

1) How do the surgical and rehabilitation outcomes compare between TKA and AKA?
2) What does current practice of TKA and AKA look like in the UK and what are the influencing factors for choosing one over the other?
3) What are UK clinicians’ perceptions of TKA compared with AKA?
4) What are the similarities and differences of the lived experiences of TKA and AKA?

Whether the finding was confirmed or expanded on between studies for each question will be discussed, as will any studies that found contradicting findings. Where the study did not address the research question will be made clear in the tables. Where the same finding transcribes across more than one research question, it is only discussed once to generate greater integration of the findings.

8.3 How do the surgical and rehabilitation outcomes compare between TKA and AKA?

Study 1 (the SPARG study) addressed this first research question by analysing a large retrospective dataset of surgical and rehabilitation outcomes, the survey and interviews further explored clinician perceptions and patient experiences of wound healing, rehabilitation, and limb fitting.

Table 8.1 displays the findings of question 1 across the four studies.

Table 8.1 – table of findings that address question 1 across the four studies

Question 1) How do the surgical and rehabilitation outcomes compare between TKA and AKA?				
Finding	SPARG	Survey	Clinician	Patient
8.3.1 Wound healing	Increased risk of non-healing wound post TKA than AKA, but potentially improves with higher numbers performed	Clinicians perceive increased risk of wound breakdown with TKA	For some vascular surgeons any risk of wound breakdown is enough reason to never choose TKA. Surgeons who use TKA often reported good wound healing	No problems regarding wound healing reported by participants
8.3.2 Rehabilitation outcomes	Rehabilitation outcomes similar between TKA and AKA but potential suggestion for better outcomes for TKA	Several rehabilitation benefits of TKA over AKA were reported by the clinicians	Clinicians suspect TKA can provide some rehabilitation advantages	Small advantages of TKA such as end-weight bearing can be important factors to the person living with the amputation
8.3.3 Limb fitting	Similar numbers of TKA and AKA limb fitted, though TKA were possibly chosen for people not expected to limb fit	Lack of consensus from clinicians regarding limb fitting differences between TKA and AKA	Some clinicians suspect TKA improves chances of successful limb fitting compared to AKA	The TKA group reported fewer prosthetic irritations than the AKA group

8.3.1 Wound healing

Non-healing wounds or wound breakdown after amputation surgery is a serious problem with vascular amputations and can lead to significant adverse patient outcomes (Sarin et al., 1991; Berli et al., 2019). Amputation should be performed at a level where the wound will have the best chance of healing but also provide the patient the best chance at rehabilitation (Sarin et al., 1991). Choosing the level of amputation is subjective, while tools do exist to predict wound healing to guide choice of level of amputation, they are not well validated or frequently used, and choice of level is often informed by clinicians past experience (Sarin et al., 1991; Gough et al., 2014; Preece et al., 2021). A non-healing wound can increase length of hospital stay, increase chance of infection, and delay rehabilitation and time to prosthetic limb casting. In worst case scenarios it may lead to further surgery, or even revision to a higher amputation level. This is detrimental to the patient, especially as vascular patients are often co-morbid and anaesthesia for operations is risky for this patient group (Ziegler-Graham et al., 2008; Berli et al., 2019).

Data from the SPARG study demonstrate that 13% of TKA had further surgery, most likely due to wound complications, compared to only 4% of the AKA group. Re-amputation was considered an unacceptable outcome by the clinicians who answered the survey, and surgeons who prioritised reducing the risks of re-amputation often chose to perform AKA instead of TKA. Murakami and Murray (2016) suggested the reason for high re-amputation rates post TKA are due to poor patient selection and a lack of physiological measures used to decide level of amputation. This current research suggested that lack of experience performing TKA also lead to greater chance of re-amputation. This means future studies investigating wound healing rates after TKA should consider the experience of the surgeon as an influencing factor. It is recommended that only experienced surgeons perform amputations due to a link between surgical inexperience and poor patient outcomes (Gough et al., 2014). Survey and interview data from the physiotherapists and prosthetists support these conclusions as they reported they would prefer surgeons to perform amputations they are familiar with to avoid problems that make prosthetic rehabilitation difficult.

8.3.2 Rehabilitation outcomes

Rehabilitation outcomes were compared between TKA and AKA in the SPARG study and differences in how clinicians deliver rehabilitation and perceive rehabilitation outcomes between TKA and AKA were explored in the survey and interviews. Patients experiences of going through rehabilitation were explored in the interviews.

The SPARG data showed similar rehabilitation outcomes between the two groups, however as discussed in chapter 4 (section 4.5) there is reason to suggest that the TKA group may have been chosen as they were believed to be non-limb wearers, and this would therefore suggest that TKA provides superior rehabilitation advantages. The TKA group were quicker to be discharged from rehabilitation, but this was not statistically significant, however, the population sizes vary significantly with the AKA group being nearly 25 times larger than the TKA group.

Other studies comparing rehabilitation outcomes of TKA and AKA have mostly focused on whether a patient is fitted with a prosthesis or not (Met, 2008; Ten Duis et al., 2009; Nijmeijer et al., 2017), however this does not tell the full story; many of the important rehabilitation advantages of TKA identified by the clinicians and patients in the qualitative studies were regarding non-limb wearers. The current studies, especially with the inclusion of non-limb wearers in the patient study, add important information regarding rehabilitation for non-limb wearers where there is a lack of validated outcome measures for this population (Miller et al., 2021).

Several of the rehabilitation benefits identified by this mixed methods study have not previously been measured or assessed quantitatively. Measuring outcomes following amputation for non-limb wearers is challenging and is often not prioritised. The measures of success currently used focus on ambulation, as such many of the potential benefits of TKA are therefore go undetected – which raises the question of whether we are measuring the ‘right’ things. An example of this is the effect of the longer lever from TKA on sitting balance, a fundamental skill in the early stages of post amputation rehabilitation. However, sitting balance between TKA and AKA has not been formally tested. Many of the identified functional and rehabilitation differences between TKA and AKA that were identified in the survey and interviews are too specific to be picked up by an outcome measure, which is why the qualitative study was of such importance as it was able to investigate these small differences which have a big impact on an individual’s QoL.

8.3.3 Limb fitting

The SPARG data showed that a similar proportion of people with TKA and AKA had a limb fitted after amputation. The proportion of people with TKA who limb fitted in the SPARG study was lower than in similar studies (Ten Duis et al., 2009; Nijmeijer et al., 2017), but as previously discussed the data has led us to believe that many TKAs were performed on patients not expected to limb fit. Therefore, it is possible more patients were limb fitted than were predicted to in that group. One physiotherapist interviewed in the clinician study believed that some of her patients only limb fitted because of their TKA and felt had they had an AKA they may not have limb fitted. This was echoed by the participants in the patient study who were grateful for the perceived advantages of their TKA enabling them to stand for longer and walk further than they perceive they would have been able to with an AKA.

Qualitative studies have explored factors which enable prosthesis use and found if the person is able to easily don the prosthesis, walk greater distances unaided, and mobilise without having to think about every step they are more likely to wear their prosthesis (Gauthier-Gagnon et al., 1999; Roberts et al., 2021). Prosthesis use is more nuanced than whether someone gets a prosthesis or not, or whether they can walk or not, and the current study adds important perspectives to the literature regarding prosthesis use for people with TKA and AKA. The patient study highlighted the real-life challenges people are faced with when using the prosthesis, including times when, even thought they could walk with the prosthesis in physiotherapy sessions, unless the prosthesis was comfortable and the patient felt confident, they would often opt for the wheelchair over the prosthesis for daily household tasks. Equally, they may choose not to wear their prosthesis in certain settings so outcomes such as frequency of limb use cannot always be relied upon.

There was no consensus from the survey or interviews whether TKA was suited for limb wearers versus non-limb wearers. This could be interpreted as TKA has potential benefits for both groups and should therefore be considered for all patients rather than trying to find a specific group to perform this procedure on. A recent multi-stakeholder meeting organised by the Vascular Society amputation special research group also agreed with these findings and concluded that “There was broad agreement from the group that both patients expected to ambulate, and those not expecting to ambulate, can derive a benefit from a TKA over an AKA, although patients expecting to ambulate should be discussed with a prosthetist prior to surgery as sometimes an AKA is preferable.” (Hinchliffe, 2022).

8.4 What does current practice of TKA and AKA look like in the UK and what are the influencing factors for choosing one over the other?

This question was answered by all four studies as presented Table 8.2; the SPARG study provided numerical data regarding prevalence and demographics of patients getting TKA or AKA, the survey and clinicians studies provided insight into these figures and provided information regarding the different variations of TKA. The patient study explored how the patients' experiences are influenced by current clinical practice.

Table 8.2 - table of findings that address question 2 across the four studies

Question 2) What does current practice of TKA and AKA look like in the UK and what are the influencing factors for choosing one over the other?				
Finding	SPARG	Survey	Clinician	Patient
8.4.1 Prevalence	Small numbers of TKA are performed in Scotland	Clinicians perform or treat small numbers of people with TKA	There is a lack of training on how to perform TKA for vascular surgeons. Small numbers of TKA seen by rehabilitation clinicians can lead to decreased confidence	People with TKA are aware they have an uncommon type of amputation but are satisfied with their amputation
8.4.2 Determination of amputation level	Many demographics similar between TKA and AKA groups but data suggests TKA may be chosen for people not expected to limb wear	Disagreement between clinical groups and regions regarding which type of patient should or should not have TKA	Arguments for TKA use for predicted limb-wearers and predicted non-limb wearers suggesting advantages for all patients. NHS hierarchy and split sites prevents rehabilitation team involvement in decision making	Patients want to be advised by clinical experts regarding the most appropriate level for them
8.4.3 Variations of technique	An unknown number of variations of TKA are used in Scotland	Different clinicians prefer different types of TKA depending on their experience	Prosthetists and physiotherapists tend to prefer KDA. Many surgeons are unaware the prosthesis implications of the different variations of TKA	Unable to draw comparisons from small patient group

8.4.1 Prevalence

It had already been established that TKA is rarely seen or performed in the UK (Moxey et al., 2010; Waton, 2021). The SPARG study showed that less than 4% of amputations performed in the study period were TKA, and this proportion would have been even smaller had the study included all levels of amputation. Only 146 primary TKAs were performed over the 11-year period in Scotland, roughly 13 per year. Approximately 100 TKA are performed annually in vascular centres in England, Scotland, Wales, and Northern Ireland, as reported in the National Vascular Registry (Waton, 2021). This trend is also consistent with other high-income countries (Hagberg, 1992; Cull et al., 2001; Ten Duis et al., 2009; Lim et al., 2018). Most of the clinicians who completed the survey reported seeing, working with, or performing, small numbers of TKA compared to the numbers of AKA they typically see or perform for patients. On average, the clinicians reported seeing fewer than six people with TKA in the 12 months prior to completing the survey. All the clinicians were specialists in the field of vascular or amputation rehabilitation, so it can therefore be safely assumed that this is a low proportion of their patient caseload.

The quantitative data clearly supports other studies that show TKA is infrequently used in the UK. The addition of the qualitative data explores firstly, reasons why this is the case, and secondly how the rarity of TKA effects patient care. Several explanations for why TKA is rarely used were identified by the survey and clinician interviews. Among the most common were lack of training, lack of guidance, lack of motivation to change practice, and barriers for rehabilitation teams to influence change in practice. However, it was unclear from the survey what kind of guidance the clinicians would like to see to influence their practice. Currently, TKA is recommended in national and international guidelines (BSRM, 2018; Conte et al., 2019) and prosthetic guidance also exists from private manufacturers (Steeper, 2011). However, no specific guidance for care of TKA for physiotherapists currently exists, and as a result many of the physiotherapists reported they treat their TKA the same as AKA. A paper from 1983 (Mensch) recommend specific treatment for TKA including manual guided stump movement, and manual distal pressure to desensitise the residuum ready for end-weight bearing. Though several of the recommendations by Mensch have since been invalidated, such as the use of outdated manual handling techniques and compression bandaging, threatening the reliability of the TKA advice. Up to date guidance for rehabilitation of TKA is urgently required. The responses from the clinicians suggest that due to their lack of familiarity with treatment post TKA there is a chance their quality of care is negatively affected. Research suggests less support is available to people living with rare conditions compared to those living with common or well-established conditions (von der Lippe et al., 2017). Specialised treatment centres have been associated with greater levels of patient satisfaction (von der Lippe et al., 2017) and lack of knowledge by local care teams can make patients feel insecure, and potentially lead them to miss out on specialist treatment interventions (von der Lippe et al., 2017). This could suggest that outcomes for TKA could improve if clinicians had more experience treating this patient group.

One consequence of the low prevalence of TKA, identified in the survey and further explored in the interviews, was the restricted range of prosthetic knee components for TKA. Prosthetists reported a frustration in lack of specialist parts for TKA, especially MPKs (which will be discussed further in 8.5.1). Several surgeons were under the impression that it was impossible to find any components suitable for TKA, providing this as their reason for not choosing TKA for potential limb wearers. At present there is little incentive for prosthetics companies to invest time and money into the development of knee units to fit a TKA given the relative scarcity of the operation being performed. It will require a significant shift in surgical practice for this to change, and until this takes place the patients will potentially miss out on optimum functionality.

8.4.2 Determination of amputation level

One important finding across the survey and clinician study is the disagreement between clinicians regarding who makes a good candidate for TKA in regard to rehabilitation potential. Nearly half (47%) of survey respondents gave “non-limb wearers” as a reason to perform a TKA, a quarter disagree and think TKA is beneficial to young, fit, active patients, and 13% felt TKA is beneficial for all patients over AKA. These responses show a mixed picture of current practice around the country. Guidelines around which level to choose advise assessing for rehabilitation potential pre-operatively and involving the MDT (Gough et al., 2014; Smith, 2016; VSGBI, 2016) but no specific guidance exists for who makes a good TKA candidate. The NCEPOD report (2014) has shown that MDT discussions, and pre-operative assessments by physiotherapists and diabetic nurses are not consistently meeting recommended guidelines. This was also evidenced in the survey and clinical interviews whereby physiotherapists and prosthetists report they are rarely asked their opinion when deciding amputation level.

Another important consideration for vascular patients is that level selection also needs to consider the best chance of wound healing. As already discussed in this chapter 8.3.1) many clinicians reported concerns over the healing rate of TKA, leading to the choice of AKA over a TKA. Some surgeons had made the choice to avoid TKA every time while others would assess this on a patient-by-patient basis.

In terms of current practice in Scotland, the SPARG data was analysed to look for patterns in the demographics of patients undergoing TKA compared to AKA. The groups were mostly similar apart from the TKA group were more likely to be obese and have a diagnosis of diabetes than the AKA group. It was also found that lower percentages of TKA from centres performing higher numbers of TKA were being referred for prosthetic rehabilitation. We suggested this may mean that the high-volume centres in Scotland are choosing patients they do not expect to limb fit for to have a TKA.

All clinicians felt patients should be involved in the decision of amputation level making whenever possible. Surgeons felt this was an important part of their role and said they always try to involve the patient, though there were often times where this was not possible, such as in medical emergencies, or if there is only one option of level. Physiotherapists hypothesised that more shared decision-making regarding amputation level would improve patient engagement with their rehabilitation and reduce the risk of patients being dissatisfied with their amputation. However, most patients in this study disagreed and expressed they did not want to be involved in the decision, rather they would prefer to be advised by the experts. Shared decision making has been shown to improve outcomes by improving the understanding of the patients' needs and therefore reducing anxiety (Vahdat et al., 2014). Communication theory in relation to loss of an anatomical part supports good communication pre-operatively, and involvements with the patient in decision making pre-operatively can help the patient recover psychologically after amputation (Al-Sahan et al., 2020). NICE guidance exists for shared decision making with patients and medical staff to empower patients to be involved with decisions regarding their care, however these guidelines do acknowledge that not every patient wants to be involved in decision making (NICE, 2021). Having to make a life changing decision about a topic a patient has little or no understanding of is not always appropriate and is potentially a huge burden which patients do not wish to take on (Ende et al., 1989; Zolkefli, 2017). If patients do not have that knowledge, the surgical team should assess the patients priorities and lifestyle to be able to choose the most appropriate level of amputation (Zolkefli, 2017). This is easily achieved by involving the physiotherapist, occupational therapist, rehabilitation consultant, and prosthetist pre-operatively, though as this study has shown, these clinicians still may not consider TKA. The clinician study showed that AHPs often do not feel confident enough to recommend TKA as they do not feel there is enough guidance or evidence available, showing again that more research is needed in this area.

Other barriers that prevent patients researching amputation levels for their own surgery include limited available time if surgery is urgent, psychological readiness for amputation, and health literacy. People choosing to undergo elective amputation for an orthopaedic problem or similar often have a long wait for surgery and therefore are more likely to access pre-amputation services, and have better health literacy than people requiring amputation for vascular disease (Koster et al., 2017; Strijbos et al., 2018). One surgeon from the clinician study wanted patients to be requesting TKA but this is unlikely to be possible for the majority patients requiring amputation.

8.4.3 Variations of technique

The SPARG data does not report which types of TKA are performed in Scotland; any type of TKA was grouped into the TKA classification. Variations of TKA and their use in the UK were however explored with the survey and clinician interviews. It was clear from the clinician survey and interviews that several types of TKA surgery are performed in the UK and that clinicians have strong feelings regarding the benefits of each type. A recent systematic review, awaiting publication, by Bosanquet, searched for all described methods of TKA in the current literature and identified eight techniques for performing TKA (Bosanquet et al., 2021a). An earlier review of quantitative studies (Murakami & Murray, 2016) compared TKA types for dysvascular patients and found conflicting outcomes between papers for the different types of TKA. It is therefore unsurprising that a range of techniques were described by the clinicians in the current studies. The survey provides some explanation into why such a range of techniques are used. Surgeons described using the technique that they were taught to do or have experienced better healing rates with. Most of the physiotherapists and prosthetists had strong feelings that KDA was superior to Gritti-Stokes for rehabilitation outcomes but had little power to influence surgical technique. Murakami (2016) agreed with this but suggested that Gritti-Stokes has superior healing rates to KDA and maybe be preferable to AKA for patients unlikely to mobilise. The patient qualitative data is unable to shed light on the benefits of specific TKA approaches from the patient's perspectives as this information was not consistently available and the sample size not large enough (see 7.7.4).

In conclusion, there is currently no established method, or consistency, in TKA surgical practice. A classification system of TKA is due to be proposed by Bosanquet based on the findings of their systematic review. Reporting and interpreting existing TKA in research is difficult, as is communication between clinicians. Bosanquet's review will provide a system which can be used to clearly report the variations of TKA. There may be one variation of TKA which proves to be more suitable to certain groups of patients, as suggested by Murakami (2016), but this has not yet been demonstrated.

8.5 What are UK clinicians' perceptions of TKA compared with AKA?

Most findings to this question came from the survey and clinician study, however integration of findings from the SPARG data and the patient study further our understanding of these findings. Several findings are shared with question 2 and 4. Clinicians perceptions of TKA compared to AKA in terms of cosmetic appearance, prosthetic components, and weight bearing, and variations of technique will be discussed here.

Question 3) What are UK clinicians' perceptions of TKA compared with AKA?				
Outcome	SPARG	Survey	Clinician	Patient
8.5.1 Prosthetic components		Componentry options are limited for TKA	There is sufficient choice of mechanical knees for TKA, but clinicians wish for an MPK for TKA to be developed	Patient's priority of cosmetic appearance or prosthesis function influences the componentry choices for TKA
8.5.2 Weight bearing		End-weight bearing is an advantage for TKA	End-weight bearing post TKA is the desired outcome, and considered superior to ischial-weight bearing with AKA, but end-weight bearing not always achieved in practice	End-weight bearing is useful for TKA prosthetic limb wearers and non-limb wearers
8.5.3 Cosmetic appearance		The cosmetic appearance of a TKA is a disadvantage when compared to AKA	Expectations of cosmetic appearance should be discussed pre-operatively	If patients dislike the appearance of TKA they can choose different componentry to compensate. Most think function is more important. People with AKA also have cosmetic complaints
8.6.1 The residual limb	See Table 8.4			
8.4.3 Variations of TKA technique	See Table 8.2			
8.6.2 Asymmetrical knees	See Table 8.4			
8.3.1 Wound healing	See Table 8.1			

Table 8.3 – table of findings that address question 3 across the four studies

8.5.1 Prosthetic components

Data was not collected by SPARG regarding components of prosthetic prescription. The subject of componentry for people with TKA was commonly reported both in the survey and interview studies, specifically the limited options of available prosthetic knees to fit to a TKA prosthetic socket. The clinician qualitative interview data shed light on the trade-offs made when deciding on type of knee for TKA; polycentric knees will provide a more anatomical centre of rotation but are expensive and heavy (Nelson et al., 2006). Patients discussed the trade-offs they made when choosing their knee, with some opting for less sophisticated componentry to achieve a better aesthetic presentation, and others were unable to achieve the function they need due to the componentry available. While these participants are victims of this componentry limitation for TKA, their satisfaction with their TKA remained high, suggesting that while this issue does exist it should not be a reason to avoid TKA.

The concern regarding limited choice of prosthetic technology for TKA has been published in prosthetic research and guidelines: "The major disadvantage of knee disarticulation is the unfavourable appearance and limited prosthetic knee options." (Nelson et al., 2006:5) and "The choice of prosthetic knees is limited, and the prosthesis may have a poor cosmetic appearance due to the bulky distal end of the socket and distal displacement of the prosthetic knee centre." (Steeper, 2011:47) are two examples. The current studies demonstrate that those clinicians with less experience working with this population are likely to reflect the common perception. However, the survey and interview data also show that clinicians who have most experience working with this population do not share this view and identify the key issue is the availability of specialist MPK knees for TKA. Several prosthetists and physiotherapists reported they would like to see prosthetic development for MPK for TKA. They felt current MPK options are not always suitable due to the space needed to fit them. A key issue identified by the clinician and patient study was that current MPK options are not suitable for TKA patients as they currently require more space than is available. MKPs have shown improved outcomes for patients compared to mechanical knees, (Davie-Smith & Carse, 2021; Stevens, 2021; Wurdeman et al., 2021). In the current patient study, the patients with MPKs reported less fear of falls than those without an MPK. However, due to the small numbers of TKA there is minimal incentive for prosthetic companies to invest in developing specialist components for such a small patient group, when other components can be used most of the time.

8.5.2 Weight bearing

The responses from the survey listed end-weight bearing as a key advantage of TKA for limb-wearers but when explored further in the interviews the complexities involved in achieving end-weight bearing were uncovered. Some clinicians described how some of their patients have difficulty tolerating end-weight bearing, with variable success. The findings from this study indicate that when prosthetic ambulation is unsuccessful it can be devastating for both patient and physiotherapist, and when small numbers of TKA are conducted, failures may leave a lasting impression on staff that TKA is not suitable for patients who wish to end-weight bear. Responses such as these support the theory that many clinicians base their opinions of TKA on a very small number of patient experiences.

End-weight bearing without the prosthesis was also listed as an advantage by the survey respondents. This was supported by some of the participants of the patient study who described using their residual limb as a lever for getting in and out of the bath, getting out of bed, and for gardening. However, some did not weight bear through their residual limb and other non-prosthetic users with TKA were not aware they could weight bear through the end of their residuum, and one had even been advised against it. This indicates that this patient group are missing out on specialist care as physiotherapists should be educating patients with TKA how to end-weight bear (Mensch, 1983).

8.5.3 Cosmetic appearance

An important finding from this thesis is how the cosmetic appearance of TKA prosthesis is considered by clinicians and patients. Most TKA studies describe the poor cosmetic appearance of TKA as a major drawback, and this also appears in prosthetic and rehabilitation guidelines (Steeper, 2011; Murakami & Murray, 2016; BSRM, 2018). This conclusion was supported by 56% of clinicians who responded to the survey, it therefore seems accepted that this is an established downside to TKA and a disincentive to perform a TKA in preference of an AKA. However, the results of the patient study question this conclusion. Not only did the people with TKA not mind the cosmetic appearance of their prosthesis, but they also felt that their functional advantages were worth the cosmetic drawbacks. In addition, cosmetic drawbacks of

AKA were found without any functional advantages over TKA to compensate. While some patients were concerned about the appearance of their TKA prosthesis, they were able to resolve this by changing the componentry. These findings suggest these concerns from clinicians are misplaced and there is a risk that clinicians impose this belief onto others influencing practice. Some clinicians did say they had patients who struggled to accept the misaligned knees, but as previously discussed the patients could be counselled on this pre-operatively. This is not to downplay the importance of a cosmetically pleasing prosthesis. Satisfaction with prosthetic appearance has been shown to improve overall prosthetic satisfaction and concerns over body image post amputation has been linked to depression (Cairns et al., 2014). It is also important to consider the change in prosthetic fashion over the last few decades. This is due to development of prosthetic componentry, and the trend of showing mechanics following Paralympics and Invictus Games. Cairns et al. (2014) found in a survey of 153 prosthesis users that people above the age of 44 were significantly more likely to choose a cosmetic covering, and that age was the only influencing factor, not gender or activity level. The topmost important cosmetic factors identified by Cairns' survey were shape matched to sound limb, free prosthetic movement under the cosmesis, and natural fit of clothes over the cosmesis. These factors fit closely with the findings of the patient interviews in the current study. People with TKA did notice that their prostheses is different from their sound side, but the functional movement of the limb was similarly important, and the people with AKA struggled with the way their clothes fitted over their prostheses. Ultimately the clinicians and the patients agreed that the TKA cosmetics were an issue, but one that could be overcome.

8.6 What are the similarities and differences of the lived experiences of TKA and AKA?

The patient study primarily addressed this question. Several aspects of the patient experiences have been described integrated into the findings of the first three questions. The final findings regarding the residual limb, and the asymmetrical knees of TKA will be discussed here.

Question 4) What are the similarities and differences of the lived experiences of TKA and AKA?				
Outcome	SPARG	Survey	Clinician	Patient
8.6.1 the residual limb	Fewer patients with TKA were fitted with a shrinker sock than patients with AKA potentially due to the longer limb length	A long lever arm is considered an advantage for bed mobility, transfers, and sitting balance	The shape of the TKA residuum allows for socket self-suspension – which is a superior suspension method than a TES belt often used for AKA	People with AKA dislike the appearance of their residual limb over time due to muscle wastage. No negative descriptors for TKA residual limb used by the participants
8.6.2 Asymmetrical knees		Prosthetic and remaining knees are not level with TKA, and this is a disadvantage compared to AKA	Prosthetic and remaining knees are not level with TKA, certain knee components can improve this, but ultimately function is more important	For TKA, having one knee that protrudes out can look odd, or can get inconvenient when sitting somewhere with little leg room, but ultimately function is more important
8.5.1 Prosthetic components	See Table 8.3			
8.5.2 Weight bearing	See Table 8.3			
8.5.3 Cosmetic appearance	See Table 8.3			
8.3.3 Limb fitting	See Table 8.1			

Table 8.4 - table of findings that address question 4 across the four studies

8.6.1 The residual limb

Advantages of a long lever arm have again been stated in papers (Ten Duis et al., 2009; Baumgartner, 2011; Albino et al., 2014; Murakami & Murray, 2016) without robust evidence to support these claims. Biomechanical outcomes have been compared between people with long and short AKA residual limbs; and it was found that a longer residuum resulted in reduced hip stress in the contralateral limb (Highsmith et al., 2016). SPARG data did not report length of residual limb, or residual limb strength, but did show a difference in type of compression therapy used, with fewer TKA patients using a shrinker sock, an easy-to-use compression garment used post-operatively to prepare the residual limb for casting the prosthesis. Other compression options are available such as plaster casts, and bandaging, but they are less convenient for the patient. One reason shrinker socks are used less frequently might be because the longest available standard size of a shrinker sock is 37cm, which may not be long enough for a TKA residual limb. This is another issue that manufacturers need to address. The survey highlighted the long lever and the importance clinicians placed on this as a biomechanical advantage for patients. The theoretical biomechanical advantages of a long lever arm may seem clear-cut but the clinical and real-life impacts of these factors have been explored in the qualitative elements of this mixed methods study for the first time. The TKA group in the patent study found their long thigh annoying in spaces with small leg room but have the advantage of using the end of the residuum for transfers and kneeling, and were overall relieved to have kept more of their leg than their AKA peers.

A related finding regarding the differences of TKA and AKA residual limbs from the clinician and patient interviews was how residual limbs change over time. A prosthetist in the clinician interview described in detail how the TKA residual limb changes shape over the months post amputation to allow for effective end-weight bearing and self-suspension. The patients in the TKA group reported satisfaction with their residual limb while the AKA group describe how the appearance of their residual limb became less satisfactory over time. This was also a finding of the qualitative evidence synthesis in Chapter 2. The findings from the patient study suggest that changes in residual limbs could potentially support continued prosthesis use over time for people with TKA, and could potentially explain one reason for abandoned prosthesis use for people with AKA (McWhinnie et al., 1994; Nehler et al., 2003). Long term follow-up studies are needed to compare longitudinal outcomes post TKA and AKA.

8.6.2 Asymmetrical knees

Knee height discrepancy following TKA was a commonly highlighted concern in both the survey and interviews. It was a more dominant topic with the clinicians than with the patients in the qualitative studies. The longer length of the TKA residual limb means that when the prosthetic socket is made to contain the residuum, and the prosthetic knee joint is implanted to the distal end of the socket, the prosthetic knee will extend beyond the end of the remaining contralateral knee. Eighteen out of 78 clinicians (physiotherapists, prosthetists, and surgeons) listed uneven knee centres as a disadvantage of TKA in the survey; they linked this disadvantage to causing a poor cosmetic appearance of the prosthesis, and for causing limitations to componentry choices as there is less room between the end of the socket and the floor to fit some of the larger prosthetic knees. This was explored further in the clinician interviews; aiming to get the knee levels as close as possible was a priority for the prosthetists as they described better gait pattern and better cosmetic outcome with level knees; this was achieved by choosing the right prosthetic knee component. In contrast to clinicians, patients value the functional advantages, something that was not prioritised by surgeons, but they did mention the long lever as discussed above but only in terms of the residual limb, not the prosthesis.

A recent biomechanics study (Schuett et al., 2019) attempted to quantify the differences in gait parameters caused by the uneven knee centres/additional length of TKA by comparing four people with TKA and four with AKA. They found no difference in velocity, cadence, stride length, or work of ambulation between the groups. The authors claimed to match the characteristics of the groups to allow for comparison, and the groups were matched on height and BMI. However, they were not matched for other important characteristics; the TKA were nearly ten years older than the AKA group and no attempt was made to match based on prosthetic componentry. Therefore, the groups may not be truly comparable.

People with TKA were asked specifically about their experience living with asymmetrical knees in the patient study. Participants did not talk about walking speed, or stride length, or any other biomechanical factors suggesting these are not important to the lived experience. Instead, participants described challenges in disguising their amputation, issues sitting in small spaces, and their priorities when trialling new prosthetic knees.

8.7 Clinical implications of key findings

1) Surgeons require training of TKA technique and need to be aware that practice is necessary to become competent in performing TKA and achieving good results
2) Physiotherapists should consider the different needs of TKA during rehabilitation, such as weight tolerance exercises
3) Surgeons, physiotherapists, and prosthetists should develop appropriate communication channels to improve care for patients having amputations
4) The cosmetic implications of a TKA should be considered pre-operatively when appropriate, but clinicians should also understand that many patients do not prioritise cosmetic outcomes, decisions of TKA or AKA should be patient centred

8.8 Recommendations for future research

One aim of this mixed methods study was to compare the surgical and rehabilitation outcomes of TKA and AKA. The SPARG study compared the available surgical and rehabilitation outcome data, but the qualitative elements of this mixed methods study identified further outcomes that were important to clinicians and patients that have not been compared including: cosmetic satisfaction with residual limb and prosthesis, satisfaction with prosthetic components, sitting balance, ability to transfer, independence within the home with or without a prosthesis, and successful end-weight bearing. Prospective studies are needed to compare these outcomes. Several of these are specific to non-limb wearers, but there are few validated measures for people with amputations who do not use a prosthesis, suggesting a potential need for the development of an outcome measure.

A study with a long-term follow-up period is also necessary. This mixed methods study suggests the potential for long term prosthetic use for TKA is greater than AKA. This hypothesis should be tested and could prove to be a significant advantage for people with amputations.

Specific prosthetic development is also needed to support this growing area. Further research into what makes a good end-weight bearing residual limb and prosthesis is required to support the use of TKA for limb wearers. Development of prosthetic componentry specifically for TKA, particularly MPKs should also be invested in.

Details of current practice and level selection need further investigation to determine how best to select patients who would benefit from TKA as opposed to AKA but with a low risk of need for re-operation. This mixed methods study has provided a cross section of detailed data, but a wider breadth of data is needed to evaluate practice across the country.

This study found that while TKA has some promising advantages to offer people over AKA, clinicians still lack confidence to recommend, perform, and rehabilitate people with TKA. Therefore, it is also important that we understand what clinicians feel they need to know or learn in order to influence or change current practice nationally. We can add reasons to choose TKA over AKA to the evidence base but there may still be other barriers that prevent its implementation in practice. These must be identified, and established frameworks followed to evaluate implementation (Bartline & Brooke, 2015; Bauer et al., 2015).

Ultimately a randomised control trial (RCT) of TKA and AKA is needed to determine the true difference between the two levels of amputation. However, this project has raised several issues that need to be addressed before an RCT can be designed. Firstly, the variation in surgical technique when performing TKA needs to be investigated. Is there one technique that is better than the rest? Do they each have different properties suitable to different patients? Do they share enough similarities that any type of TKA is equivalent? One way to investigate this would be to undertake a Delphi study to compare current practice among leading specialists. Secondly, the current project highlighted that most UK surgeons are not trained how to do a TKA and that there is potentially a learning curve to achieving acceptable wound healing. A training package would need to be considered and a feasibility study needed. Finally, there is already some evidence recommending that TKA be used in place of AKA, but this is not reflected in current surgical practice. This study identified there are several barriers to adopting this change. Prior to an RCT it would be sensible to research what evidence and/or training surgeons and other clinicians would need in order to change their practice.

8.9 Conclusion

This mixed methods study has compared outcomes and experiences of TKA and uncovered some promising features of TKA. Qualitative enquiry has been used for the first time to explore experiences and perceptions of TKA from the point of view of people working with, and people living with TKA and AKA. This study has produced strong evidence that people with TKA have potential advantages that can improve life after amputation.

Amputation level should be chosen to offer the patient the best of rehabilitation. This study has found TKA has the potential to offer people who need amputations a better chance of rehabilitating. Successful rehabilitation means a return to independent living, better health, and greater QoL.

This study also identified a compartmentalised approach to amputations surgery and rehabilitation which threatens the patient's chance of getting the level amputation which is best for them. Communication and MDT working must improve across the surgical and rehabilitation sectors in the UK to ensure best chance of wound healing and rehabilitation.

Finally, this study found several advantages that TKA offers to the people living with the amputation, all of which are too specific to be picked up by any current validated outcome measures, but from this study suggest TKA, when successfully performed, improves overall QoL.

The adoption of TKA in place of AKA, when suitable, would be a relatively straightforward change in practice, with potentially life changing advantages that last the patient's lifetime.

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Appendix

Appendix 1

Consultant Questionnaire Pilot Version

Thank you for agreeing to complete this questionnaire. The aim is to gather the opinions of health professionals regarding through knee amputation. This questionnaire will provide important data for students at Hull York Medical School, and will direct future work in this topic. The term through knee amputation is used to cover all types of through knee amputation surgery (including Gritti-stokes). No identifying information is required. The questions should take less than 5 minutes to complete.

Approximately how many major lower limb amputations have you performed in the last year?

How many through knee amputations have you performed in the last 12 months?

☐ 0

☐ 1-5

☐ 6-10

☐ >10

If you are answer is 0 please specify why

The format of the above question was changed to a slide bar on the electronic version of the survey to help with participant engagement.

What do you see as the advantages of through knee amputation?

Is there a specific patient group you feel benefit from through knee over an above knee?

In your opinion what are the disadvantages to through knee amputation?

What are the specific factors that would make you avoid through knee amputation?

Why do you think through knee amputations are relatively uncommon?

What points do you consider most important when deciding on level of amputation? Please order in levels of importance

_____ Primary healing

_____ Patient and/or MDT opinion

_____ Function including sitting balance, bed mobility, transfers and wheelchair use

_____ Prosthetic ambulation

_____ Body image

_____ Maintaining maximum residuum length

The above question was removed after piloting because the relevant answers had already been addressed in the above questions, the format of the question did not work well in that participants did not correctly order the answers, and MDT was interpreted differently to how it was meant by the author. The author meant MDT to include the physiotherapist, prosthetist, occupational therapist etc., whereas many participants thought it was referring to MDT with other vascular surgeons.

Please add any other relevant comments about through knee amputation…

Job Title:

☐ Vascular Registrar

☐ Vascular Consultant

Region of work:

☐ Scotland

☐ Northern England

☐ Midlands

☐ Southern England

☐ Wales

☐ Northern Ireland

☐ Ireland

☐ Other: Please state _______________

Appendix 2

Surgeon Invitation Email

Dear all,

I am a PhD student at Hull York Medical School investigating the outcomes of through knee amputation.

Part of my project is a survey to establish the views of the UK vascular workforce regarding through knee amputation. Data will be collected from prosthetists, physiotherapists and vascular surgeons.

The views and opinions of the vascular surgeon regarding through knee amputation is an essential part of this project.

Therefore, you are invited to complete this short survey following this link:

https://york.qualtrics.com/jfe/form/SV_9pJarWlddAYGNdH

The survey can be completed in less than 5 minutes, however, the more detail you are able to provide the more we will understand about the surgeons views.

Physiotherapist Invitation Email

Dear all,

I am a first year PhD student at Hull York Medical School investigating the outcomes of individuals post **through knee amputation**.

An important part of my project is to establish the views of health professionals working with this patient group.

The results of this survey (and similar surveys for prosthetists and vascular surgeons) will be combined with results from face to face interviews with through knee amputees exploring their perceptions of quality of life and body image post amputation.

Please follow this link to complete a short survey about your opinions of through knee amputation:

https://york.qualtrics.com/jfe/form/SV_2bPzrYvGloy9u4Z

The survey can be completed in less than five minutes, but if you have the time please provide as much detail as possible.

Prosthetist Invitation Email

Dear prosthetists,

I am a first year PhD student at Hull York Medical School investigating the outcomes of through knee amputation. An important part of my project is to establish the views of health professionals working with patients post through knee amputation. The results of this survey (and similar surveys for physiotherapists and vascular surgeons) will be combined with results from in-depth interviews with through knee amputees exploring quality of life and body image. The overall aim of the project is to determine whether further research in to through knee amputation is required and/or appropriate.

Please complete the short survey by following the link:

https://york.qualtrics.com/jfe/form/SV_78uBXKoEUgGsZtb

The survey can be completed very quickly but if you have the time please provide as much detail as possible.

Appendix 3

Surgeons Survey

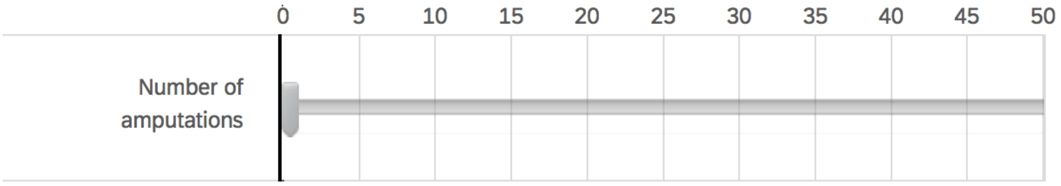
Welcome

This survey asks about your experiences of through knee amputation (TKA). Your responses will be combined with those of physiotherapists and prosthetists to establish the views of through knee amputation in the UK vascular workforce.

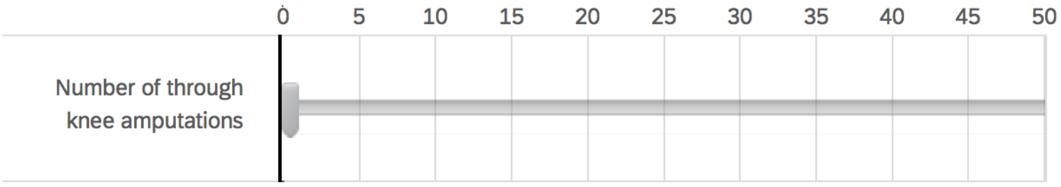
Survey responses will be used as part of a PhD project at Hull York Medical School. Participation in the survey is voluntary and data will be processed on the basis of participant consent.

Many thanks for your participation.

Q1 Approximately how many major lower limb amputations have you performed in the last 12 months? (this includes cases performed under your supervision)



Q2 Approximately how many THROUGH KNEE amputations (all types of amputation at the level of the knee, including Gritti-Stokes) have you performed in the last 12 months?



Number of through knee amputations

Q3 Which type of THROUGH KNEE amputation do you perform?

○ Knee disarticulation

○ Gritti-Stokes

○ Both

○ Other ________

Q4 Why do you perform that type?

Q5 In your opinion, what are the **advantages** of THROUGH KNEE amputation?

Q6 In your opinion, what are the **disadvantages** of THROUGH KNEE amputation?

Q7 Which of these patient groups do you feel **benefit** from THROUGH KNEE rather than ABOVE KNEE amputation? Select all that apply.

☐ Bilateral

☐ Younger

☐ Bed bound

☐ Elderly

☐ Unwell

☐ Trauma

☐ Not for prosthetic rehab

☐ No groups benefit from TKA over AKA

☐ Other ________

☐ × Don't know

☐ × Not applicable

Q8 Which of these specific factors would make you **avoid** THROUGH KNEE amputation? Select all that apply.

☐ Tissue loss around knee

☐ Poor circulation

☐ Previous knee replacement

☐ Poor rehab potential

☐ Young

☐ Patient preference

☐ Previous below knee amputation

☐ Hip contracture

☐ No specific factors

☐ Other

☐ × Don't know

☐ × Not applicable

Q9 Why do you think THROUGH KNEE amputations are relatively uncommon? Select all that apply.

☐ Unfamiliarity with technique

☐ Lack of training

☐ Difficult to perform

☐ Issues with prosthetics

☐ Poor surgical outcomes

☐ Poor functional outcomes

☐ Lack of evidence

☐ Other

☐ × Don't know

☐ × Not applicable

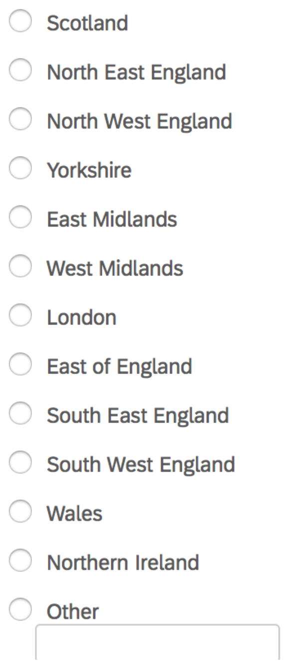
Q10 Please add any other relevant comments about THROUGH KNEE amputation...

Q11 Please select your job title

○ Vascular registrar

○ Vascular consultant

Q12 Please select the region where you work



○ Scotland
○ North East England
○ North West England
○ Yorkshire
○ East Midlands
○ West Midlands
○ London
○ East of England
○ South East England
○ South West England
○ Wales
○ Northern Ireland
○ Other

Physiotherapist Survey

Welcome

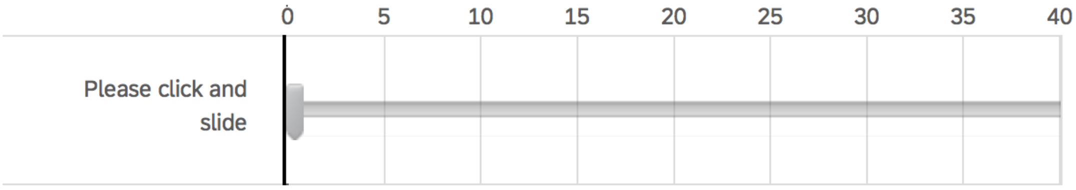
This survey asks about your experiences of through knee amputation (TKA). Your responses will be combined with those of vascular surgeons and prosthetists to establish the views of through knee amputation in the UK vascular workforce.

Through knee amputation, for the purpose of this survey, refers to all types of amputation at the level of the knee, including Gritti-Stokes.
Above knee amputation, for the purpose of this survey, refers to all amputations through the thigh/transfemoral level (excluding hip disarticulation).

Survey responses will be used as part of a PhD project at Hull York Medical School. Participation in the survey is voluntary and data will be processed on the basis of participant consent.

Many thanks for your participation.

Q1 Approximately how many patients with THROUGH KNEE amputation have you seen in the last 12 months? (please include new and existing amputees, and base your answer on the number of different patients you have seen, not the number of appointments they have had)



Q2 In your opinion, what are the **advantages** of THROUGH KNEE amputation?

Q3 In your opinion, what are the **disadvantages** of THROUGH KNEE amputation?

Q4 Please list any patient groups who, from your experience, **benefit** from a THROUGH KNEE amputation rather than an ABOVE KNEE amputation.

Q5 Please list any patient groups who, in your opinion, **should not** be considered for a THROUGH KNEE amputation, and should undergo ABOVE KNEE amputation instead?

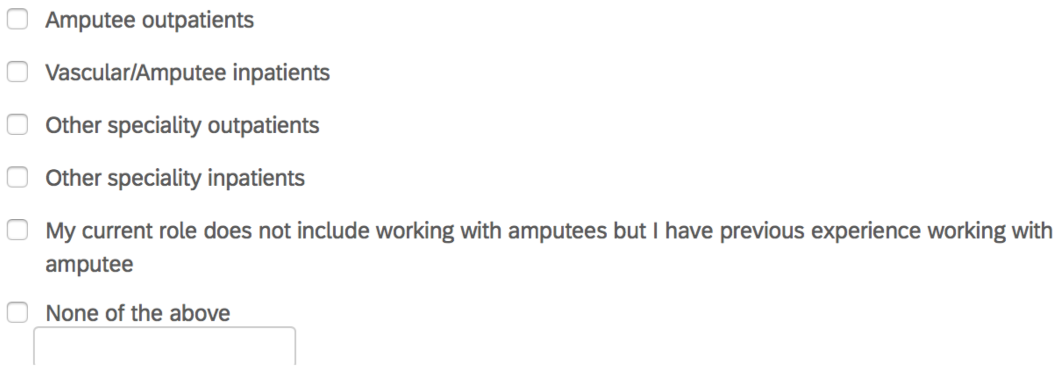
Q6 Do you think THROUGH KNEE amputation is uncommon, and if so, why?

Q7 From your experience, what do **patients** generally report about the cosmetic appearance of a THROUGH KNEE residuum and prosthesis?

Q8 What are **your** thoughts about the cosmetic appearance of prosthetic limbs for THROUGH KNEE amputees?

Q9 Please provide any further comments relevant to THROUGH KNEE amputation.

Q10 Please select the options that describe your job role.
This may be more than one, please select all that apply.



☐ Amputee outpatients

☐ Vascular/Amputee inpatients

☐ Other speciality outpatients

☐ Other speciality inpatients

☐ My current role does not include working with amputees but I have previous experience working with amputee

☐ None of the above

Q11 Please select the region where you work.

○ London

○ South East

○ South West

○ East of England

○ Yorkshire

○ East Midlands

○ West Midlands

○ North East

○ North West

○ Scotland

○ Northern Ireland

○ Other

Prosthetist Survey

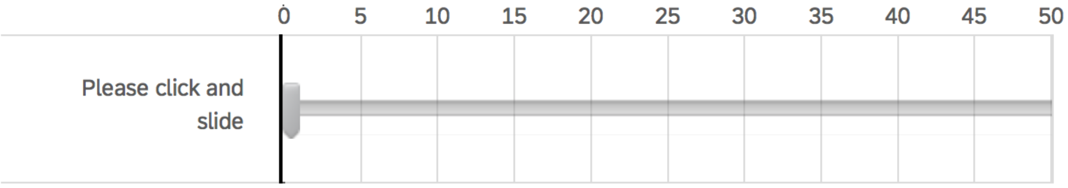
Welcome

This survey asks about your experiences of through knee amputation (TKA). Your responses will be combined with those of vascular surgeons and physiotherapists to establish the views of through knee amputation in the UK vascular workforce.

Survey responses will be used as part of a PhD project at Hull York Medical School. Participation in the survey is voluntary and data will be processed on the basis of participant consent.

Many thanks for your participation.

Q1 Approximately how many patients with THROUGH KNEE amputation have you seen in the last 3 months? (please include primary and established patients and base your answer on the number of different patients you have seen, not the number of appointments they have had)



Q2 In your opinion, what are the **advantages** of THROUGH KNEE amputation? (please consider all advantages you are aware of from your clinical experience, including prosthetics, activities of daily living, patient reported advantages etc.)

Q3 In your opinion, what are the **disadvantages** of THROUGH KNEE amputation? (please consider all advantages you are aware of from your clinical experience, including prosthetics, activities of daily living, patient reported disadvantages etc.)

Q4 Please list any patient groups who, from your experience, **benefit** from a THROUGH KNEE amputation rather than an ABOVE KNEE amputation.

Q5 Please list any patient groups who, from your experience, **demonstrate poorer outcomes** with a THROUGH KNEE amputation than those with ABOVE KNEE amputation?

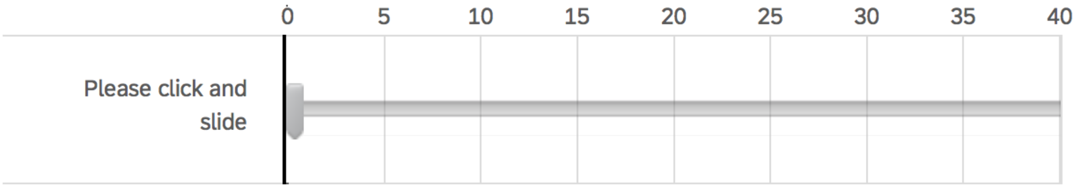
Q6 Why do you think THROUGH KNEE amputations are relatively uncommon?

Q7 What are **your** thoughts about the **cosmetic appearance** of prosthetic limbs for THROUGH KNEE amputees?

Q8 From your experience, what do **patients** generally report about the cosmetic appearance of a THROUGH KNEE residuum and prosthesis?

Q9 Please add any other comments you think are important about THROUGH KNEE amputation.

Q10 How long, in years, have you been working as a prosthetist?



Q11 Which sector do you work in?

- ○ Private
- ○ NHS
- ○ Both
- ○ Other

Q12 Where did you study?

- ○ University of Salford
- ○ University of Strathclyde
- ○ Other

Appendix 4

Physiotherapist Semi-Structured Interview Topic Guide

Opening: thank you, explain aims, data will be kept anonymously, password protected, pseudonyms, can pause/stop/withdraw at any time without reason, check happy to be recorded, ask if any further questions.

consent form

start recording

1. **Describe experience**
   How many in the last 12 months/why are the uncommon/success rates compared to AKA

2. **Type**
   Gritti-stokes/disarticulation/other/why

3. **Advantages**
   Compare to AKA/prosthetics/systematic review list/ why

4. **Disadvantages**
   Compare to AKA/prosthetics/systematic review list/ why

5. **Non-prosthetic users**
   How suitable/functional differences to AKA/advantages/disadvantages/why

6. **Patient groups**
   Suitable for vascular/experience/bilaterals/decision making

7. **Prosthetics**
   Gait/components/sockets/donn and doff/balance/knee symmetry/your views vs the patients

8. **Body image**
   Why/residuum/prosthesis

9. **Quality of life**
   Satisfaction with prosthesis/compare to AKA

   Close: thank you, anything else we should have discussed?

Prosthetist Semi-Structured Interview Topic Guide

Opening: thank you, explain aims, data will be kept anonymously, password protected, pseudonyms, can pause/stop/withdraw at any time without reason, check happy to be recorded, ask if any further questions.

consent form

start recording

1. **Describe experience**
   How many in the last 12 months/why are the uncommon/success rates compared to AKA/education

2. **Type**
   Gritti-stokes/disarticulation/other/why

3. **Advantages**
   Compare to AKA/prosthetics/systematic review list/ why/do they reflect real practice

4. **Disadvantages**
   Compare to AKA/prosthetics/systematic review list/ why/componentry/mpk

5. **Non-prosthetic users**
   How suitable/functional differences to AKA/advantages/disadvantages/why

6. **Patient groups**
   Suitable for vascular/weight bearing/skin/wound/diabetic

7. **Prosthetics**
   Gait/components/sockets/donn and doff/balance/knee symmetry/your views vs the patients/mpk

8. **Body image**
   Why/residuum/prosthesis/versus function

9. **Quality of life**
   Satisfaction with prosthesis/compare to AKA

   Close: thank you, anything else we should have discussed?

Surgeon Semi-Structured Interview Topic Guide

Opening: thank you, explain aims, data will be kept anonymously, password protected, pseudonyms, can pause/stop/withdraw at any time without reason, check happy to be recorded, ask if any further questions.

1. **Describe experience**
   How many in the last 12 months/why are the uncommon/success rates compared to AKA/training

2. **Type of procedure**
   Why that type/what do you think of the others/rehab and prosthetic differences between types

3. **Decision making**
   How do you decide/patient groups/MDT/predicted rehab outcomes/patient involvement

4. **Advantages**
   Surgery time/wound healing/prosthetics/weight bearing

5. **Disadvantages**
   Wound healing/revision rates/body image/aware of prosthetic disadvantages

6. **Further surgery**
   How to decide when to return to theatre/options for failing wound

7. **Pathway**
   Communication with MDT/prosthetic input/feedback to you/decision making/outcomes/data/patient follow up

   Close: thank you, anything else we should have discussed?

Appendix 5

HULL YORK MEDICAL SCHOOL

Hull York Medical School

Hull
University of Hull
Hull, HU6 7RX, UK

York
University of York
York, YO10 5DD, UK

T 0870 1245500
info@hyms.ac.uk
www.hyms.ac.uk

17 December 2020

Hayley Crane
PhD Student
Hull York Medical School

Dear Hayley

20 74 – Experiences and perceptions of through-knee amputation compared to above-knee amputation

Thank you for submitting your application to the HYMS Ethics Committee. The application has been reviewed on behalf of HYMS Ethics Committee with respect to the documents received on 14 December 2020.

I am pleased to inform you that I do not have any HYMS specific ethical concerns and am happy to confirm HYMS Ethics approval.

On behalf of the Ethics Committee, we wish you success with this study.

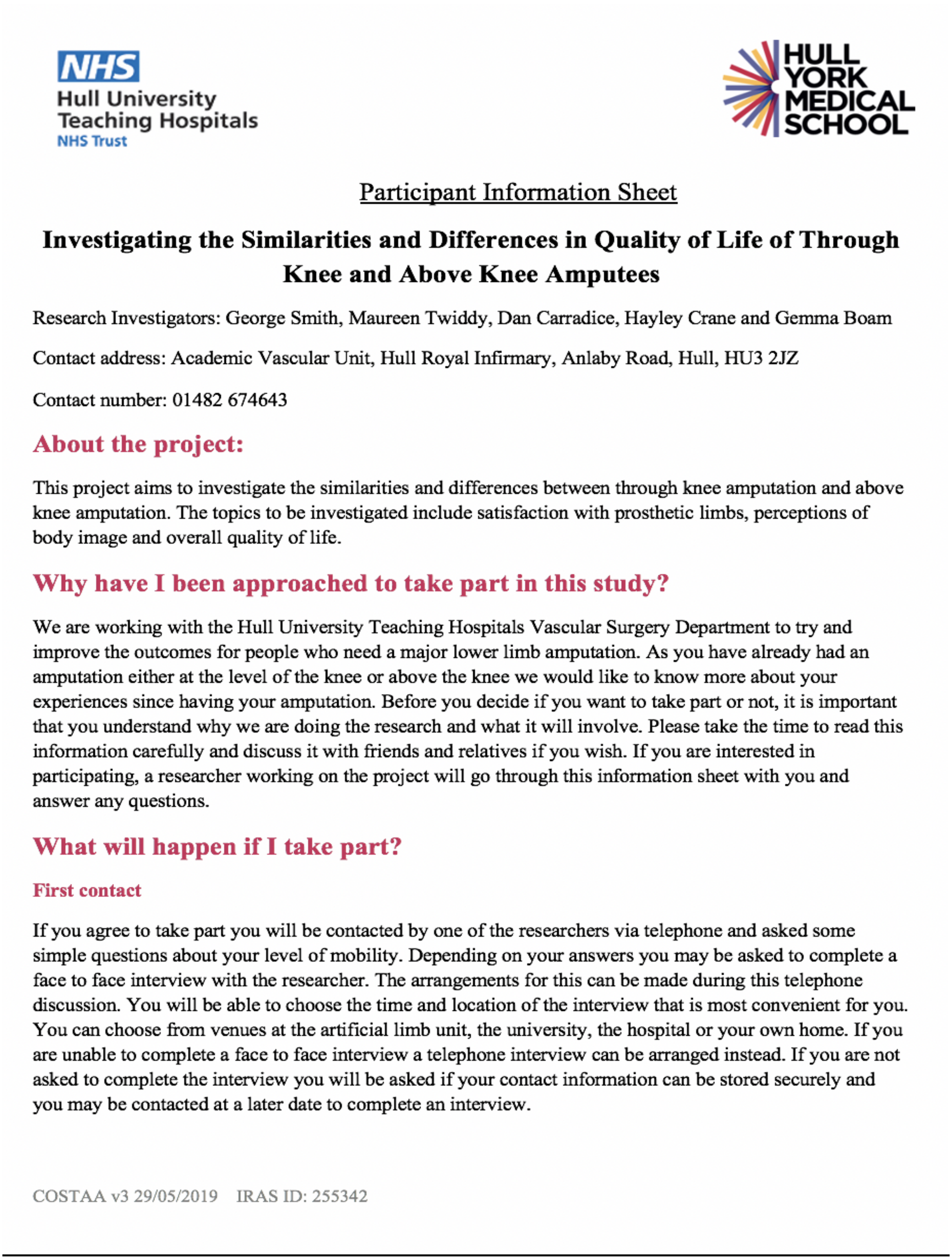
Kind regards

Yours sincerely

Professor Thozhukat Sathyapalan
Chair
HYMS Ethics Committee

Appendix 6

Participant Information Sheet for Study 4



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Participant Information Sheet

Investigating the Similarities and Differences in Quality of Life of Through Knee and Above Knee Amputees

Research Investigators: George Smith, Maureen Twiddy, Dan Carradice, Hayley Crane and Gemma Boam

Contact address: Academic Vascular Unit, Hull Royal Infirmary, Anlaby Road, Hull, HU3 2JZ

Contact number: 01482 674643

About the project:

This project aims to investigate the similarities and differences between through knee amputation and above knee amputation. The topics to be investigated include satisfaction with prosthetic limbs, perceptions of body image and overall quality of life.

Why have I been approached to take part in this study?

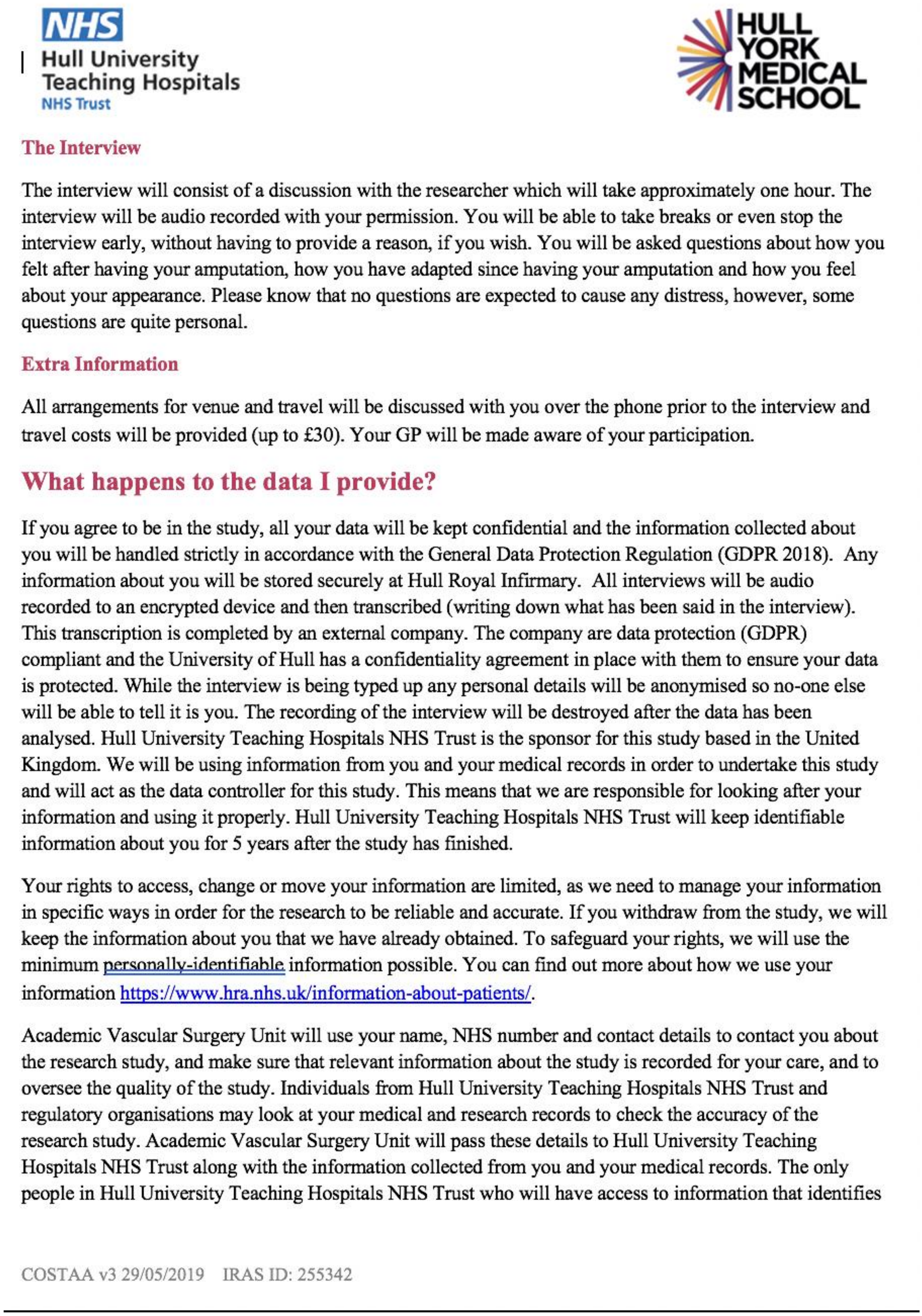
We are working with the Hull University Teaching Hospitals Vascular Surgery Department to try and improve the outcomes for people who need a major lower limb amputation. As you have already had an amputation either at the level of the knee or above the knee we would like to know more about your experiences since having your amputation. Before you decide if you want to take part or not, it is important that you understand why we are doing the research and what it will involve. Please take the time to read this information carefully and discuss it with friends and relatives if you wish. If you are interested in participating, a researcher working on the project will go through this information sheet with you and answer any questions.

What will happen if I take part?

First contact

If you agree to take part you will be contacted by one of the researchers via telephone and asked some simple questions about your level of mobility. Depending on your answers you may be asked to complete a face to face interview with the researcher. The arrangements for this can be made during this telephone discussion. You will be able to choose the time and location of the interview that is most convenient for you. You can choose from venues at the artificial limb unit, the university, the hospital or your own home. If you are unable to complete a face to face interview a telephone interview can be arranged instead. If you are not asked to complete the interview you will be asked if your contact information can be stored securely and you may be contacted at a later date to complete an interview.

COSTAA v3 29/05/2019 IRAS ID: 255342



The Interview

The interview will consist of a discussion with the researcher which will take approximately one hour. The interview will be audio recorded with your permission. You will be able to take breaks or even stop the interview early, without having to provide a reason, if you wish. You will be asked questions about how you felt after having your amputation, how you have adapted since having your amputation and how you feel about your appearance. Please know that no questions are expected to cause any distress, however, some questions are quite personal.

Extra Information

All arrangements for venue and travel will be discussed with you over the phone prior to the interview and travel costs will be provided (up to £30). Your GP will be made aware of your participation.

What happens to the data I provide?

If you agree to be in the study, all your data will be kept confidential and the information collected about you will be handled strictly in accordance with the General Data Protection Regulation (GDPR 2018). Any information about you will be stored securely at Hull Royal Infirmary. All interviews will be audio recorded to an encrypted device and then transcribed (writing down what has been said in the interview). This transcription is completed by an external company. The company are data protection (GDPR) compliant and the University of Hull has a confidentiality agreement in place with them to ensure your data is protected. While the interview is being typed up any personal details will be anonymised so no-one else will be able to tell it is you. The recording of the interview will be destroyed after the data has been analysed. Hull University Teaching Hospitals NHS Trust is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Hull University Teaching Hospitals NHS Trust will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information https://www.hra.nhs.uk/information-about-patients/.

Academic Vascular Surgery Unit will use your name, NHS number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from Hull University Teaching Hospitals NHS Trust and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Academic Vascular Surgery Unit will pass these details to Hull University Teaching Hospitals NHS Trust along with the information collected from you and your medical records. The only people in Hull University Teaching Hospitals NHS Trust who will have access to information that identifies you will be the researchers who need to contact you to about participating in this research study or people who need to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

Even though we will protect your confidentiality at all times we do have a duty of care towards you. This means that if a researcher believes that you might be in danger to yourself (e.g. you are thinking about harming yourself) or others we are obliged to alert appropriate services.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

What are my rights as a participant?

Your participation in this study is completely voluntary. You are within your rights to withdraw from the study at any time without providing a reason. Your participation, and if you withdraw, will not affect your medical care or legal rights in any way.

Will I receive any payment?

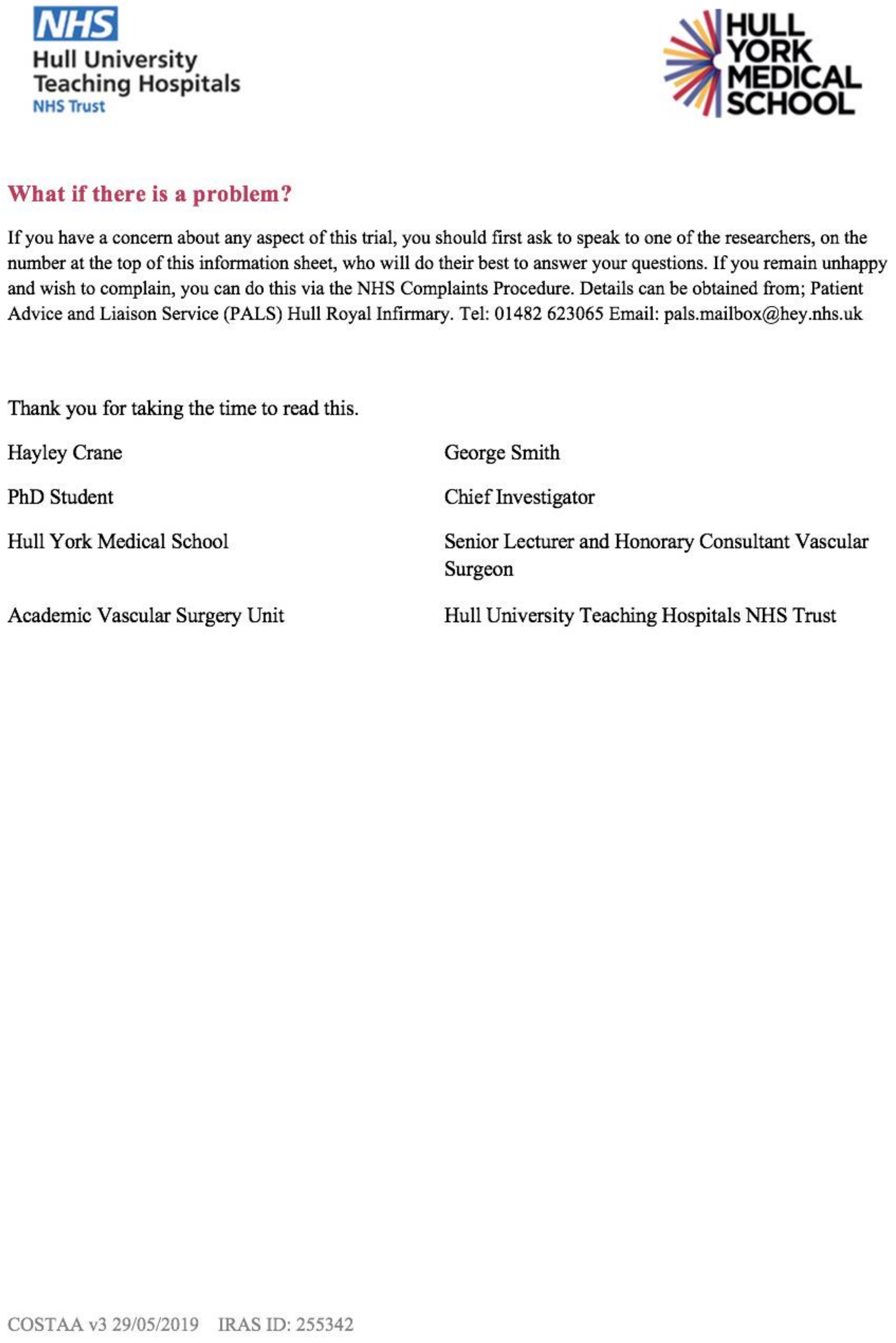
If you attend an interview you will receive a £10 shopping voucher as a thank you for participating in the study and helping with our research. All your travel costs, such as taxi fares and parking charges, will be provided. Complimentary refreshments during the interview will also be available.

What happens now?

You will be contacted via telephone call in the next few days. You will be able to ask any questions you have before deciding whether you wish to take part.

Who has reviewed this study?

The ethics behind this study have been independently reviewed by the Wales REC 6 (REC reference 19/WA/0124), an NHS Research Ethics Committee.



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What if there is a problem?

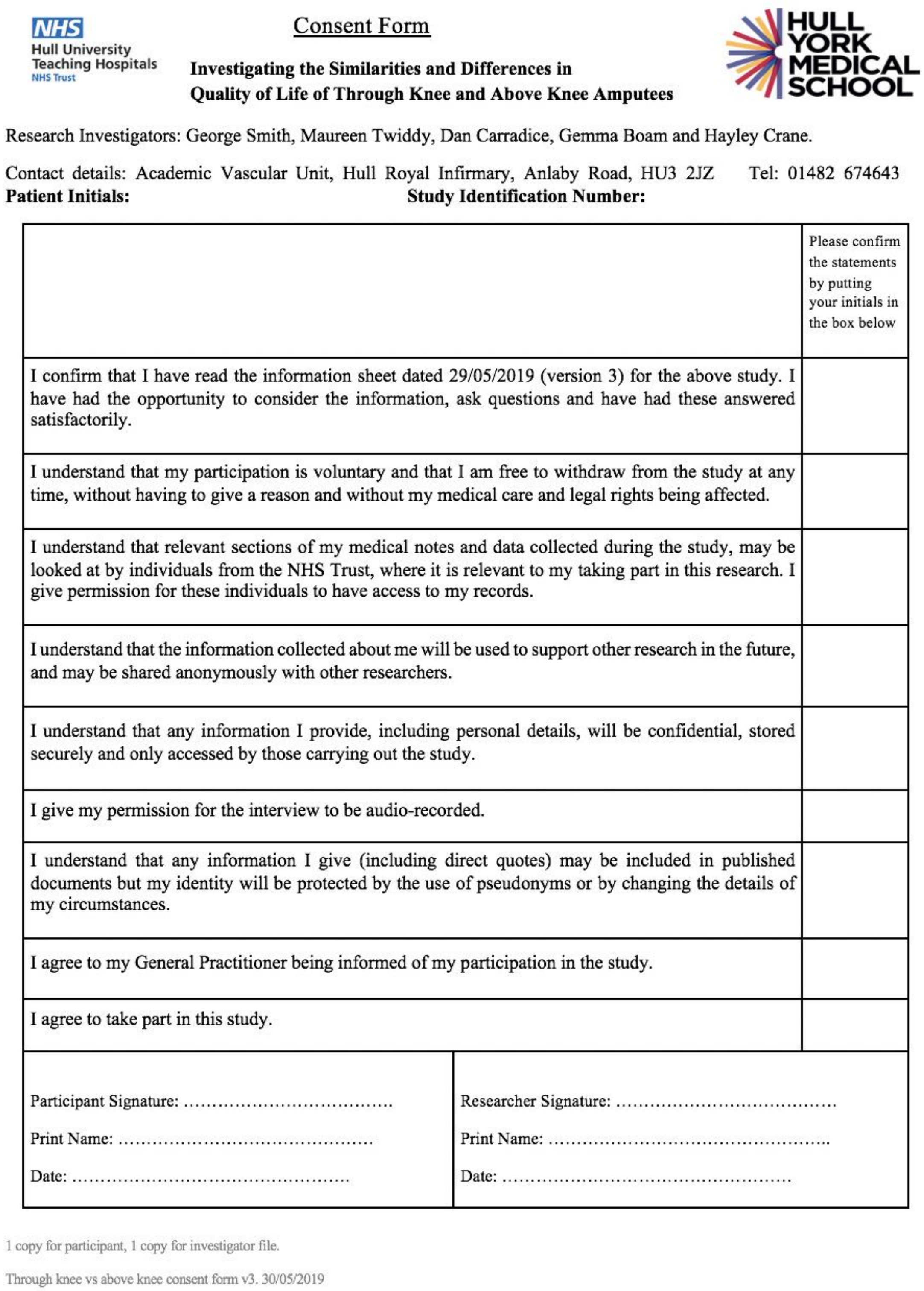
If you have a concern about any aspect of this trial, you should first ask to speak to one of the researchers, on the number at the top of this information sheet, who will do their best to answer your questions. If you remain unhappy and wish to complain, you can do this via the NHS Complaints Procedure. Details can be obtained from; Patient Advice and Liaison Service (PALS) Hull Royal Infirmary. Tel: 01482 623065 Email: pals.mailbox@hey.nhs.uk

Thank you for taking the time to read this.

Hayley Crane	George Smith
PhD Student	Chief Investigator
Hull York Medical School	Senior Lecturer and Honorary Consultant Vascular Surgeon
Academic Vascular Surgery Unit	Hull University Teaching Hospitals NHS Trust

Appendix 7

Consent form for study 4



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Consent Form

Investigating the Similarities and Differences in Quality of Life of Through Knee and Above Knee Amputees

HULL YORK MEDICAL SCHOOL

Research Investigators: George Smith, Maureen Twiddy, Dan Carradice, Gemma Boam and Hayley Crane.

Contact details: Academic Vascular Unit, Hull Royal Infirmary, Anlaby Road, HU3 2JZ Tel: 01482 674643

Patient Initials: **Study Identification Number:**

	Please confirm the statements by putting your initials in the box below
I confirm that I have read the information sheet dated 29/05/2019 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without having to give a reason and without my medical care and legal rights being affected.	
I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.	
I understand that any information I provide, including personal details, will be confidential, stored securely and only accessed by those carrying out the study.	
I give my permission for the interview to be audio-recorded.	
I understand that any information I give (including direct quotes) may be included in published documents but my identity will be protected by the use of pseudonyms or by changing the details of my circumstances.	
I agree to my General Practitioner being informed of my participation in the study.	
I agree to take part in this study.	

Participant Signature: ………………………………	Researcher Signature: …………………………………
Print Name: ……………………………………	Print Name: ……………………………………….
Date: …………………………………………	Date: ……………………………………………

1 copy for participant, 1 copy for investigator file.

Through knee vs above knee consent form v3. 30/05/2019

Appendix 8

Topic Guide for study 4

Warm up – *PIS, questions, consent form* Thank you. Introduce self; explain study and aim of interview. Once all interviews completed and the recordings analyzed it will be written up as my PhD and hopefully published and presented at conferences. All data is anonymous, if you wish to pause, stop or withdraw at any time you are free to do so without providing a reason, can refuse to answer any question. Check participant is happy for the interview to be audio recorded ***turn recording on***

Tell me about yourself, when did you have your amputation?

1. **Initial reaction**
   Time in hospital/ decision re level/ expectations – look and function/ initial feelings/ first time seeing residuum/ mirrors/ family/ moving/ wheelchairs
2. **Change over time**
   Thoughts on change and adaption/ emotions/ coping mechanisms/ what bothers you most about having an amputation
3. **Without prosthesis**
   Feel about yourself/ way stump looks/ how activities are affected
4. **With prosthesis**
   Your prosthetic leg/ expectations/ people's satisfaction/ personal feelings/ activities affected/ cosmetic appearance of leg
5. **Body image**
   Impact on personal body image/ clothing choices- function, practicality, looks, any to avoid and why/ activity choices- functional ability, looks, any avoid based on looks
6. **Comparison**
   show picture *similarities/ differences/ better/ worse*

   Close – What is the best thing about being an amputee? Thank you. General overview. Anything else we should have discussed? If you wish to follow up anything we have discussed today or be referred to any specialist services please call my office number 01482 674643. Will you be happy to be contacted in the future about a focus group? A group of approx 6-8 people with both types of amputation will get together to discuss this topic in more detail, answering a few more questions as a group discussion.

Appendix 9

Adapted Topic Guide for Study 4

Warm up – *PIS, questions, consent form* Thank you. Introduce self; explain study and aim of interview. Once all interviews completed and the recordings analyzed it will be written up as my PhD and hopefully published and presented at conferences. All data is anonymous, if you wish to pause, stop or withdraw at any time you are free to do so without providing a reason, can refuse to answer any question. Check participant is happy for the interview to be audio recorded ***turn recording on***

Tell me about yourself, when did you have your amputation?

1. **Initial reaction**
   Time in hospital/ decision re level/ expectations – look and function/ initial feelings/ first time seeing residuum/ mirrors/ family/ moving/ wheelchairs /early rehab/learning to walk- how challenging/option to keep knee or keep half the knee
2. **Change over time**
   Thoughts on change and adaption/ emotions/ coping mechanisms/ what bothers you most about having an amputation
3. **Without prosthesis**
   Feel about yourself/ way stump looks/ how activities are affected How would you describe your stump? How has stump changed? Skin problems/ thoughts about others seeing your stump/ Using the wheelchair/ How do you feel about using the wheelchair? ADLS without limb on/ bath transfers/ bed transfers/ moving around without leg or wheelchair/ gardening/ using a stand turner
4. **With prosthesis**
   Your prosthetic leg/ expectations/ people's satisfaction/ personal feelings/ activities affected/ cosmetic appearance of leg/ standing for long periods of time/ Do people make assumptions about you based on your amputation? Do you think that's the same for all amputees or any different for you being an above knee? Sitting comfortably on public transport or in public places/riding a bike/prosthetic adaptions over the years/ Rotation devise etc/ Do you like to disguise your amputation? Is it easy to disguise? How easy is kneeling
5. **Body image**
   Impact on personal body image/ clothing choices- function, practicality, looks, any to avoid and why/ activity choices- functional ability, looks, any avoid based on looks

6. **Comparison**

   explain TKA*similarities/ differences/ better/ worse*

   Close – What is the best thing about being an amputee? Thank you. General overview. Anything else we should have discussed? If you wish to follow up anything we have discussed today or be referred to any specialist services please call my office number 01482 674643.