

**From perspective to prescription:  
Bridging stakeholder experiences in the  
development of a decision aid for partial  
hand prostheses**

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A handwritten signature in black ink that reads "K. Carlyle". The signature is written in a cursive style with a large, prominent 'K' and a long, sweeping underline.

Date: 12<sup>th</sup> July 2025

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## Abstract

Partial hand prostheses offer both functional and psychosocial benefits to support people with partial hand limb difference. However, the prescription process can be complex due to factors such as unique individual presentation and a lack of education among stakeholders, including both prescribers and end users. Decision-making aids are a potential support mechanism to assist stakeholders in making decisions about treatment or prescription options.

This thesis aimed to explore the use of partial hand prostheses and to develop an understanding of how devices are selected for end users. This was achieved through a series of studies that explored the experiences and views of clinicians who prescribe partial hand prostheses, and people with partial hand limb difference who have undergone prescription.

A literature review found that there is no recommended set of outcome measures for assessing hand activity in the partial hand limb difference population. This finding was further supported by a survey exploring clinicians' experiences working with individuals with partial hand difference. The survey revealed that funding often drives prescription decisions, despite clinicians viewing user-centred factors, such as occupation and hobbies, as more important. These findings informed the design of a qualitative focus group study aimed at gathering deeper insights into the challenges and perspectives of those experienced in prescribing partial hand prostheses. Shared decision making and education emerged as key themes. Following this, a decision-

making aid was developed and shared with individuals using partial hand prostheses to gain their feedback, alongside insights from their own prescription journeys.

This thesis presents a decision-making aid – a practical tool designed to support both users and clinicians by addressing challenges identified in the preceding studies.

Validation of the decision aid is recommended to enable its implementation in clinical practice and to improve prosthetic outcomes for people with partial hand limb difference.

## Publications and presentations

### Publications

- Carlyle, K., & Day, S. (2022). Outcome measures used to assess hand activity in amputee and intact populations: A literature review. *Canadian Prosthetics & Orthotics Journal*, 5(2), 39023. <https://doi.org/10.33137/cpoj.v5i2.39023>
- Carlyle, K., Buis, A., Donovan-Hall, M., & Day, S. (2025). Working with partial hand prostheses: An investigation into experiences of clinicians. *Prosthetics and Orthotics International*, 49(2), 207–213. <https://doi.org/10.1097/PXR.0000000000000371>

### Conference Presentations

- Carlyle, K., Buis, A., Donovan-Hall, M., Day, S. Investigating experiences of clinicians working with partial hand prosthetics. International Society for Prosthetics and Orthotics (ISPO) World Congress, Guadalajara, April 2023.
- Carlyle, K., Buis, A., Donovan-Hall, M., Day, S. Exploring partial hand prosthetics from the perspective of clinicians. British Association of Prosthetists and Orthotists (BAPO) Regional Conference, Glasgow, June 2023.
- Carlyle, K., Buis, A., Donovan-Hall, M., Day, S. Partial hand prosthetics: the decision-making behind the prescription. Bionic Reconstruction Conference (BReCON), New York City, December 2023.

- Carlyle, K., Buis, A., Donovan-Hall, M., Day, S. Development of a decision-making aid for partial hand prosthesis prescription. Trent International Prosthetics Symposium (TIPS), Rotterdam, Netherlands. March 2025.

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## List of abbreviations

400-PA - 400 Point Assessment

9HPT - 9 Hole Peg test

ACMC - Assessment of Capacity for Myoelectric Control

AM-ULA - Activity measure for upper limb amputation

ASHT – American Society of Hand Therapists

BAPO – British Association of Prosthetists and Orthotists

BBT - Box and Block test

COPM - Canadian Occupational Performance Measure

DASH - Swedish Disabilities of the Arm Shoulder and Hand Questionnaire

DIPJ - Distal interphalangeal joint

DTO - Direct observation by therapist while performing tasks

EHI - Edinburgh Handedness Inventory

FC - Force Control

FS - Functional scales

GB - Gaze behaviour

HTSS - Hand Transplantation Score System

IPDAS – International Patient Decision Aid Standards

ISPO – International Society for Prosthetics and Orthotics

JPS - Proprioception

JTHFT - Jebsen-Taylor Hand Function test

m-ARAT - Modified Action Research Arm test

MCPJ - Metacarpophalangeal joint

MHQ - Michigan Hand Outcomes Questionnaire

mKI - Modified Kapandji Index

MSC - Prevalence of musculoskeletal complaints

NHS – National Health Service

NICE – National Institute for Health and Care Excellence

OMT – Outcome measurement tool(s)

OPUS - Orthotics and Prosthetics User's Survey

PDA - Patient Decision Aid(s)

PIPJ – Proximal interphalangeal joint

PIS – Participant Information Sheet

PPIE – Patient and Public Involvement and Engagement

PPT - Purdue Pegboard test

PR-WP - Patient-reported work productivity

ROM - Range of Motion

SF-36 - 36-Item Short Form Survey

SHAP - Southampton Hand Assessment Procedure

SSGE - Self-subjective global evaluations

TAPES - Trinity Amputation and Prosthetic Experience Scale

TG - Tactile gnosis

TM - Temporal measures

UEFT - Carroll Upper Extremity Function test

UEWD - Upper extremity work demands score

UNB-SST - University of New Brunswick Skill and Spontaneity tests

VAS - Visual Analogue Scale

VR-12 - Veterans SF-12 Health Survey with physical and mental components

# 1 Introduction

## 1.1 The human hand

### 1.1.1 Anatomy

The human hand is a complex structure that forms the terminal part of the upper limb. The hand is connected to the forearm through the wrist, and includes the palm as well as five fingers, also referred to as digits. The hand is composed of bones, joints, muscles, tendons, ligaments, nerves and blood vessels. These structures are supported and protected by cartilage, fascia, fat, connective tissue and skin. A total of 27 bones make up the hand including those in the wrist (carpal), palm (metacarpal) and fingers (phalanges) (Learn Human Anatomy 2024). Phalanges are described as distal, intermediate or proximal based on their location in the hand. Bones in the hand are connected at joints. Joints are described based on the bones in which they connect, as shown in the grey areas in Figure 1. For example, the DIP joint is the distal interphalangeal joint which connects the distal and intermediate phalanges.

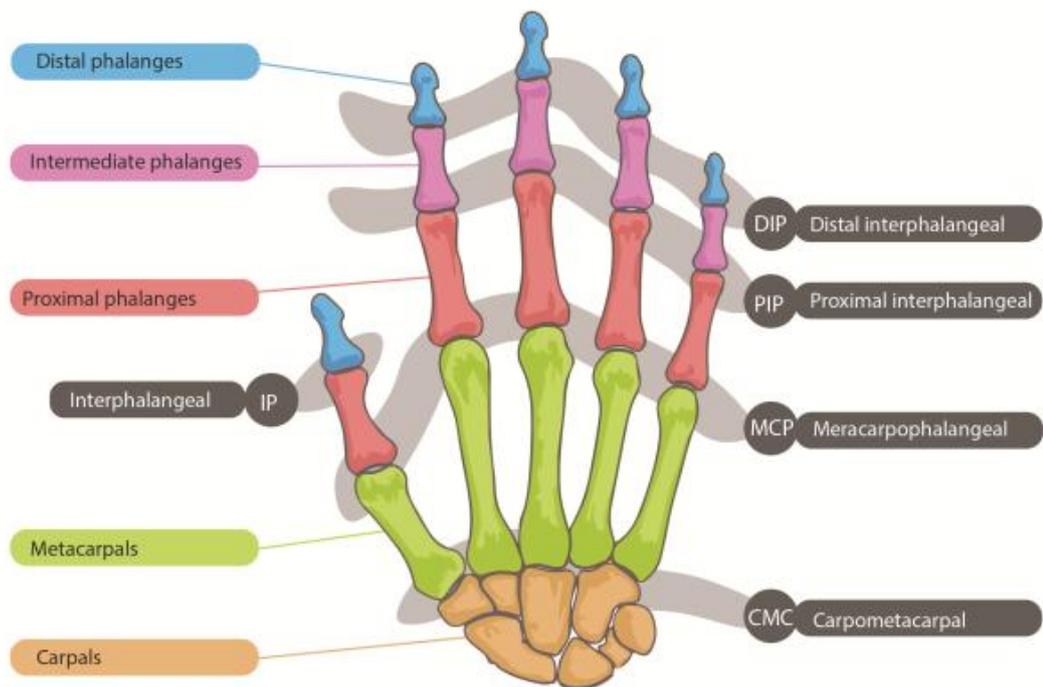


FIGURE 1 - BONE STRUCTURE OF THE HAND WITH JOINTS HIGHLIGHTED IN GREY AREAS (ILLUSTRATED BY CRUNCH DESIGN)

Hand muscles are categorized as extrinsic and intrinsic. Extrinsic muscles originate from the forearm and connect to the hand, whereas intrinsic describes muscles that reside entirely within the hand. Extrinsic muscles control gross movements such as finger and thumb extension. Intrinsic muscles control fine movements such as abduction and adduction. Tendons and ligaments provide stability and enable movements of the hand powered by muscles. Additionally, three major nerves innervate the hand: median, ulnar and radial. Blood is supplied to the hand by two arteries: radial and ulnar (Learn Human Anatomy 2024).

### 1.1.2 Grip patterns

The hand is responsible for powerful prehension and precise control which allows it to provide a wide range of functional purposes. The range and adaptability of functional movements achieved by the hand is enabled due to the complex anatomical structure and precise control of movement and feedback by the central nervous system (Biryukova and Yourovskaya 1994).

The hand can perform a number of grip patterns which allow the individual to perform tasks and signal gestures. Different grip patterns are required to perform different functions, for example a pinch grip may be used to pick up and place small objects such as a coin, and a hook grip may be used to carry heavier objects such as a suitcase. Examples of grip patterns corresponding to hand function are shown in Figure 2.

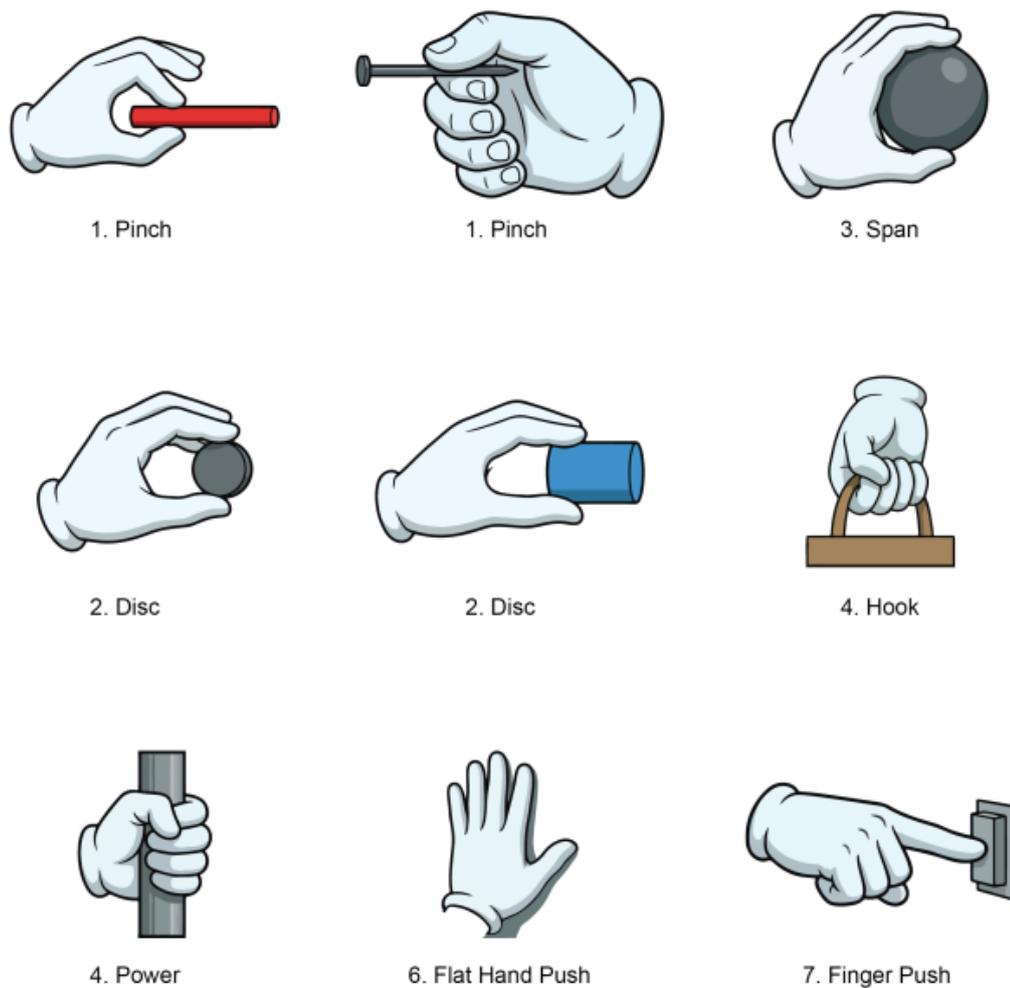


FIGURE 2 - EXAMPLES OF HAND GRIPS (ILLUSTRATED BY CRUNCH DESIGN)

### 1.1.3 Activities of daily living

Furthermore, hands are crucial end effectors in enabling people to carry out activities of daily living (ADL) and participate in society (Edemekong 2022). Hands are vital for carrying out basic ADL such as dressing, cooking and hygiene. The ability to carry out ADL allows people to live independently with good quality of life. Beyond ADL, hands allow people to partake in work, hobbies and leisure activities which contributes further to good quality of life.

In addition, the nerves that innervate the hand facilitate the function of the sensory system, enabling perception and differentiation of physical objects based on characteristics such as size, shape, texture, weight and thermal properties (Jones and Lederman 2006). Additionally, hands can be used as communication tools, including assisting those with hearing or visual impairments through the use of sign language, touch reading, and creative tools in arts such as music and dance. The hand also contributes to body temperature regulation as sweat glands in the hand dissipate heat, and blood vessels located within the hand can aid loss or retention of heat.

#### 1.1.4 Impairment

Hands can be affected by a range of conditions, disease or injury. Impairment of the hand can result in physical and mental deficits, therefore may be described as disability (Farzad, Asgari et al. 2015). The various functions of the hand previously described can be affected or non-existent due to impairments. Moreover, impairment of the hand can also impact range of motion, control, strength, comfort and sensation. Comfort may be considered in terms of thermal, physical, cosmetic, and psychosocial aspects. Thumb impairment alone can significantly reduce functionality as it contributes to approximately 40% of total hand function (Moran and Berger 2003).

#### 1.1.5 Amputation

The hand can be regarded incapacitated for a number of reasons including trauma, tumour, infection, peripheral vascular disease, or congenital anomaly. Surgical removal, known as amputation, may be carried out on the affected hand(s) as a result of incapacitation. Some amputations are planned, for example due to disease or

infection, and others such as traumatically injured hands may not be planned. Revision surgeries may also take place after initial amputation. Roughly five to six thousand amputations are undertaken in the United Kingdom each year (Blesma 2025) and of these amputations, roughly one fifth are upper limb amputations (Health Technology Wales 2019).

## 1.2 Partial hand limb difference

'Limb difference' is a term used to describe the presentation of impaired limbs due to deformation or amputation. This may also be referred to as 'limb absence'. Limb difference can exist in both upper and lower limbs. Partial hand limb difference is defined as absence of whole or part of at least one of the metacarpals, or more distal, and can be congenital or acquired through trauma, disease, or malignancy (Nelson and Blauvelt 2014, Ilmbinto, Peccia et al. 2016). This absence can be through the hand segment or complete removal. The structural complexity of the hand contributes to the variability in presentation and severity of partial hand limb differences. Individuals in this population may exhibit a range of presentations, such as absence of a small portion of distal phalanges to presence of only a partial metacarpal with no further distal segments.

### 1.2.1 Congenital limb difference

Congenital limb difference occurs when an individual is born without part of their limb due to the affected limb not forming during fetal development. In congenital partial hand limb difference, someone is born without part of their fingers or palm. People with congenital limb difference may or may not adapt to live with their limb difference. They may or may not undergo surgeries to attempt to correct the limb

difference or reduce the extent of functionality impairment (McCarroll 2000). The most common congenital hand difference is said to be when digits are fused together which results in less digits on the hand overall (syndactyly) (Goldfarb, Shaw et al. 2017). There is limited data related to congenital limb difference in comparison to amputation, as persons with congenital limb difference may not undergo treatment or interventions compared to those who undergo amputation.

### 1.2.2 Partial hand amputation

Partial hand amputation is the surgical removal of part of the hand or fingers. There are various levels of removal that are classified under the term 'partial hand amputation'. Reasons for partial hand amputation include severe trauma, gangrene, infection, deformity, frostbite, malignancies of the hand or digit, peripheral vascular disease, diabetes, complex regional pain syndrome and unsuccessful replantation (Maender 2024). Similar to other levels of amputation, people with partial hand amputation may experience challenges such as post-operative pain, scarring and psychological deficits such as stress and anxiety disorders (Grob, Papadopulos et al. 2008). A retrospective cohort study which aimed to identify limb amputations over a ten- year period found that 4,166 upper limb amputations were conducted in Scotland between 2012 to 2021. Of these amputations, 97% were partial hand amputations (Day 2024). Another investigation which examined data from the Global Burden of Disease Study found that finger amputations were the most common type of traumatic amputation (Yuan, Hu et al. 2023).

### 1.2.3 Limb loss

There are numerous aspects of loss that individuals may experience as a result of amputation or absence of a limb. Loss of a limb is said to be comparable to loss of a

loved one and individuals with this condition may experience a grief cycle consisting of denial, anger, bargaining, depression and acceptance (Bennett 2016). Feelings of grief may be experienced at various stages in the limb loss journey, such as immediately after loss or later in the recovery stages (Yong, Chew et al. 2011). In addition to emotional loss, individuals may feel cosmetic loss. Negative thoughts and views of body image can impact mental health and therefore quality of life (Rodgers, Laveway et al. 2023). Another type of loss one may experience is sensory loss. Loss of sensation means no sense of touch, which can affect an individual both in terms of functionality and psychosocially through interactions with others (Schiefer, Tan et al. 2016).

### 1.3 Management and solutions

The implications of partial hand limb difference can be managed through a number of means. Such means include adaptive tools such as attachments that allow an individual with limb difference to drive a car. Prosthetic devices are a potential means of managing functional or psychosocial impairments. Further, people with limb difference may receive physiotherapy to support training to use other muscle groups or movement patterns to perform tasks.

#### 1.3.1 Prosthetic solutions

Prosthetic devices are a potential solution to assist people with upper limb amputation in carrying out functional tasks, and/or improving satisfaction and quality of life. A number of prosthetic devices have been developed for people with partial hand limb difference. Prostheses can be made of various materials such as metals and plastics. Depending on the prosthesis type, a socket may be custom made to

allow the prosthesis to interface with the residual limb. Prostheses for partial hand may be described as active or passive, where active prostheses can be controlled by the user from residual function or muscle signals. Passive prostheses may not move with input from the residual limb.

A review by Graham et al (Graham, Hendrycks et al. 2021) categorised prosthesis options for various levels of partial hand amputation. The authors recognised that various levels of amputation come with varying levels of functional loss, impairment and associated treatment options, therefore the following levels of absence were described by the authors:

1. Distal to DIPJ
2. Through DIPJ and middle phalanx
3. Through PIPJ and proximal phalanx
4. Through MCPJ and metacarpal
5. Thumb, partial or complete.

Following categorisation of level of absence, different types of prostheses were described for each presentation and classed as passive functional, externally powered or body-powered. Examples of commercially available prostheses were provided for each level of amputation and prosthesis class. The authors also list activity specific prostheses as a standalone type of device but did not include this in their classification across different levels of limb difference. The authors also detail barriers to prosthetic rehabilitation including a perceived lack of options which discourages professionals from prescribing partial hand prostheses. Additionally, the

authors describe prosthesis fitting as a key factor in successful outcomes, rather than the prosthetic device itself being the true reason for abandonment or rejection.

A narrative review by Kim et al (Kim, Powell et al. 2023) searched existing literature to review prosthetic options included in investigations or marketed directly by the companies who manufacture them. Like Graham et al, the authors of this work categorised partial hand prostheses as body-powered and externally powered, however used the term 'passive' instead of passive functional. Passive prostheses were described as not having active movement but their main feature being the aesthetic design which makes the prosthesis appear to look like a natural hand. Nonetheless, the purpose of passive prostheses is not only cosmetic but may be passive functionally. Passive movement is sometimes enabled as the user can use the device to push, pull or manipulate objects. Passive prostheses were further categorised as static, adjustable and activity specific. Body-powered prostheses which use residual hand function can sometimes be coupled with external components such as cables, harnesses and springs, to drive the device. These were categorised by the authors as residual hand-driven and cable-driven. Externally powered prostheses were described as using motors and batteries to drive the device and were not further categorised. These are the only publications known to date that categorise partial hand prostheses, each through different approaches. While both studies categorise partial hand prostheses, there were no studies found which categorise prostheses based on alternative factors which may influence candidacy or device selection.

The following categorisation types are used throughout this thesis:

**Body-powered** prostheses use remaining function in fingers, hand or wrist to move the prosthesis.

**Myoelectric** prostheses use signals from muscles to control the prosthesis. The prosthesis responds to different muscle signals by creating various grips – such as pointing a finger or closing the device round an object.

**Mechanical** prostheses use mechanical systems, such as a ratcheting system, to move. An existing contralateral hand, or a surface such as a table, may be used to move the fingers.

**Activity-specific** prostheses are designed for specific tasks like sports, work, hobbies or activities of daily living. Activity specific devices include tools for sports such as swimming or fixtures that allow the user to hold a specific object such as a power tool.

**Passive prostheses** are designed to look like the missing body part can include details like hair and nails. These devices are not designed with a functional purpose. If partial hand limb difference affects only one hand, this type of device may be modelled based on the contralateral hand.

**Assistive devices** may not look like a hand and may not have fingers. Some attach to the residual limb and use features like plates or hooks. They may require the user to utilise existing function in their residuum to press against an existing thumb or palm for example to create a grip.

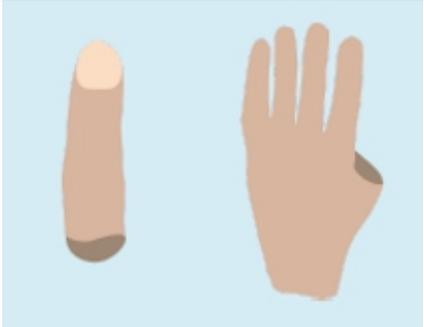
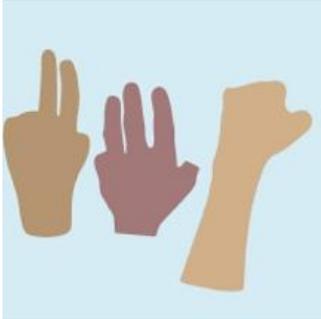
**Hybrid prostheses** are an option which combines a selection of the above options on one device. For example, a hybrid prosthesis may consist of myoelectric digits and a body-powered digit for an individual who has a presentation that allows this option.

**No prosthesis** is an option in which the individual chooses not to use a device. They may perform tasks and feel satisfied without using a device.

Examples of each device are shown in Figures 3 to 10 within Table 1 including commercially available options. The device types listed above may be referred to using different terminology by manufacturers, users, or professionals in the field or in literature. For example: 'cosmetic' may be used to describe passive and prostheses may also be referred to as 'tools', 'devices', 'prostheses' or 'hands'. In addition, the terms 'user' and 'patient' may be used in this thesis to describe people with partial limb difference to use devices.

TABLE 1 - EXAMPLES OF TYPES OF PARTIAL HAND PROSTHESES

Type	Body-powered	Myoelectric	Mechanical	Activity specific
Photo	 <p data-bbox="322 807 817 863">FIGURE 3 – ILLUSTRATION OF BODY POWERED PARTIAL HAND DEVICES</p>	 <p data-bbox="842 823 1308 914">FIGURE 4 – ILLUSTRATION OF MYOELECTRIC DEVICE WITH BATTERY ATTACHED ON WRISTBAND</p>	 <p data-bbox="1332 802 1756 858">FIGURE 5 – ILLUSTRATION OF MECHANICAL DEVICE WITH RATCHETING FINGERS</p>	 <p data-bbox="1839 812 2112 868">FIGURE 6 - CUSTOM-MADE PROSTHESIS FOR KAYAKING</p>
Reference	Illustrated by Crunch Design	Illustrated by Crunch Design	Illustrated by Crunch Design	Photo used with permission, courtesy of prosthesis user

Type	Passive	Assistive device	Hybrid	No prosthesis
Photo	 <p data-bbox="295 903 719 991">FIGURE 7 – ILLUSTRATION OF CUSTOM SILICONE FINGER AND PARTIAL HAND PROSTHESES</p>	 <p data-bbox="743 903 1043 927">FIGURE 8 - OPPOSITION TOOL</p>	 <p data-bbox="1084 895 1671 951">FIGURE 9 - COMBINATION OF NAKED PROSTHETICS AND POINT DESIGNS ON ONE USER</p>	 <p data-bbox="1697 895 2074 951">FIGURE 10 – ILLUSTRATION OF PARTIAL HAND LIMB DIFFERENCE</p>
Reference	Illustrated by Crunch Design	Photo used with permission, courtesy of prosthesis user	Illustrated by Crunch Design	Illustrated by Crunch Design

#### 1.3.1.1 Prescription

Prosthetic devices are typically prescribed by a professional such as a prosthetist. The process of prescription can vary for a number of reasons specific to the individuals' situation. Reasons for variation in prescription can include, but are not limited to, geographical location, healthcare provider (Henao, Cuartas-Escobar et al. 2025), presentation of limb difference, funding sources (Biddiss, McKeever et al. 2011), time since amputation (Kurichi, Kwong et al. 2015), whether it is the first prescription for the individual or not. In the United Kingdom, prosthetic devices may be prescribed through the National Health Service (NHS) or privately.

#### 1.3.1.2 Areas for improvement

It has been noted that statistics relevant to the prevalence of limb amputation and prosthetic device provision are limited and often inconsistent (Chadwell, Kenney et al. 2016). However, studies have shown that hand prostheses prescribed to users often do not reach their desired potential as users can find them difficult to control and not fully functional (Chadwell, Kenney et al. 2016). Studies have shown that many people reject (Biddiss and Chau 2007) or do not use their prosthesis frequently (Raichle, Hanley et al. 2008, van Heijningen and Underhill 2022). As previously mentioned, rejection or abandonment may be the result of ill-prescription or ill-fitting by the professional (Graham, Hendrycks et al. 2021). Research and knowledge acquisition regarding partial hand prostheses may allow better prescription and design of prostheses which ultimately could lead to better outcomes for users in this population.

### 1.3.2 Surgical interventions

Surgical interventions for partial hand limb difference include revision surgery, replantation or osseointegration. Revision surgery may be undertaken to improve function with or without prosthesis use, as well as to improve pain management. Surgery may involve altering or preserving length of the residual limb (Graham et al 2021). Prosthesis use may be considered at the time of first surgery or secondary revision surgeries. Revision surgery may be necessary or recommended to improve success in terms of residual limb function or prosthesis use, in particular improved prosthesis fit (Guerrero, Mastracci et al. 2023). Revision surgery may include lengthening or shortening the residual limb, skin flap revisions, muscle and nerve procedures (Graham et al 2021). The starfish procedure is a recent surgical advancement which aims to improve muscle signals that can be produced by a person with partial hand limb difference which may allow them to have more advanced control of a myoelectric prosthesis (Guerrero, Mastracci et al. 2023). Targeted muscle reinnervation is another example of a surgical intervention which may allow better control of myoelectric prostheses as well as decreasing pain (Chepla and Wu-Fienberg 2020). Replantation is a potential option when the detached limb is available for reattachment and reconstruction following traumatic amputation. Additionally, toe to thumb replantation has been carried out to reinstate hand function in eligible candidates. Osseointegration is an alternative reconstruction method which involves implanting a device into residual bone which protrudes through skin and can attach to an external prosthesis (Li, Kulbacka-Ortiz et al. 2019). While various established surgical interventions exist for partial hand amputation, a

study found that hand surgeons are unfamiliar with prosthetic solutions available for this population (Graham, Baschuk et al. 2023). The majority of participants in the study did not consult with prosthetists before performing revision surgery. To provide the best outcome for the individual, whether that is surgical intervention or prosthesis provision, education and collaboration in hand surgery and related fields is required.

### 1.3.3 Alternative management

Partial hand limb difference can be managed by non-prosthetic interventions. People can adapt to their limb difference and learn to use their residuum, unaffected side (if applicable), or other means to perform functional tasks. They may undergo physiotherapy sessions to achieve this or learn methods to manage on their own. As well as managing functionality, people with partial hand limb difference may also manage pain. Pain may be managed through a number of means including therapeutic, surgical, and pharmaceutical interventions.

## 1.4 Thesis outline

This research aimed to develop an understanding of partial hand prosthetic prescription in the real world. The output of this research is a decision aid for partial hand prosthesis prescription.

This thesis describes a set of studies which lead towards and contribute to the development of a decision aid for prescription of partial hand prostheses. The initial studies investigate how prostheses, then specifically partial hand prostheses, are assessed, selected and prescribed. Later studies involve clinician and user involvement, investigating decision aids, and development of the decision aid. The

decision aid document is presented. A flowchart showing the stages of this research is contained in Figure 11.

This thesis contains the following Chapters:

- Chapter 2: A review of outcome measures used to assess hand activity is described. From this, the research direction is confirmed. (Study 1)
- Chapter 3: An understanding of who works with partial hands and how devices are selected is obtained. (Study 2)
- Chapter 4: A qualitative study around partial hand decision-making from the clinicians' perspective is detailed. (Study 3)
- Chapter 5: A draft decision aid is presented and design process is described.
- Chapter 6: User insights and feedback on the decision aid is provided through a Patient and Public Involvement and Engagement (PPIE) study. (Study 4A & B)
- Chapter 7: The final version of the decision aid is presented and evaluated.
- Chapter 8: General discussion, limitations and recommendations for future work are discussed.

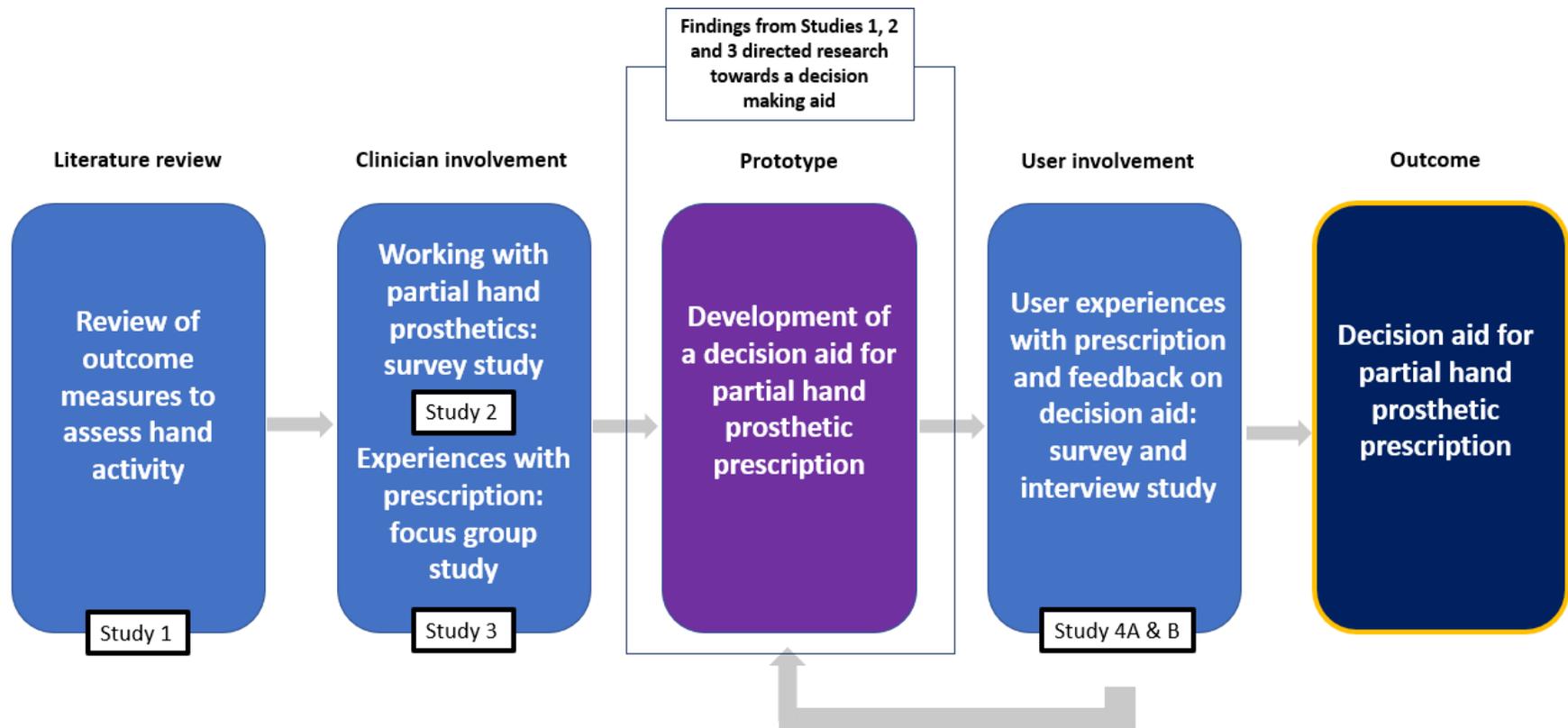


FIGURE 11 - FLOWCHART ILLUSTRATING STAGES OF RESEARCH CONDUCTED

## 2 Study 1: Outcome measures used to assess hand activity in amputee and intact populations

### 2.1 Introduction

This Chapter presents Study 1 of this thesis, a scoping review conducted to examine outcome measures used in both amputee and non-amputee, referred to as “intact”, populations as shown in the flowchart in Figure 12. This Chapter contains work from the author’s publication “Outcome Measures Used to Assess Hand Activity in Amputee and Intact Populations: A Literature Review” in the Canadian Journal for Prosthetics and Orthotics (Carlyle and Day 2022). This work was co-authored by Sarah Day who granted permission for it’s reproduction in this thesis. The article was published under a CC-BY 4.0 license. The author’s (KC) contribution encompasses the design of the study, data collection, data analysis, interpretation and preparation of the manuscript draft. This study was initially conducted in 2021 and findings published in 2022. A review of literature was carried out in August 2024 to update findings.

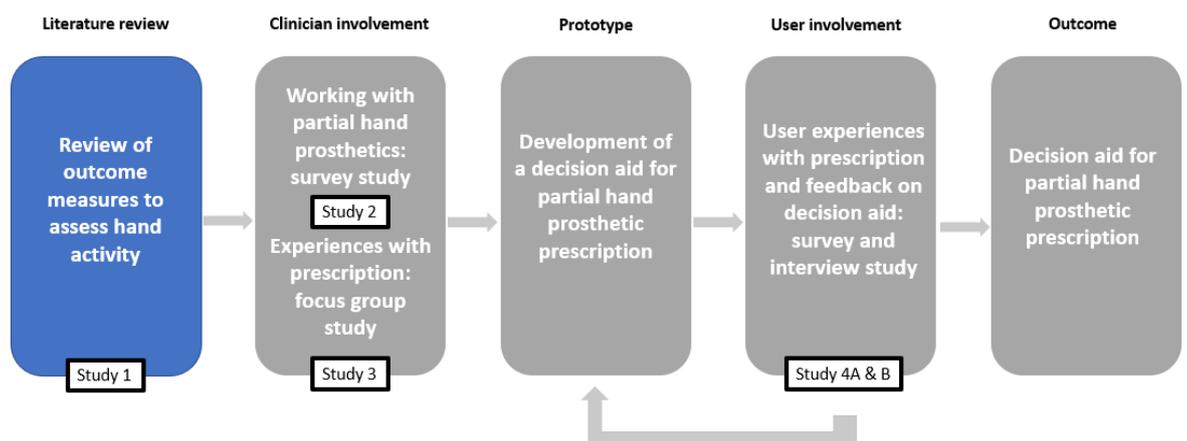


FIGURE 12 - FLOWCHART HIGHLIGHTING STUDY DESCRIBED IN CHAPTER 2 IN BLUE

## 2.2 Background

The human hand is critical in assisting with ADL. Injury or amputation of the hand can affect a person in a variety of forms including physically, socially and psychologically. Outcome measures may be used to assess hands through measuring functionality and gauging satisfaction with hand activity. Knowledge of outcome measures used to assess upper limb activity of intact and amputee populations could aid in guiding research towards designing tools, devices, interventions or further studies specific to limb different populations. Tools could aid developments in prosthetic design and prescription, which benefit both users and healthcare researchers. Understanding which outcome measures are most appropriate to assess prosthetic technologies or measure function with or without a prosthesis may provide useful information to feed into design and development. Furthermore, understanding and measuring functional loss due to amputation or limb difference may highlight the direction in which technology should move forward, such as towards faster devices or technology which is user-friendly.

### 2.2.1 Outcome measures in healthcare

Recording patient and user outcomes is a recognised means of driving further research and development of technology (Biddiss and Chau 2007). In healthcare, outcomes can be seen as a measure of quality status or change over time (Porter 2010). Outcome measures can capture crucial information about people such as their ability to function or physically perform at a certain level, levels of pain experienced and satisfaction. They can include self-reported, performance based or clinician-reported measures. Outcome measures can be used to assess a number of health-

related conditions or interventions, from stroke and musculoskeletal complaints to depression and therapeutic treatments, for example.

### 2.2.2 Outcome measures used in upper limb prosthetics

Outcome measurement tools (OMT) have been used in clinical practice and research to assess limb activity. Such tools include quantitative functional tests and qualitative self-report questionnaires. For health practitioners, standardised OMT may allow them to better prescribe treatments for their patients. In addition, standardised outcome measures for certain presentations, such as partial hand amputation, could provide information which can drive research and development of better devices.

There are benefits to using outcome measures, such as proof of a treatment or device delivering positive outcomes. This can lead to justification for acquisitions or funding for a particular device or treatment.

Examples of outcome measures used in upper limb prosthetics include the Box and Blocks test, Disabilities of the Arm Shoulder and Hand (DASH) questionnaire and range of motion. These outcome measures are an example of the variety of formats in which an OMT can be presented in, the method in which it is delivered and observed, and different levels of standardisation. For example, in the Box and Blocks test the participant uses unilateral movement to move blocks from one side of a box to another as shown in Figure 13. This test is observed by a practitioner, timed and scored by counting the number of blocks which have been transferred. Dexterity is tested through this outcome measurement assessment as the participant must place one block at a time without their fingertips (or prosthetic equivalent) crossing the midline of the equipment. In terms of people with upper limb difference, the Box and

Blocks test could be carried out after device fitting and following training with device to assess if the user is adapting to the device and it performs as expected.



**FIGURE 13 - PARTICIPANT CARRYING OUT THE BOX AND BLOCKS TEST (ILLUSTRATED BY CRUNCH DESIGN)**

A different style of outcome measure, the DASH is a 30-item self-report questionnaire designed for people with upper extremity musculoskeletal disorders. An extract of the DASH is shown in Figure 14. Participants are asked to rate activities such as using a knife to cut food or washing themselves based on levels of difficulty and interference. This questionnaire has been translated to allow use across many languages and uses a 5-point Likert scale which allows for quantification of results (Physiopedia 2022).

Please rate your ability to do the following activities in the last week by circling the number below the appropriate response.

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. Open a tight or new jar.	1	2	3	4	5
2. Write.	1	2	3	4	5
3. Turn a key.	1	2	3	4	5
4. Prepare a meal.	1	2	3	4	5
5. Push open a heavy door.	1	2	3	4	5
6. Place an object on a shelf above your head.	1	2	3	4	5
7. Do heavy household chores (e.g., wash walls, wash floors).	1	2	3	4	5
8. Garden or do yard work.	1	2	3	4	5
9. Make a bed.	1	2	3	4	5
10. Carry a shopping bag or briefcase.	1	2	3	4	5

FIGURE 14 - EXTRACT OF THE DASH QUESTIONNAIRE (DASH 2025)

Self-report questionnaires such as the DASH consider quality of life as the participant assesses their satisfaction and ability to perform tasks in their day to day life, without performing a functional assessment outwith their home environment. For people with upper limb difference, the DASH outcome measure could be used to assess satisfaction with a prosthetic device by comparing scores before and after prescription. On the other hand, unlike the DASH, range of motion is an outcome measure which considers only function. Range of motion is used in a number of fields of research, but specifically in the upper limb prosthesis user population it can be used to provide objective data on joint mobility (Shanahan 2024). Measurements of joint motion, for example across the wrist or fingers, are taken in degrees and compared to an unaffected side or a control group. This is another example of an observed test, and the practitioner may note factors such as pain during assessment. For prosthesis users, range of motion could be useful to determine whether the

participant is a candidate for a specific device or whether a device is being used as expected.

### 2.2.3 Challenges

Despite benefits, there are a number of reasons for not using an outcome measure. Outcome measurements can vary in terms of time taken to complete the assessment. Some tests could be carried out at home, such as self-reported outcome measures where the participant completes a survey or tracks their own data to feed back to the assessor. Thus, completing in their own time. Nonetheless, this can mean the assessor spends time following up with the participant and can lead to bias in findings due to lack of observation. For some outcome measures, training is required to be able to conduct the assessment. Researchers may not have the clinical skills or setting required to carry out an outcome measurement. Likewise, a clinician may not have the time available in their practice to carry out an assessment. Some outcome measures are not open access and require purchase. It could also be said that some outcome measures are not used because the assessor, whether that be a researcher or clinician, does not have knowledge of all outcome measures available for a particular assessment. Further, outcome measures are often used which have not been designed specifically for the population (Arm Dynamics 2024). For people with bilateral limb difference, there is no unaffected side to compare with. Additionally, people with congenital limb difference cannot be compared in terms of before or after device prescription or treatment as they have never experienced life without said limb difference.

#### 2.2.4 Study aims and objectives

This review considers the current outcome measures used to assess hand activities. Both amputee and intact populations were chosen for this review as literature specific to amputee populations is limited. The specific aim was to examine OMT used to assess hand activities. The objectives of the review were to evaluate the range of existing OMT for intact and amputee populations when assessing hand activity and examine various OMT used for hand activities.

## 2.3 Method

### 2.3.1 Study design

Reporting findings in a non-biased, usable format aids in advancing research and informing clinical decision-making in the field of prosthetics and orthotics, and related fields. Since qualitative and quantitative tools are used to report outcome measures related to hand activity, a literature review was selected as a strong approach to synthesise such data and put it into context (Cooper-Ryan 2020). The rationale for using a scoping review was that the aim of the study is to depict the current state of knowledge and practice in outcome measuring tools for hand activities (Cooper-Ryan 2020) and no such review existed in the literature at the time of the study. Due to the different natures of the outcome measures expected to be found in the review, narrative synthesis was performed to summarise data.

### 2.3.2 Protocol

The literature review was pre-registered on PROSPERO (Reference: CRD42021259954) and conducted in accordance with PRISMA guidelines (PRISMA 2009) as shown in Figures 15 and 16. Searches were run in PubMed, Cochrane, ProQuest databases. Relevant keywords used in the search were ("outcome measures" OR "outcome measurement tool" OR "outcome measurement tools" OR "outcome measurement") AND ("hand activity" OR "hand activities" OR "hand function") AND (function\* OR "quality of life" OR satisfaction) AND (amputee OR intact OR amputation) NOT (foot OR feet OR lower limb). Results were filtered to meet the following inclusion criteria: written in English, including adult human

participants, published between August 2009 and August 2024. The initial search was conducted to include publications up to August 2021, then an update carried out to capture data up until August 2024. Duplicates were removed. Study titles were screened and excluded if they reported on children, measurement tools that focus on arm movement (not hands), interventions not specific to population, feasibility studies and participants with neurological conditions without involvement of healthy controls. The following types of study were excluded: systematic reviews, pilot studies, protocol developments, narrative reviews, feasibility studies and non-peer reviewed articles. Systematic reviews were excluded so the study only considered original research. Studies were included if they reported outcome measures and tools to assess adult human hand function and quality of life of unilateral upper limb amputees, bilateral upper limb amputees and the intact population. Abstracts were screened from studies which passed or remained unclear following title screening. Full texts were obtained from studies which passed or remained unclear following screening. Full text screening was then conducted. The final studies were assessed for quality using a method derived from the CASP checklists (CASP 2018). This method involved applying a set of questions to each study which considered the validity of results, risk of bias, quality of data, ethical considerations and the applicability of results in the context of the research question and study population (Appendix A). The CASP tool was selected as it provides a standardised framework to appraise quality of studies relevant to this research topic. Studies which declared a conflict of interest were included as such disclosures were not thought to have impacted the quality or reputability of the work in relation to the research question.

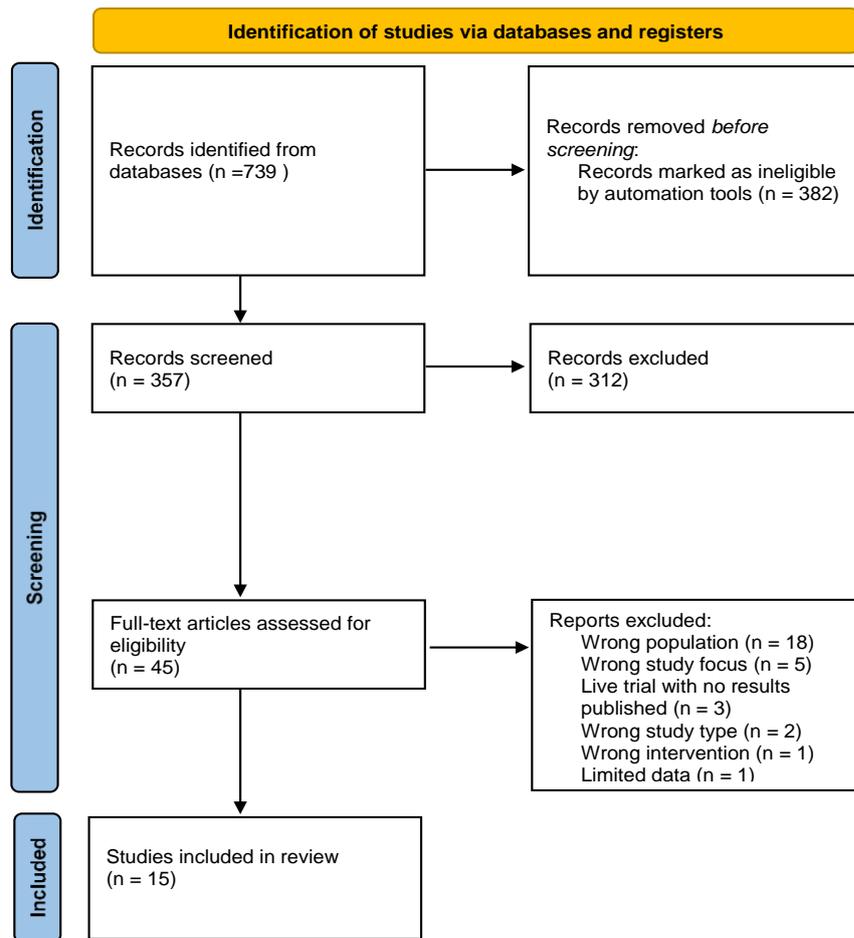


FIGURE 15 - INITIAL STUDY SELECTION FLOWCHART

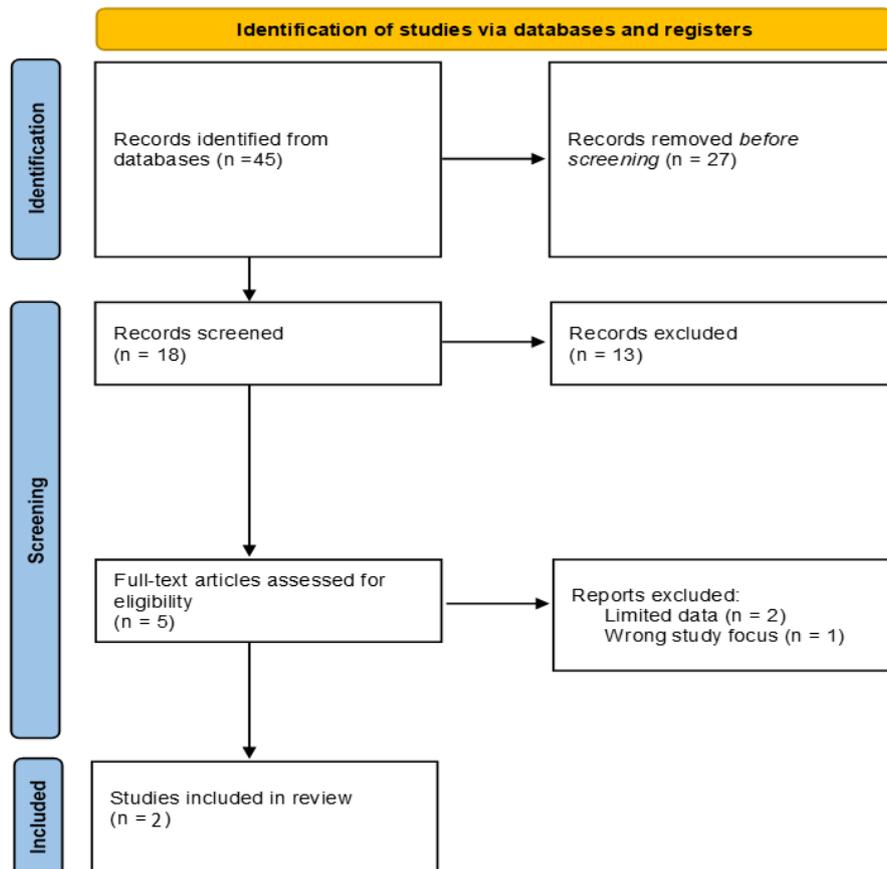


FIGURE 16 - SECONDARY STUDY SELECTION FLOWCHART AFTER UPDATED SEARCH

Ethical approval was not required to complete this review as no subject participation or handling of sensitive information were carried out. All studies involving subjects and confidential information were checked to ensure quality data were collected with appropriate ethical approval.

### 2.3.3 Data analysis

All outcome measures used in studies were recorded and the frequency of use of each outcome measure was noted. Modified or adapted versions of tools - such as the original DASH and QuickDASH – were grouped together. Measures which were similar in nature through describing the same variables were grouped together. Strength variables such as grip strength and precision force were grouped together to represent force control (FC). Joint angle measures describing range of motion were grouped together (ROM). Shape texture identification test and self-rating of tactile gnosis were grouped together (tactile gnosis/TG). Upper extremity functional scale and patient specific functional scales were grouped together (functional scales/FS). Duration of hand movements and task movement times were grouped together (temporal measures/TM). Outcome measures were also grouped into the following types: 'functional', 'quality of life (QoL)' and 'functional and QoL' measures. Narrative synthesis was carried out. Codes were created and grouped together to define themes across the studies in relation to the research topic.

## 2.4 Results

Following searching and screening, 17 studies were reviewed (Table 2). The first review in 2021 found 15 studies for review, and a second search in 2024 found an

additional two. A data extraction table (Table 3) was used to record number of outcome measures, types of outcome measures, participant demographics and ethical considerations.

**TABLE 2 - LIST OF INCLUDED PAPERS**

<b>Authors</b>	<b>Title &amp; Reference</b>	<b>Year</b>	<b>Study Number</b>
Lee, Seungjae: Lee, Hyejeong: Lee, Jongshill: Ryu, Hokyoung: In Young, Kim: Kim, Jieun	Clip-On IMU System for Assessing Age-Related Changes in Hand Functions (Lee 2020)	2020	1
Lawrence, Emily L.: Dayanidhi, Sudarshan: Fassola, Isabella: Requejo, Philip: Leclercq, Caroline: Winstein, Carolee J.: Valero-Cuevas, Francisco J.	Outcome measures for hand function naturally reveal three latent domains in older adults: strength, coordinated upper extremity function, and sensorimotor processing (Lawrence 2015)	2015	2
Eklund, Elsine: Svensson, Elisabeth: Hager-Ross, Charlotte	Hand function and Disability of the Arm, Shoulder and Hand in Charcot-Marie-Tooth disease (Eklund 2019)	2019	3
Hruby, Laura A.: Gstoettner, Clemens: Sturma, Agnes: Salminger, Stefan: Mayer, Johannes A.: Aszmann, Oskar C.	Bionic Upper Limb Reconstruction: A Valuable Alternative in Global Brachial Plexus Avulsion Injuries-A Case Series (Hruby 2019)	2019	4
Resnik, L. J.: Borgia, M. L.: Clark, M. A.	A National Survey of Prosthesis Use in Veterans with Major Upper Limb Amputation: Comparisons by Gender (Resnik 2020)	2020	5
Resnik, L.: Borgia, M.: Clark, M.	Function and Quality of Life of Unilateral Major Upper Limb Amputees: Effect of Prosthesis Use and Type (Resnik 2020)	2020	6
Resnik, L.: Borgia, M.	Responsiveness of outcome measures for upper limb prosthetic rehabilitation (Resnik 2016)	2016	7
Raveh, E.: Portnoy, S.: Friedman, J.	Myoelectric Prosthesis Users Improve Performance Time and Accuracy Using Vibrotactile Feedback When Visual Feedback Is Disturbed (Raveh 2018)	2018	8

Speth, K. A.: Yoon, A. P.: Wang, L.: Chung, K. C.	Assessment of Tree-Based Statistical Learning to Estimate Optimal Personalized Treatment Decision Rules for Traumatic Finger Amputations (Speth 2020)	2020	9
Wang, S. L.: Bloomer, C.: Civillico, G.: Kontson, K.	Application of machine learning to the identification of joint degrees of freedom involved in abnormal movement during upper limb prosthesis use (Wang 2021)	2021	10
Sobuh, M. M.: Kenney, L. P.: Galpin, A. J.: Thies, S. B.: McLaughlin, J.: Kulkarni, J.: Kyberd, P.	Visuomotor behaviours when using a myoelectric prosthesis (Wang 2021)	2014	11
Hruby, L. A.: Sturma, A.: Mayer, J. A.: Pittermann, A.: Salminger, S.: Aszmann, O. C.	Algorithm for bionic hand reconstruction in patients with global brachial plexopathies (Hruby 2017)	2017	12
de Boer, E.: Romkema, S.: Cutti, A. G.: Brouwers, M. A.: Bongers, R. M.: van der Sluis, C. K.	Intermanual Transfer Effects in Below-Elbow Myoelectric Prosthesis Users (de Boer 2016)	2016	13
Bouma, S. E.: Postema, S. G.: Bongers, R. M.: Dijkstra, P. U.: van der Sluis, C. K.	Musculoskeletal complaints in individuals with finger or partial hand amputations in the Netherlands: a cross-sectional study (de Boer 2016)	2018	14
Bernardon, L.: Gazarian, A.: Petruzzo, P.: Packham, T.: Guillot, M.: Guigal, V.: Morelon, E.: Pan, H.: Dubernard, J. M.: Rizzo, C.: Feugier, P.: Streichenberger, T.: Bincaz, L.: Urien, J. P.: Mezzadri, G.: Rousselon, T.: Plotard, F.: Seulin, C.: Braye, F.: Mojallal, A.: Herzberg, G.: Kanitakis, J.: Abrahamyan, D.: Kay, S.: Badet, L.	Bilateral hand transplantation: Functional benefits assessment in five patients with a mean follow-up of 7.6 years (range 4-13 years) (Bernardon 2015)	2015	15
Cantero-Tellez, R., Algar, L.A., Valdes, K.A., Naughton, N.	Clinical effects of proprioceptive thumb exercise for individuals with carpometacarpal joint osteoarthritis: A randomized controlled trial	2022	16
Simon A.M., Turner K.L., Miller L.A., Dumanian G.A., Potter B.K., Beachler M.D., Hargrove L.J., Kuiken T.A.	Myoelectric prosthesis hand grasp control following targeted muscle reinnervation in individuals with transradial amputation	2023	17

TABLE 3 - DATA EXTRACTION TABLE

Study Number	Ethical Concerns?	Type of Study	Participant Demographics	Number of Participants	Intact, amputee, prosthesis user or combination	Setting	Self-reported, clinician observed or combination?
1	No	cohort study	healthy adults (aged 20-31 and 75-89)	34	intact	university	clinician observed
2	No	case-control study	healthy older adults and older adults with osteoarthritis of the CMC joint	99	intact	university/rehab centre	clinician observed
3	No	case-control study	adults with with charcot marie tooth and healthy controls	60	intact	hospitals/clinics	combination
4	No	case study	adults with complete brachial plexus injury who underwent bionic reconstruction after high level upper limb amputation	5	prosthesis user	university	combination
5	No	cross-sectional survey	adult veterans with upper limb amputation who had been treated between 2010 and 2015	808	amputee	telephone survey	self-reported
6	No	cross-sectional survey	adult veterans with unilateral upper limb amputation who had been treated between 2010 and 2015	755	amputee	telephone survey	self-reported
7	No	quasi-experimental study	adult upper limb amputees	39	amputee	veterans affairs sites	combination

8	No	quasi-experimental	transradial amputees using a myoelectric prosthesis with normal or corrected eyesight	12	prosthesis user	laboratory	combination
9	No	cohort study	adult patients who underwent revision amputation or replantation	185	amputee	various research centres	combination
10	No	cross-sectional	adults with no upper limb disability, trained on deka bypass or body powered bypass	24	intact	laboratory	clinician observed
11	No	experimental	intact adults and adult myoelectric prosthesis users	11	combination (intact and prosthesis user)	university	clinician observed
12	No	case study	adults with posttraumatic global brachial plexopathies	5	prosthesis user	university	combination
13	No	case-control study	myoelectric prosthesis users and controls	44	combination (intact and prosthesis user)	university/rehab centre	clinician observed
14	No	cross-sectional study	adult finger and hand amputees and healthy controls	201	combination (intact and amputee)	questionnaire sent to participants	self reported
15	No	case study	adults who underwent hand and forearm allotransplantation following trauma	5	intact (post transplantation)	rehabilitation clinic	combination

16	No	randomised control trial	healthy adults and adults with osteoarthritis (thumb)	52	intact	clinic	clinician observed
17	No	mixed methods	adults with unilateral amputation below able with ability to use myoelectric prosthesis	7	amputee	clinic and home	combination

Studies were published between the years 2009 and 2023. Across the studies, participants were categorised in the following populations: able bodied, able bodied using upper limb bypass equipment, upper limb prosthesis users, people with osteoarthritis, Charcot-Marie-Tooth disease, upper limb/finger/hand amputation and recipients of hand and forearm allotransplantation. Studies were conducted using intact only, intact and amputee/prosthesis user, and amputee/prosthesis user only populations. Studies involving participants with osteoarthritis and Charcot-Marie-Tooth disease used healthy controls, enabling their inclusion within the review.

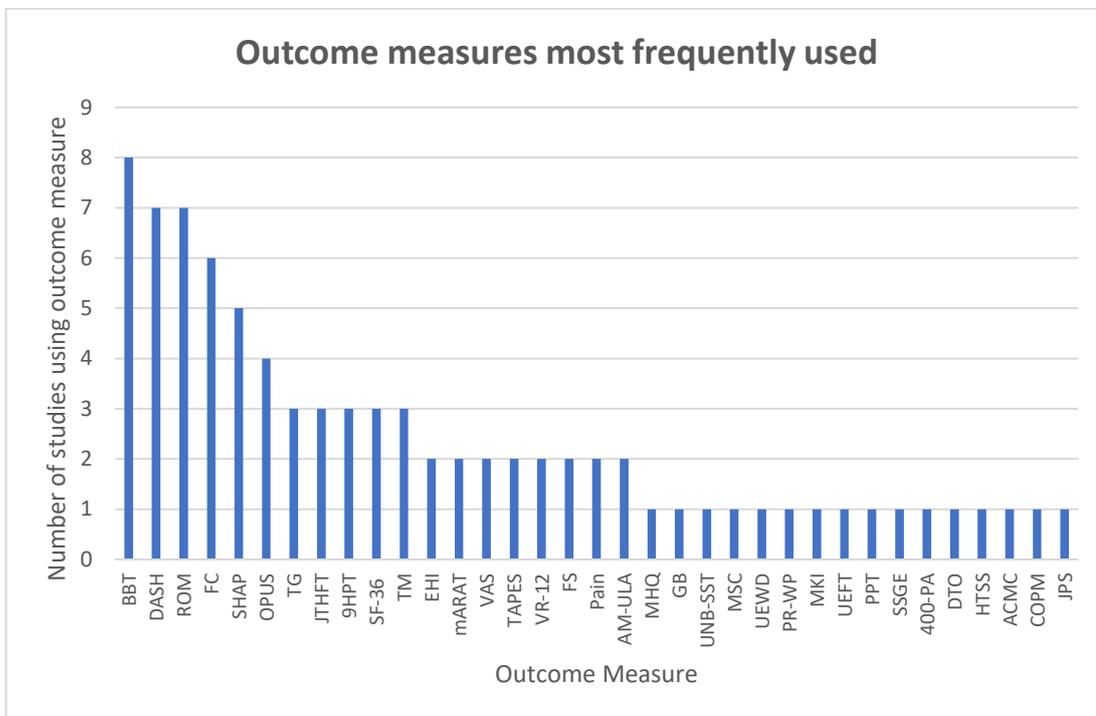
A total of 35 outcome measures were identified within the studies reviewed (Table 4).

**TABLE 4 - OUTCOME MEASURES USED, ACRONYMS, TYPES AND DESCRIPTIONS**

<b>Outcome Measure</b>	<b>Acronym</b>	<b>Type</b>	<b>Description</b>
Box and Block test	BBT	Functional	Test of manual dexterity
Swedish Disabilities of the Arm Shoulder and Hand Questionnaire	DASH	Functional & QoL	Self-reported measure of disability and symptoms in relation to the upper limb
Range of Motion	ROM	Functional	Measure of level of movement achieved
Force Control	FC	Functional	Measure of strength achieved
Southampton Hand Assessment Procedure	SHAP	Functional	Test of hand function using abstract objects and ADL
Orthotics and Prosthetics User's Survey	OPUS	Functional & QoL	Self-reported survey of outcomes and satisfaction with orthotic/prosthetic devices and services
Tactile gnosis	TG	Functional	Ability to detect information through touch
9 Hole Peg test	9HPT	Functional	Measure of finger dexterity
36-Item Short Form Survey	SF-36	QoL	Self-reported measure of quality of life
Temporal measures	TM	Functional	Time-based activities and tasks
Edinburgh Handedness Inventory	EHI	Functional	Assessment of hand dominance
Modified Action Research Arm test	mARAT	Functional	Assessment of hand function during grasp, pinch, grip and gross movements
Visual Analogue Scale	VAS	QoL	Measure of severity of symptoms
Trinity Amputation and Prosthetic Experience Scale	TAPES	QoL	Self-reported measure of experiences and satisfaction with regards to acquired amputation and prosthesis adjustment
Veterans SF-12 Health Survey with physical and mental components	VR-12	Functional & QoL	Self-reported measure of health

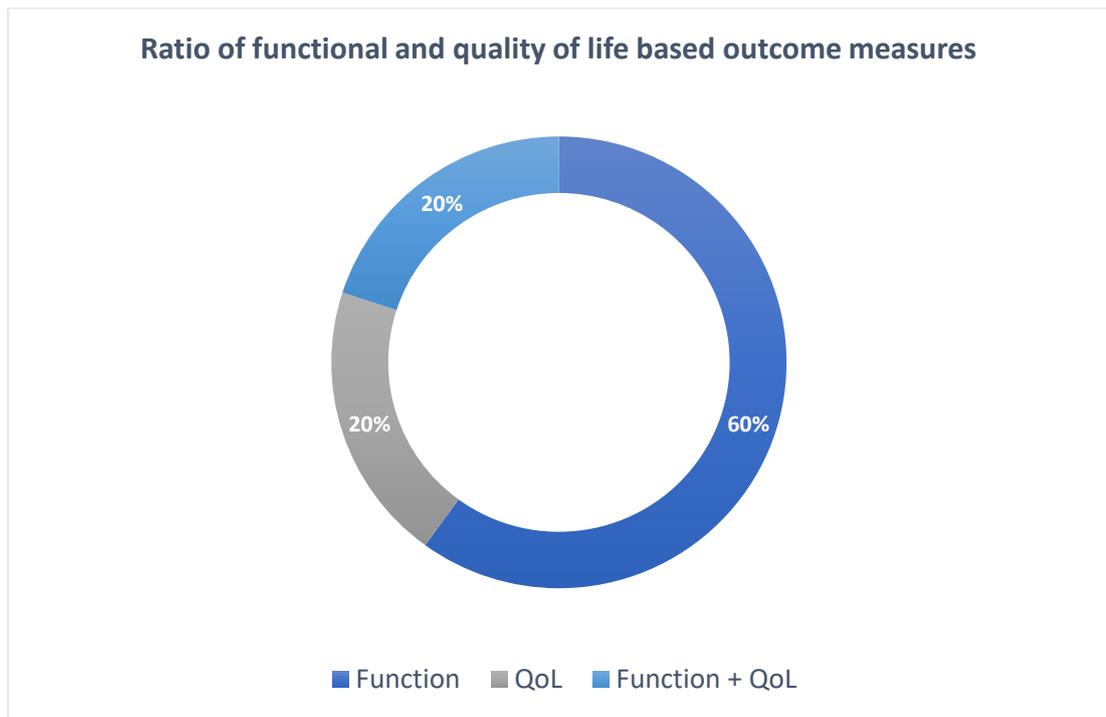
Jebsen-Taylor Hand Function tests	JTHFT	Functional	Test of hand function carrying out a range of different ADL-based tasks
Functional scales	FS	Functional	Measure of function
Pain	Pain	QoL	Assessment of patient/user pain
Activity measure for upper limb amputation	AM-ULA	Functional	Measure of upper limb activity performance
Michigan Hand Outcomes Questionnaire	MHQ	Functional & QoL	Self-reported measure of hand outcomes including pain, function, aesthetics, ADL, work and satisfaction
Gaze behaviour	GB	Functional	Assessing visual responses during tasks
University of New Brunswick Skill and Spontaneity tests	UNB-SST	Functional	Non-timed measure of function
Prevalence of Musculoskeletal Complaints	MSC	QoL	Self-reported indication of physical symptoms
Upper extremity work demands score	UEWD	Functional & QoL	Measure specifically related to work tasks
Patient-reported work productivity	PR-WP	QoL	Self-reported indication of level of ability to participate in work
Modified Kapandji Index	mKI	Functional	Measure of hand mobility
Carroll Upper Extremity Function test	UEFT	Functional	Measure of functional impairment and severity
Purdue Pegboard test	PPT	Functional	Measure of gross upper limb movement and finger dexterity
Self-subjective global evaluations	SSGE	QoL	Self-reported measure of quality of life
400 Point Assessment	400-PA	Functional	Test of function in tasks, strength, mobility and handling
Direct observation by therapist while performing tasks	DTO	Functional	Clinician-researcher observing participant without using a specific measure
Hand Transplantation Score System	HTSS	Functional & QoL	Measure of ability and quality of life following hand transplantation
Assessment of Capacity for Myoelectric Control	ACMC	Functional	Observed test of performance in functional tasks
Canadian Occupational Performance Measure	COPM	Functional & QoL	Self-reported measure of performance in occupational tasks
Proprioception	JPS	Functional	Assessment of conscious sensory motor impairment

The most frequently used tools and measures, as shown in Figure 17, were the BBT (8), DASH (7), ROM (7) and FC (6). All studies used a combination of measures, ranging from two to 12 outcome measures assessed per study.



**FIGURE 17 - GRAPH DEPICTING NUMBER OF TIMES EACH OUTCOME MEASURE WAS USED ACROSS THE INCLUDED STUDIES**

The majority (60%) of outcome measures listed in Table 4 are functional based measures. While these outcome measures were more prevalent within studies, some OMT (20%) assess both function and quality of life (Figure 18).



**FIGURE 18 - PIE CHART SHOWING THAT MOST OUTCOME MEASURES ASSESS FUNCTION, WITH A SMALLER PROPORTION ASSESSING QoL**

The following quotes of relevance to the research topic were extracted from included studies:

- *"the most objective of the commonly used upper limb evaluation tools are based on time to perform a structured set of tasks, but use of these in isolation gives limited insight into ease of use of a prosthesis" (Sobuh 2014)*
- *"the central question here is, what should we use to quantify hand function considering that we have so many choices of assessment tools and even more outcome measures stemming from these tools?" (Lawrence 2015)*

- *"leaders in upper limb prosthetic rehabilitation understand the importance of choosing outcome measures that have been evaluated for persons with upper limb amputation and that are reliable, valid, and responsive to change" (Resnik 2016)*
- *"another important aspect in prosthetic rehabilitation research is the use of valid outcome measures" (Raveh 2018)*

Three themes were derived from the papers in relation to assessing hand activity as follows:

1. Importance of function and quality of life when assessing hand activity
2. The need for realistic tasks when assessing hand activity
3. The need for outcome measures specific to the population.

## 2.5 Discussion

The themes generated from this study are discussed in sections 2.5.1-2.5.3.

### 2.5.1 Theme 1: Importance of function and quality of life when assessing hand activity

A key theme was the value of both functional and quality of life focused assessments of hand activity. Despite this finding, 60% of outcome measures used were functional measures and only 20% quality of life measures. By using a combination of OMT, the researchers of various studies were able to capture functional, and quality of life data. However, there is no standard combination, or designed pairing of tools to obtain all information. This highlights the need for development of guidelines that are comparative of both contexts. It could also be said that in the field, such as in clinical

practice, carrying out multiple assessments may not be feasible and time consuming so therefore not always achieved (Hafner, Spaulding et al. 2017).

Although functional domains and tasks were accounted for in many studies, it is known that these attributes can affect ones quality of life. For example, impact on function can subsequently impact quality of life and participation in society. If a person has functional issues which affect their occupation or participation in social environments, they may experience reduced quality of life. Further, some may argue that quality of life is function as a person requires a certain standard of quality of life to be able to participate in society (Cegarra, Cattaneo et al. 2023).

Pain was another common factor in hand activity assessments which was found throughout studies. Pain should be considered throughout performance of various functional tasks as such tasks may conversely impair function as presence of pain is likely to have a negative effect on quality of life. Self-reported outcomes of parameters such as pain can paint a picture of their overall satisfaction. Nonetheless, self-reported outcomes are limited due to self-reporting bias and lack of observation by professionals who interpret results (Zini and Banfi 2021).

Outcome measures which consider functional failures, such as failed grasp or dropping objects may be advantageous in the amputee and prosthetic user population to account for actions such as failed prehension. This could provide key information about device performance as well as participant function. In turn, good device performance and function can directly impact quality of life.

### 2.5.2 Theme 2: The need for realistic tasks when assessing hand activity

Another theme derived from the studies was the importance of including ADL in assessments of hand activity. Many of the functional outcome measures found in studies were used in combination with other tools to put function into context. Most of the studies investigating hand function, alongside outcome measures included, were structured in that the participants were given precise instructions to complete specified tasks. It must be noted that the ability to place pegs in a board, as instructed in outcome measures such as the 9HPT and PPT, does not necessarily correlate to information about key parameters such as strength in everyday activities. Moreover, this process does not correlate with the skill required to carry out typical ADL due to increased levels of complexity in such tasks compared to the simplified movements in the outcome measurement assessment. Likewise, the BBT was one of the most frequently used measures. This outcome measure could be considered simple to set up, however, transferring blocks between compartments is one repetitive process which is not implemented in most ADL (Raveh 2018). Thus, it could be questioned that assessors may find outcome measures such as the BBT preferential due to ease of set up and time taken to complete rather than the value provided. Likewise, people may value certain ADL more than others. Some may wish to cook and others may participate professionally in sports. The activities in which each person carries out day to day can differ. Therefore, outcome measures which assess tasks that are realistic and considered valuable to the person undergoing assessment would be beneficial in hand activity testing.

An overlooked element contributing to realism is participant-led activities during assessment. In prosthetic user populations, it would be pragmatic to ask the participant to complete tasks with their prosthesis on and off to account for a range of scenarios. It should not be assumed that users wear their device consistently (Davidson 2002), or if presenting with unilateral limb difference always lead with one specific side. Studies should include both unilateral and bilateral tasks to represent a wider range of real-life scenarios. In addition, most studies were carried out in research laboratories, clinics, and universities. This means the researcher has control within the study and this weakens the link between the hand activities and real-world applications (Jones, Webb et al. 2022). Shifting frequently used outcome measures which involve performing basic tasks to measures which instruct real world object manipulation, such as turning keys or picking up a mug, would provide an extra dimension in relating clinical studies to applications in the real world.

### 2.5.3 Theme 3: The need for outcome measures specific to population

Different populations are known to have different key components of hand function, so the focus of functional assessment tools should be tailored to the prosthesis user population. It was also highlighted within the reviews that people value parameters differently, for example dexterity may be of more importance than strength (Biddiss, Beaton et al. 2007). It would be advantageous to understand the parameters which are of importance to prosthesis users before using tools to assess hand activity. Performance-based outcome measures used to assess hand activity often compare the performance of an amputee or prosthesis user with the intact population. This is not an optimal comparison since the populations have various levels of function and

goals. Low level strength is required to facilitate ADL and functional tasks, so people with amputation who may have a level of strength too low to carry out such tasks may be unable to be assessed with such tools. Also, there is a level of dexterity required for tools such as tactile gnosis assessments. If OMT can only be used in populations with a baseline level of ability, then tools must be adapted or developed to involve people who do not satisfy this criterion. Further, many of the tools used are temporal based and therefore do not give indications into ease of use, which is an important parameter when investigating the amputee and prosthesis user populations (Wang, Hsu et al. 2018). Another argument for using outcome measures specific to the population is that a specific measurement may alleviate the need for recruiting healthy, intact participants when researchers are interested in outcomes of amputee or prosthesis users only.

## 2.6 General discussion

The review depicts a range of outcome measures used to measure hand activity in amputee and intact populations. There was a clear indication that use of multiple outcome measures is optimum to evaluate hand activity. It could be true that it is difficult to select one tool due to lack of tools which bring together various aspects of hand activity such as function, pain, and satisfaction. The reason behind choice of tool may be due to location of the study – for example in-clinic or telephone surveys. Additionally, choice of tool may be a consequence of the fact that not all tools are validated for use in amputee populations. It is possible that researchers select tools based on personal preference, training acquired, or education rather than appropriateness. Tools involving participant-reporting of data may not reflect true

physical performance, so may not be sufficiently reliable. Nonetheless, self-reported studies, which may present as questionnaires, can attract larger sample sizes. No specific guidelines related to assessment of hand activities were highlighted within the included studies, which could be an indication that such guidelines should be developed in this area. There was a lack of diverse devices included in the studies with most studies involving prostheses featuring only myoelectric devices, rather than the full range of prosthetic devices available for upper limb difference. Finally, there is limited information on outcome measures for cosmetic devices. Despite not being considered functional devices, some may use cosmetic prostheses for functional tasks such as pressing buttons or may experience improved quality life when using such a device which subsequently can go unreported.

### 2.6.1 Limitations

A limitation of this review is that data from pilot studies, reviews and protocol development studies were not included. Therefore, outcome measures considered are not a comprehensive list. Inclusion was limited to studies published in more recent years to ensure conclusions were reflective of the current state of technology and practice. Studies which only included participants with neurological conditions were excluded to ensure the correct population was analysed. Studies which used stroke-specific tools such as the Fugl-Meyer (Physiopedia 2021) were excluded as OMT selection by the research may be biased towards the stroke population and thus not a true reflection of amputee or intact populations. This exclusion explains the small amount of studies which included intact populations. Small sample sizes within many included studies are another limiting factor, as this restricts data available for assessment. Studies with larger sample sizes were self-reported surveys which are limited in terms of OMT which can be used. Only one reviewer screened and selected articles for inclusion, thus presenting a potential element of bias in terms of study selection. In addition, there is scope for subjectivity in the interpretation of the CASP tool which was also used by only one researcher. The CASP tool focuses on methodology and all papers used in this study were good with some notices of conflict of interest. An additional tool may have been used to delve deeper into the studies to assess if the papers were all truly good as found by the CASP tool.

### 2.7 Conclusion

There is a gap in research surrounding OMT used to assess hand activity in the amputee and prosthesis user population. Results from this review of outcome

measures used in amputee and intact populations showed that a combination of outcome measures are currently used to capture information about hand activities of intact and amputee populations. There are no set guidelines or recommended pairings of outcome measures, therefore critical information about hand activity could potentially be missed during investigations. A combination of tools is used partially because currently used OMT are limited for use in amputee and prosthesis user populations. Some measurement tools were not validated for people with upper limb amputations, and some involving temporal based tasks may not have been appropriate for assessing function in prosthesis users. Additionally, combinations of tools are used because both function and quality of life measurements are deemed important. These aspects are of particular interest in amputee and prosthetic user populations where factors such as pain, social participation and satisfaction are of high importance to both the person themselves, healthcare practitioners and prosthesis developers. Tools should be developed with both functional and quality of life measurements taken into consideration as well as tasks which pose a likeness to carrying out ADL. Finally, tools should be developed specific to the population to ensure that measurements are valid, useful, and specific.

## 2.8 Chapter summary

This Chapter explored outcome measures used in both amputee and intact populations, highlighting the importance of function and quality of life in evaluating hand activity. Although functional assessments were more commonly reported, the review emphasized the need for outcome measures that incorporate realistic tasks and are specific to individuals with limb difference. The findings raised key questions

regarding who assesses outcomes, which measures are appropriate, and what clinicians should consider during assessment. The gaps identified through this review informed the research direction and led to the development of the next study, described in Chapter 2, which focused on partial hand prosthetic prescription and assessment.

### 3 Study 2: Working with partial hand prosthetics – survey study

#### 3.1 Introduction

Chapter 2 found that there are limited outcome measures that can be used in both intact and limb different populations to assess hand activity. Therefore, it could be interpreted that there are limited outcome measures for use in the upper limb prosthesis user population. There is a lack of evidence that establishes methods or factors influencing the clinical prescription of prostheses specifically designed for this population. Chapter 2 covered upper limb including partial hand, but no partial hand specific measures were found in the study. Considering this, it was decided that the next steps should be to find out how partial hand prostheses are selected and assessed by those who prescribe them as shown in Figure 19. This Chapter presents Study 2 of this thesis, a survey study designed to explore who prescribes partial hand prosthetic devices and the factors influencing device selection.

This Chapter contains work from the author's publication "Working with partial hand prostheses: An investigation into experiences of clinicians" in *Prosthetics Orthotics International* (Carlyle, Buis et al. 2024). This work was co-authored by Sarah Day, Arjan Buis and Maggie Donovan-Hall, all of whom permitted its reproduction in this

thesis. The article is distributed under a Creative Commons license. The author's (KC) contribution encompasses the study design, dissemination of recruitment materials, data collection, data analysis, interpretation and preparation of the manuscript draft.

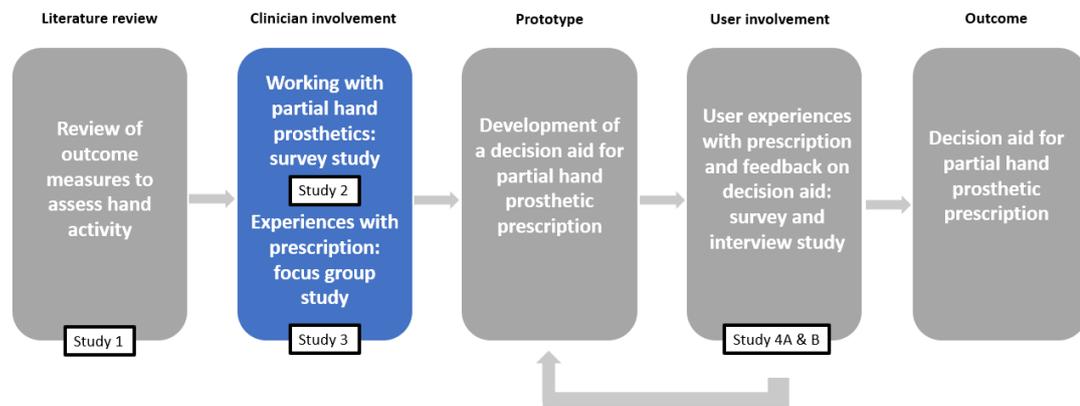


FIGURE 19 – FLOWCHART HIGHLIGHTING STUDY DESCRIBED IN CHAPTER 3 IN BLUE

### 3.2 Background

In terms of the upper limb, the most commonly presented type of amputation is partial hand (Ilmbinto, Peccia et al. 2016). Physical presentation of partial hand limb difference can vary and, subsequently, the extent of implications such as functional loss, psychological impact, aesthetics, social participation and user expectations vary significantly (Grob, Papadopulos et al. 2008, Bouma, Postema et al. 2018). People who have undergone partial hand amputation have been found to experience an increased risk of pain and psychological reactions in comparison to other levels of limb loss (Kearns, Jackson et al. 2018). Therefore, people with partial hand absence should be supported by being offered appropriate prosthetic options, education and rehabilitation to reduce the level of detriment and ensure quality of life.

There is a lack of literature which evaluates and compares partial hand prostheses and evaluates outcomes. At the time of this study, there were no known outcome measures in use which had been developed specifically for partial hand, as demonstrated in Chapter 2. The literature described in Chapter 2 found that outcome measures should be developed or adapted to assess hand activity specifically in the population of people with amputations. Lack of knowledge is said to have impacted partial hand prosthetic prescription historically (Graham, Hendrycks et al. 2021) and there is little known about the clinical decision-making processes applied during the prescription and assessment period. Sometimes individuals are provided with a 'tester' or 'loan' unit which allows them to trial a device before the prescription is made. However, the benefits and scale of this practice for partial hand devices is unknown.

### 3.2.1 Survey methodology

Surveys are frequently employed in healthcare research and may be exploratory, descriptive or explanatory (Safdar, Abbo et al. 2016). Surveys can be used as scoping tools to gather quantitative and qualitative data from participants and can be conducted through various means including online, face-to-face or via telephone interview (Coe 2009). Surveys should be designed to ensure they are consistent, easy and simple to navigate and not laborious in terms of effort and time required (Safdar, Abbo et al. 2016).

### 3.2.2 Study aims

The purpose of the study was to investigate the factors involved in prescribing partial hand prostheses from the perspective of the workforce who develop, assess or prescribe these devices. The objectives of the investigation were to gain understanding of who is prescribing partial hand prostheses, outcome measures used to drive prescription, and factors which influence the selection of devices for the end user.

### 3.3 Methods

#### 3.3.1 Design

An anonymous online survey consisting of 36 items was created using Qualtrics software (Qualtrics 2023) under the University of Strathclyde license. The survey was created by the researchers who each have backgrounds in engineering, prosthetics and health psychology. An external individual who works as an occupational therapist reviewed the survey questions. The survey included a selection of multiple choice, 6-point Likert-type, closed and open-ended questions. Survey content was organised into five main sections: demographics, partial hand prosthetic devices, outcome measures, decision-making and funding. The five sections were based on the objectives of this study and information which was not available in literature. A Participant Information Sheet (PIS) and consent form (Appendix B) were provided at the start of the survey for the participant to provide informed consent before proceeding to answer the survey questions. Participants were given the opportunity to provide contact details on a separate survey following completion, however, no identifiable data were collected as part of the research survey.

Survey questions are contained in Appendix C. The study was granted ethical approval by the Departmental Ethics Committee, University of Strathclyde (DEC.BioMed.2022.325).

#### 3.3.2 Participants and recruitment

Participants were qualified healthcare professionals who work with, or have worked with, partial hand prosthetics. Participants were recruited globally. Inclusion criteria listed in the PIS were as follows: currently works, or has worked within the past five years, in the field of partial hand prosthetics, experience working with partial hand

patients and/or devices, able to read and comprehend English and access to a device which enabled them to take part in an online survey. The only exclusion criterion was not having worked with partial hand in the last five years.

Participants were recruited via a link to the online survey which was distributed using a poster on social media channels including X (formerly Twitter), LinkedIn, Instagram with relevant tags used to increase visibility within the target population (Appendix D and E). The link was also distributed via email to members of International Society of Prosthetics and Orthotics (ISPO UK) and American Society of Hand Therapists (ASHT). These organisations were targeted as their member lists were known to contain individuals who work in partial hand prosthetics and the researchers were each members of one or both of these groups.

### 3.3.3 Data analysis

Data were collected from 15<sup>th</sup> June 2022 until 31<sup>st</sup> October 2022 then analysed by the first author. Data were filtered in Qualtrics to include completed responses only. Qualtrics Crosstabs iQ feature was used to select suitable variables for analysis and explore relationships between different responses. Data were then exported to Microsoft Excel where descriptive statistics were calculated. No statistical tests were performed on the data due to the sample size and exploratory nature of the study. Qualitative analysis was performed on text-based responses to identify key themes in the experiences of the participants. Complete coding on open-ended questions was performed on quotes extracted from participants. Codes were reviewed then grouped together to generate themes specific to each question (Appendix F). Themes were reviewed as an iterative process and proposed themes which were not strongly

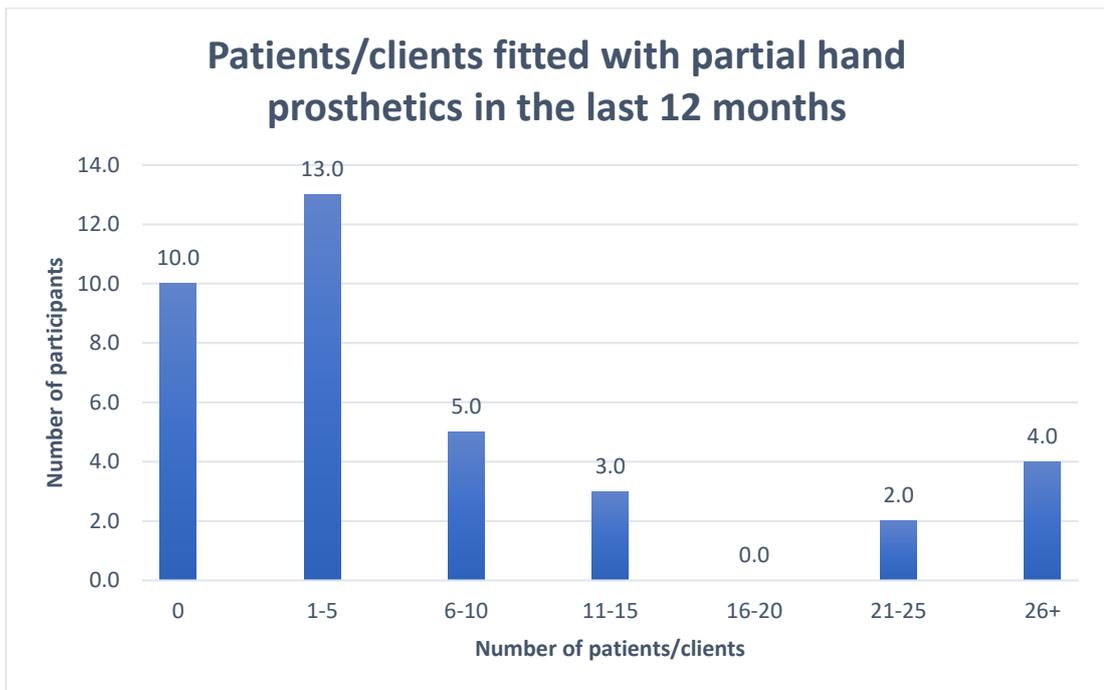
supported by the data were discarded. Themes which were representative of the quotes and associated codes were confirmed and included in analysis.

### 3.4 Results

#### 3.4.1 Demographics

37 participants in total completed the survey. Most of the participants in the study work in United States of America (n=22), followed by Netherlands (n=4) and United Kingdom (n=4), Canada (n=2) and Sweden (n=2), Ghana (n=1), Ireland (n=1) and United Arab Emirates (n=1). Participants were provided with a list of occupations and asked to select which role they currently work in. Participants were able to select more than one occupation as some work across multiple roles, for example 'prosthetist and orthotist'. Participants identified their occupation(s) as occupational therapist (47%), prosthetist (34%), hand therapist (32%), orthotist (10.5%), physiotherapist (7.9%) and other (10.5%). Those who selected 'other' identified their occupations in text-based responses as medical doctor, certified hand therapist, certified prosthetist/orthotist and seller.

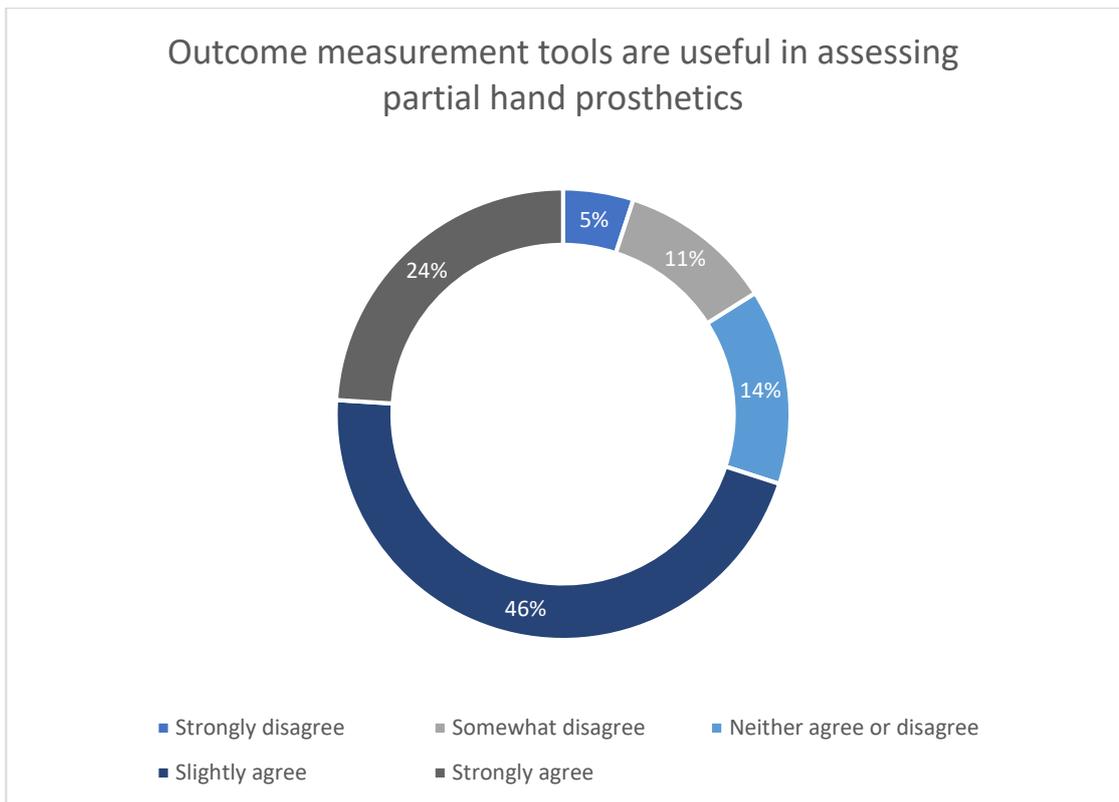
The number of prosthetic devices fitted by participants varied (Figure 20). Over a quarter (n=10) of participants had not fitted any partial hand prostheses within 12 months prior to taking the survey. On the contrary, six participants had fitted a high number of 21+ partial hand prostheses in the 12 months before taking the survey.



**FIGURE 20 - GRAPH SHOWING THE NUMBER OF PATIENTS/CLIENTS FITTED WITH PARTIAL HAND PROSTHETICS (X) PER PARTICIPANT (Y)**

#### 3.4.2 Outcome measures

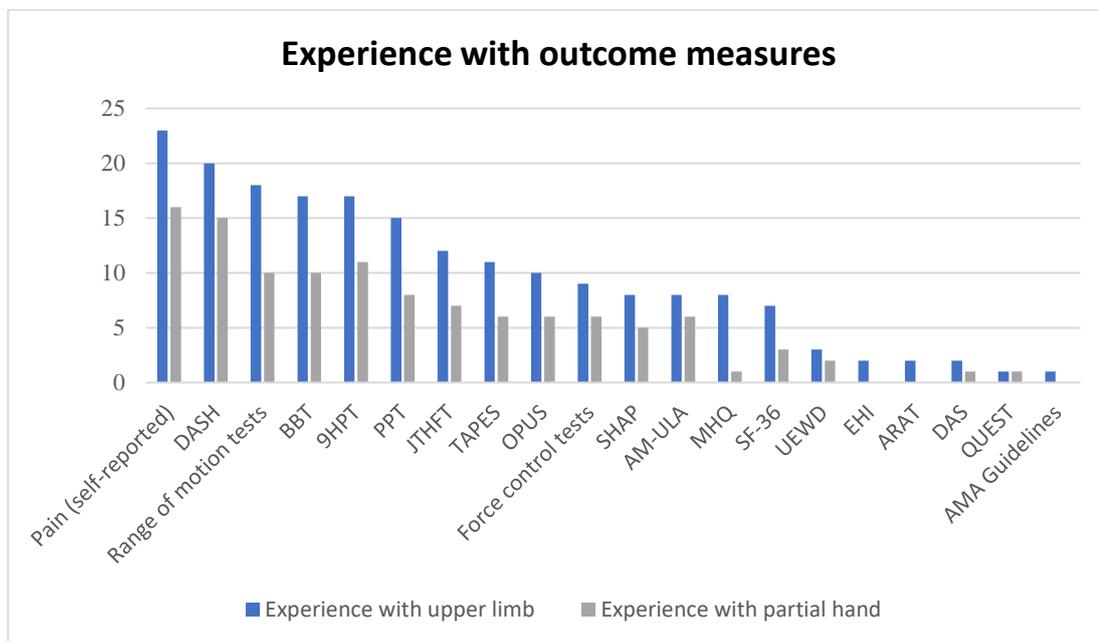
The majority of participants agreed or strongly agreed that OMT are useful in assessing partial hand prostheses (Figure 21). Nonetheless, there were participants who disagreed somewhat (11%) or strongly (5%) in OMT usefulness for this population.



**FIGURE 21 - PIE CHART DESCRIBING PERCENTAGE OF PARTICIPANTS WHO AGREE OR DISAGREE THAT OMT ARE USEFUL IN ASSESSING PARTIAL HAND PROSTHETICS**

All participants were asked if they had experience in using outcome measures with the upper limb population. Those who responded ‘yes’ were presented with a list of 20 OMT and a text box to declare ‘other’ OMT not listed. Participants were then asked if they had experience in using outcome measures in assessing partial hand prosthesis users and provided the same list. Participants indicated experience with more outcome measures in the general upper limb population than specifically in assessing partial hand prosthesis users. Figure 22 shows that participants do not always use outcome measures they are experienced in to assess partial hand prosthesis users. Results show 17 outcome measures have been used by participants to assess partial hand prosthesis users. The most commonly used were: pain (self-reported), DASH, 9HPT, BBT and ROM tests. Participants showed that a range of functional

assessments and self-reported measures are used to assess partial hand prosthesis users.



**FIGURE 22 - GRAPH ILLUSTRATING PARTICIPANTS HAVE MORE EXPERIENCE USING OM'S FOR UPPER LIMB THAN SPECIFICALLY PARTIAL HAND**

All participants agreed (62%) or were unsure (38%) if OMT could be improved. The majority (69%) of those who have experience using OM's with the UL population agreed that they could be improved (Table 5). Most of the participants who were unsure were those who do not have experience using OM's with the UL population (Table 5). Themes generated from text-based responses about how OMT can be improved for partial hand are: developing partial hand specific OMT, assessing patient satisfaction, including psychosocial aspects and ensuring ease of OMT use for the professional. Some comments from participants which reiterate that there is a lack of suitable OMT for the population included:

- *“have only seen one outcome tool applicable to assessing partial hand prosthesis users”*
- *“it would be helpful to have more outcome measure tests that are created specifically for upper limb prosthetic users”*
- *“outcome tools could be adapted for prosthetic usage”*
- *“outcome measures need to be more customizable”*
- *“there is no specific tool [for] partial hand prostheses”.*

The majority of the participants who prescribe partial hand prostheses also have experience using outcome measures to assess upper limbs (Table 5). Similarly, most of the participants who do not have experience using OM’s with the upper limb population also do not prescribe partial hand prostheses.

**TABLE 5 - RELATIONSHIPS BETWEEN EXPERIENCE OF OUTCOME MEASURES IN UPPER LIMB, OPINION ON IMPROVEMENT OF ASSESSMENT TOOLS AND PRESCRIBING PARTIAL HAND PROSTHESES**

		Total (n)	Could outcome measurement tools be improved for assessment of partial hand prosthesis users?			Do you prescribe partial hand prostheses?	
			Yes	Unsure	No	Yes	No
			23	14	0	16	21
Do you have experience with using outcome measures with the upper limb population?	Yes	29	20 (69%)	9 (31%)	0	14 (48%)	15 (52%)
	No	8	3 (37.5%)	5 (62.5%)	0	2 (25%)	6 (75%)

### 3.4.3 Decision-making

Less than half of the participants (43%) indicated that they prescribe partial hand devices to end users. All participants were asked about their involvement in the prescription process. Most participants (72%) work with their colleagues on decision-making for prescription, two participants (6%) are the sole decision-makers and the remainder (22%) are not involved in prescription. One of the sole decision-makers indicated their occupation as prosthetist, and the other listed both prosthetist and orthotist. Participants were provided a list of professions and asked which occupations they work with in their role. Those who prescribe devices indicated working with a variety of professions in their practice (Table 6). Professions not listed by the authors were provided in text input responses and included in Table 6.

TABLE 6 - NUMBER OF PARTICIPANTS WHO PRESCRIBE PARTIAL HAND PROSTHESES AND WORK WITH THE PROFESSIONS LISTED

<b>Professions</b>	<b>Number of prescribers who work with the profession</b>
Prosthetist	13
Occupational Therapist	11
Physiotherapist	11
Orthotist	7
Engineer	2
Funding source/insurance	2
Surgeon	2
Technician	2
Doctor	1

User-centred factors such as existing function, occupation and hobbies are of highest importance when deciding which device to prescribe (Figure 23). Cost of device to insurers was found to be the least important factor.

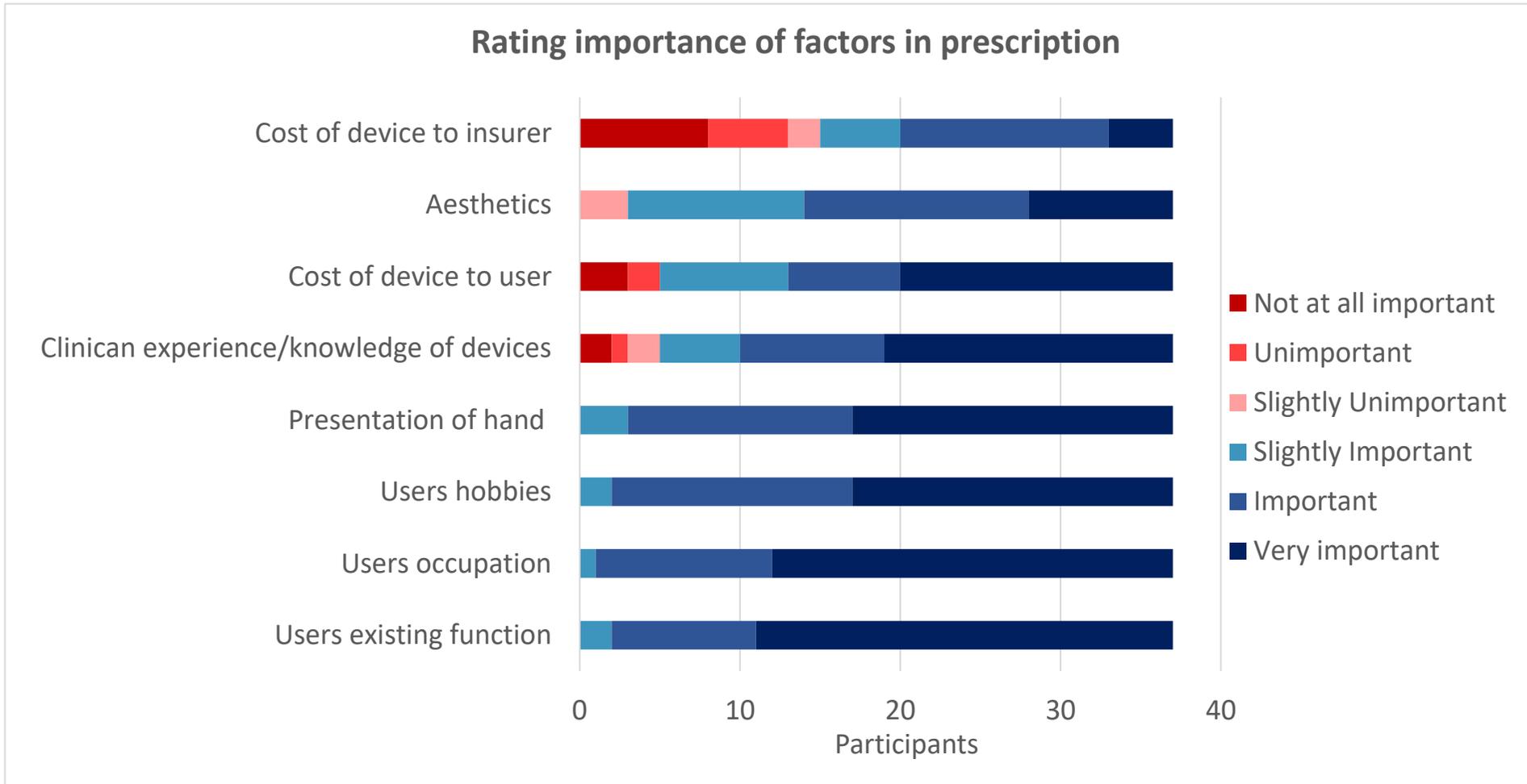


FIGURE 23 - PARTICIPANTS RATING IMPORTANCE OF FACTORS IN PRESCRIPTION FROM NOT AT ALL TO VERY IMPORTANT, WITH USER-CENTRED FACTORS BEING MOST IMPORTANT

### 3.4.4 Tester/loan units

Approximately half (49%) of participants use tester/loan units in their practice, allowing the end user to trial their device before prescription. However, tester/loan units are used in the majority (n=7) of countries in which participants work in (Table 7).

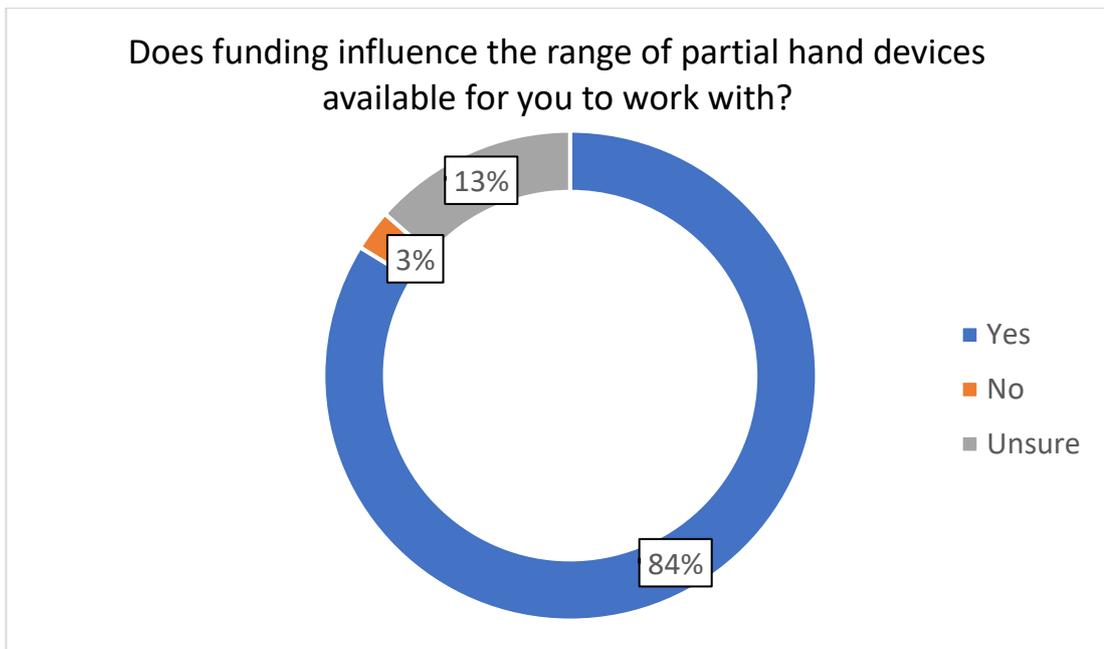
TABLE 7 - USE OF TESTER/LOAN UNITS ACROSS EACH COUNTRY

	Do you use tester/loan units?	
	Yes	No
Total (n)	18.0	19.0
Country	n (%)	
Canada	0 (0%)	2 (10.5%)
Ghana	1 (5.6%)	0 (0%)
Ireland	1 (5.6%)	0 (0%)
Netherlands	4 (22.2%)	0 (0%)
Sweden	2 (11.1%)	0 (0%)
United Arab Emirates	1 (5.6%)	0 (0%)
United Kingdom of Great Britain and Northern Ireland	2 (11.1%)	2 (10.5%)
United States of America	7 (38.9%)	15 (78.9%)

Five themes were generated from text-based responses about experiences working with tester/loan units. These themes are: opportunity to provide user with practical experience, increases chance of success, increases chance of acceptance, provides the end user with more autonomy in decisions and allows an opportunity for feedback between clinician and user.

### 3.4.5 Funding

The majority of participants (n=31) agreed that funding influences the range of partial hand devices available for them to work with. One participant did not agree that funding influences device availability, and the remainder were unsure (Figure 24).



**FIGURE 24 - FUNDING INFLUENCES THE MAJORITY OF PARTIAL HAND DEVICES AVAILABLE FOR PARTICIPANTS TO WORK WITH**

Insurance pays for the majority (73%) of partial hand devices that the participants work with. A combination of funding sources are involved in providing devices for some participants (27%) to work with. Participants defined 'other' sources as workers compensation (n=8), NHS (n=2), injury claims/insurance (n=2), grants (n=1), charity (n=1).

### 3.5 Discussion

Eight countries were identified as places of work. However, the majority (n=22) of participants work in the United States of America. The majority of devices the participants work with are funded by insurance. There is a possibility that healthcare and insurance systems specific to certain countries, such as the United States, may allow greater provision of partial hand devices compared to other countries. Further investigation to compare the rates of prescription across various countries could be beneficial to understand where most provision takes place. A high number of participants identified workers compensation as a funding source, which was not listed in the survey.

Ten participants had not fitted any partial hand prostheses within 12 months before taking the survey. On the contrary, six participants had fitted over 21 partial hand prostheses in the same period. This may be an indication that some clinicians specialise in partial hand, however, exposure to the partial hand population may be varied. Results suggest that there is variation in number of patients/users seen by each participant which could be due to geographical location or funding, for example. The majority of participants (n=5) who fitted high numbers of patients within the last year were involved in both the prescription and fitting processes. No relationship was found between occupation and number of devices fitted. Only two participants indicated that they work as sole-decision makers and come from prosthetic and orthotic occupations. Those who prescribe devices work alongside a variety of occupations with prosthetist, occupational therapist, physiotherapist and orthotist being the most frequent colleague across participants. Nonetheless, the

multidisciplinary team for some includes engineers, funders, surgeons, technicians and doctors. It is evident that some prescribers practice differently than others and not everyone utilises the various stakeholders involved as part of a multidisciplinary decision-making process.

Despite the majority of participants agreeing that OMT are useful in assessing partial hand prosthetics, some participants strongly disagreed (5%) or somewhat disagreed (11%) with this statement. The majority agreed that outcome measures could be improved for assessment of the partial hand prosthesis user population. Participants had experience of using more outcome measures, more frequently in the upper limb population than the partial hand population specifically. This could be a result of seeing less partial hand cases in comparison to upper limb. In addition, a range of outcome measures were identified by participants as being used to assess the specified population. Further, lack of specialised tools for the population was identified as a clear theme in text input responses regarding improving OMT. These findings solidify the idea that outcome measures currently used are limited in their efficacy and should be adapted or re-designed for the partial hand, or upper limb, prosthetic user population.

All themes generated surrounding the participants experiences working with tester/loan units were positive. The themes could be inter-related. For example, an increased chance of success is likely to mean an increased chance of acceptance, and vice versa. Similarly, the user having the opportunity to provide feedback on device use will encourage and foster autonomy. This finding suggests that provision of tester/loan units should be recommended practice due to short- and long- term

benefits provided to the user. Nonetheless, only approximately half of participants use tester/loan units in practice. This result does not appear to be influenced by geographical location as tester/loan units were used in each country except one (Canada).

The majority of participants agreed that funding influences the range of devices available for them to prescribe. This aspect of prosthetic device prescription may well be beyond the control of the clinician, therefore, the devices they can prescribe are limited to those which are financially feasible. This creates a barrier for clinicians and patients as the best or most appropriate device for the user may not be considered an option due to funding implications. On the contrary, participants indicated that user-centred factors (existing function, occupation, hobbies) are the most important factors when selecting a device to prescribe. Meanwhile, cost to both the user and the insurer ranked lower in importance. Therefore, there is a conflict between what limits devices available for prescription and factors which clinicians rank most important in decision-making, as cost is a barrier but it is not believed to be one of the key factors in the selection process. Further, with the majority of participants working alongside colleagues on decision-making for prescription, it could be the case that different perspectives provide varying opinions on suitable devices to prescribe.

### 3.5.1 Limitations

A limitation of this study is that it is not known whether the collected data is representative of clinical experiences on a global scale. It is worth noting that a large proportion of participants work in the United States. This high concentration of

participants from a single country could introduce location bias in to the data, thus limiting its generalisability. No further demographic data such as years of experience of clinician was considered in data analysis. Such information may have been useful for interpreting further relationships between demographical considerations and prescription experiences in the data. The professional bodies targeted for disseminating the survey to their members were groups based in the United States and United Kingdom. This may have influenced the large proportion of workers from the United States who completed the survey. Further, distribution of the survey could have resulted in selection bias as those who are active on social media were more likely to have seen the advert and taken part than non-social media users. Thus, those who took part may be more actively involved and/or interested in ongoing partial hand prosthetics research than the general workforce. It is not known how many people chose not to take part and there may be people who thought the survey was not relevant to them as they do not work with many partial hand prostheses. The survey was anonymous so it is expected that data collected is accurate and a true reflection on the participants' experience, however, there was no collection of further qualitative data such as body language to capture thoughts and feelings on the subject.

### 3.6 Conclusions

Multiple stakeholders and considerations are involved in prescribing partial hand prostheses. Clinical decision-making is often a joint decision between multiple colleagues, rather than the conclusion of one clinician and colleagues who work in the partial hand decision-making process come from a variety of occupations. A high

number of OMT are used by clinicians, and some do not use these for assessing the partial hand population despite having experience with use in the upper limb population. OMT could be improved by means of adapting or developing tools specifically for use in the partial hand prosthesis user population, such as by incorporating psychosocial and patient satisfaction aspects. Despite user-driven factors (function, occupation, hobbies) being of highest importance to a clinician when prescribing partial hand prostheses, funding is a key component in the decision-making process as it often drives the range of devices available for use. Results suggest that insurance may be the most common funding source for partial hand prosthetics. Around half of the clinicians in the various countries represented in this study use tester/loan units and note positive experiences which indicates recommendation for this practice. Protocols and recommended practice for the provision of partial hand devices could improve and standardise the methods in which prescription is carried out in this field. The aims of the study were met, albeit with the limitation of a relatively small sample of participants which may not reflect the population as a whole.

### 3.7 Chapter summary

This Chapter investigated the experiences of clinicians involved in the prescription of partial hand prosthetic devices. Although user-centred factors were rated as the most important considerations during prescription, funding was identified as a significant driver of device selection. Additional findings included the types of outcome measures used, the number of patients seen by clinicians, and feedback on the use

of tester or loaner units. Nonetheless, the sample size in this study cannot be said to be representative of the partial hand workforce as a whole. These findings informed the design of the next study described in Chapter 4, which aimed to explore clinical perspectives in greater depth using qualitative methods.

## 4 Study 3: Clinicians' experiences of partial hand prosthetic prescription – focus group study

### 4.1 Introduction

Research conducted in Chapter 3 focused on investigating who prescribes partial hand prosthetic devices, outcome measures used, and factors that drive prescription. The findings indicated inconsistencies in how prostheses are selected for end users and gave insight into the professions involved in prescription. It was then decided that the next study should examine decision-making to develop a tool to support partial hand prescription as shown in Figure 25.

This Chapter presents Study 3, a qualitative investigation using focus groups to explore decision-making processes among clinicians who prescribe partial hand prostheses. This study built upon findings from Study 2 and aimed to delve further into decision-making from the perspective of clinicians. The objectives of the investigation were to gain understanding of factors which influence the selection of prostheses, experiences with selecting devices for end users and tools which may be used in practice. The study also aimed to gather opinions on a decision tool for prescription of partial hand prostheses.

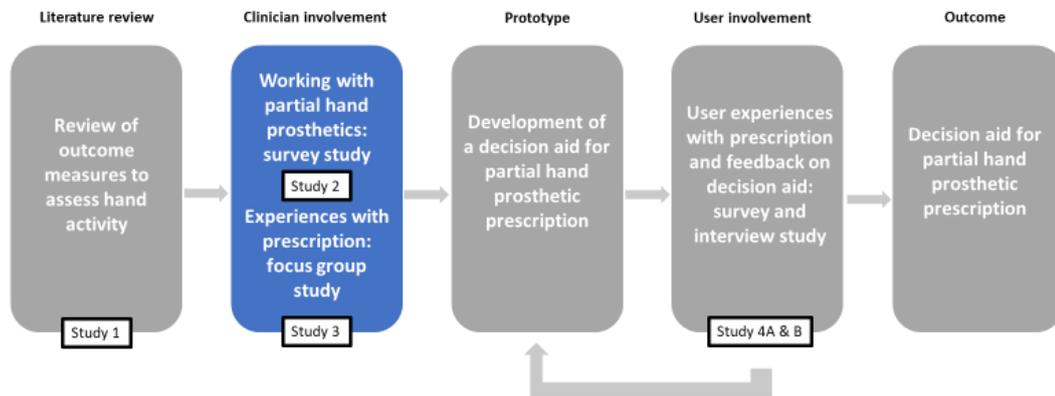


FIGURE 25 – FLOWCHART HIGHLIGHTING STUDY DESCRIBED IN CHAPTER 4 IN BLUE

## 4.2 Background

### 4.2.1 Decision-making theory

Decision theory involves taking known information to produce an optimal, feasible and reasonable outcome (North 1968). It is the process of using a logical framework to analyse possible outcomes. This concept has been studied in depth by Synder, Bernard and Simon (Sociology Group 2020).

The decision-making process is said to consist of two parts: deciding on the approach and then the process of implementing said approach. This process should take in to account the steps needed for implementation, implications, feasibility and desired outcomes. Decision-making takes place in everyday life, inside or outside of work, and can involve consequences ranging from trivial to life threatening. There are numerous decision-making models used globally in a range of use cases. Such models differ in various industries such as business, healthcare, people management and policy making. The stages and styles in models may also differ. Styles which are frequently reported in a business leadership capacity - although relevant to many decision-making contexts - can include directive, analytical, conceptual and behavioural. Directive decision-making is quick and based on existing knowledge, whereas analytical decision-making involves methodical analysis of information and options before reaching a conclusion. Behavioural decision-making is more collaborative and can include the views of others, and conceptual decision-making considers other perspectives and out-of-the-box solutions (theMBAins 2023).

#### 4.2.2 Decision-making in healthcare

Evidence-based medicine is a means of combating the issue of uncertainty and variation between clinical treatment in individuals and across services. Moreover, clinical guidelines are a means of providing information to clinicians that can guide their practice in an approach which is standardised within their field (Kaplan and Frosch 2005).

There are two types of decisions in healthcare: decisions made by professionals and decisions shared between professionals and patients or end users (Kaplan and Frosch 2005). The latter may be described as 'shared decision-making'. There is evidence to suggest that clinician preference may influence decision-making more than the requirements of the patient (Wennberg, Fisher et al. 2004).

#### 4.2.3 Shared decision-making

Shared decision-making in healthcare is a process involving both the professional and patient to reach a joint decision about a treatment, intervention or prescription. The patient is part of the process and informed about the options and choices available to them (NICE 2021). This process encourages the individual to become independent and empowered in the process. Subsequently, this may lead to improved outcomes and satisfaction with the treatment, intervention or prescription. Clinicians must be familiar with the decision-making process related to the medical specialism in order to facilitate the process of shared decision-making.

#### 4.2.4 Decision-making in prosthetics

The term 'decision-making' in healthcare often relates to the process of selecting a treatment plan, pharmaceutical solution or medical device for a patient or end user. In terms of prosthetics, decision-making may refer specifically to the process of

selecting a device for the end user. This term can also describe the process in which an end user selects device option(s) or chooses not to receive a prosthesis. Additionally, a study in lower limb prosthetics found that decision-making can also consider the rehabilitation process and prosthesis design (Anderson, Kittelson et al. 2023).

#### 4.2.5 Focus group methodology

Focus groups are structured discussions used across various fields to explore and understand how people feel or think about a specific topic (Krueger 2015). They typically involve a small group of participants led by a facilitator who asks questions about a predefined research topic. These focus group discussions can take place online or in-person, and everyone in the group is encouraged to participate in the discussion by the facilitator. Focus groups are a widely used qualitative research method, particularly valuable when existing information is limited or lacks depth in understanding the perceptions, experiences, and emotions of those involved (George 2023). Furthermore, focus groups can be used to gather evaluative feedback on what does or does not work well. Compared to one-to-one interviews, they offer a more natural and interactive setting that can enable richer thoughts and feelings to be captured through group discussion (Krueger 2015).

Focus groups can be structured in varying levels, each level involving different amounts of guidance from the facilitator. Focus groups may be structured, unstructured or somewhere in between, known as semi-structured. Structured focus groups have a set agenda with questions almost always asked in the same way and do not deviate from the topic, whereas unstructured are more free-flowing

discussions. Semi-structured focus groups are in between structured and unstructured. In semi-structured focus groups, participants are asked open-ended questions which allows them to convey their opinions and feelings on the topic rather than 'yes' or 'no' style questions that are asked in surveys or structured sessions (Clifford 2023). The following questions funnel down from central topics to specific questions.

Sampling for focus group studies can be different from that used in other research methods, such as the methods employed in the survey study (Chapter 3). Participants in a focus group must be able to contribute to discussions and input their thoughts on the topic, which may not be guaranteed if drawn from a random sample, therefore convenience sampling can be carried out. Convenience sampling is a means of selecting participants who are suitably aligned with the project goals (Morgan, Krueger et al. 1998).

The recommended number of participants for a focus group varies throughout literature, with some stating a typical size of five to eight (Krueger 2015), and others stating six to 10 (Morgan, Krueger et al. 1998), or rarely more than 12 (Wilkinson 1998). Groups with fewer participants allow for more time on average for each participant to speak. This can encourage active participation, and providing the opportunity to speak may result in deeper, more detailed, discussions. Further, smaller groups are recommended in instances where participants have a high level of involvement or experience with the topic, the topic is convoluted and where recruitment factors are of concern (Morgan, Krueger et al. 1998). However, larger groups may offer more varied and diverse insights.

The typical number of focus group sessions used in this style of research is three to five. Nonetheless, there are occasions when fewer groups are necessary or adequate. Fewer groups are suitable when diversity is not expected within the research topic and further discussions do not add to the findings. This concept is known as data saturation – a stage in thematic research where no new information, codes or themes are interpreted from data (Braun and Clarke 2021).

Benefits of carrying out online focus groups include reduced time and costs associated with travel, allowing participants to take part from the comfort of their own chosen space, and may encourage participation from those who may not be able to travel to an in-person session (Morgan, Krueger et al. 1998). Advantages of in-person focus groups, however, include easier detection of and response to participant distress. Another advantage of in-person sessions is easier encouragement of less active participants through use of non-verbal cues (Lobe, Morgan et al. 2022). In-person focus groups are less likely to be impacted due to technical issues due to low-level technology typically required. On the other hand, the technology used for online focus groups such as Zoom or Microsoft Teams can be advantageous as sessions can be recorded and transcripts can be downloaded using the inbuilt tools in the software.

#### 4.2.6 Study aims

The purpose of the study was to investigate clinical perspectives from the workforce who prescribe partial hand prostheses. The objectives of the investigation were to gain understanding of factors which influence the selection of prostheses, experiences with selecting devices for end users and tools which may be used in

practice. Additionally, this study aimed to gather opinions on whether a decision tool is desired and what it should look like.

### 4.3 Method

#### 4.3.1 Research design

A semi-structured discussion guide (Appendix G) was designed by the researchers which included an introduction and reminder of the research purpose followed by introductory, transition and then funnelled down to key questions. Questions were selected based on findings from the survey study described in Chapter 3 and the researchers drive to find out about decision-making in partial hand prosthetic prescription as no such literature existed at the time of study design. The questions in the discussion guide asked participants to share their experiences with selecting devices for end users, tools used in their practice and their opinions on whether a decision aid is desired and what it should look like. The discussion guide was reviewed by an external researcher, Sisary Kheng, who has experience in qualitative research studies in clinical and prosthetics settings, but was not involved in the research team. During the sessions, participants made use of audio, video and chat functions on Zoom during the meeting to communicate their ideas or show agreement/disagreement as appropriate.

This study was granted ethical approval by the Department of Biomedical Engineering Ethics Committee, University of Strathclyde (DEC.BioMed.2023.341).

#### 4.3.2 Focus group schedule development

Two focus groups were conducted which adhered to the same protocol. Two sessions were conducted due to the volume of participants being too large for one session,

but too little for three sessions. The sessions took place online using Zoom software on 31<sup>st</sup> August and 8<sup>th</sup> September 2023 and each lasted one hour. Participants were given session times to choose, or were allocated a session, based on availability. Participants were allocated groups to ensure that there were at least six and no more than 10 participants scheduled for each session.

#### 4.3.3 Piloting

A pilot focus group was conducted online by the author (KC) and attended by Maggie Donovan-Hall (MDH) as well as two peers from the Centre for Doctoral Training in Prosthetics and Orthotics within similar research areas. The purpose of the pilot session was for the author to assess the logistics of setting up and recording the session, generating conversation starters using a discussion guide, and guiding an online discussion. MDH is experienced in qualitative research methods in healthcare research.

#### 4.3.4 Sampling and participants

Participants were recruited globally and self-identified as clinicians who currently prescribe, or have prescribed, partial hand prostheses. The inclusion criteria were as follows: currently works, or has worked within the past five years, in the field of partial hand prosthetics, experienced in prescribing partial hand prosthetic devices, either alone or in conjunction with colleagues, able to take part in a discussion in English, and had access to a device which enables them to take part in an online Zoom meeting with audio and video.

A convenience sampling method was applied by sending email invitations to participants who voluntarily provided contact details in Study 2 (Appendix H). This approach was taken as these individuals met the eligibility criteria and had demonstrated interest in the topic through completing the survey.

#### 4.3.5 Recruitment

Advertisement of the study was conducted on social media through sharing a poster (Appendix I) on platforms and inviting interested parties to contact the researcher for further information. ISPO UK shared information about the study alongside the advertisement poster on their website, social media pages and through an E-bulletin to members. This organisation was targeted directly as their member list is known to contain individuals who work in partial hand prosthetics and the researchers are members of this group. Those who responded to social media calls or referrals were sent the PIS following their interest. Recruitment by referral was applied by encouraging participants to share information about the study with their colleagues and network.

A PIS and consent form were created for the study (Appendix J). The PIS was sent to a total of 35 potential participants made up of 18 survey participants alongside interested respondents who reached out via Twitter (3), LinkedIn (5), email (5) and referrals (4). After sending the PIS, 19 participants were noted as being interested in taking part. Consent forms were sent to participants and receipt of forms confirmed their position on the study. Consent forms were received from 19 participants who were then confirmed as participating in one of two sessions. Participation was voluntary and no monetary incentive was provided for taking part.

#### 4.3.6 Protocol

Focus group transcripts were downloaded from Zoom and pseudo-anonymised. Data were pseudo-anonymised to enhance the security of the personal data obtained from the participants, encourage participation by sharing personal experiences while safeguarding participants so they are not identified by any resulting publications. This was carried out by replacing each participants' name with a code. Pseudo-anonymisation was selected over anonymisation as the researchers were present in the focus groups. There was a need to identify speakers from audio or video recordings in order to prepare the data for analysis. Therefore, if the data were completely anonymous, the researchers would have had to outsource facilitators to carry out the focus group sessions. This was not desired due to the nature of the research and the expertise of the researchers in the topic discussed in the focus groups. No identifiable data were retained for data analysis or dissemination.

#### 4.3.7 Data analysis

Data analysis was carried out by the author (KC) and findings cross-checked with two other researchers MDH and Sarah Day (SD); one of whom was present at the sessions and the other watched the video recordings. Analysis was carried out using NVivo – a software used for qualitative and mixed-methods research (NVivo 2025). NVivo is said to increase organisation of data, efficiency and may increase rigour of coding (Braun 2013). NVivo was used for analysis of unstructured text, audio and video data collected from the focus group sessions. Thematic analysis was performed by means of an inductive, data-driven approach in accordance with Braun and Clarke's six step

process for reflexive thematic analysis (Braun and Clarke 2006). The six step process is outlined in Figure 26.



**FIGURE 26 - FLOWCHART OF BRAUN AND CLARKE'S SIX STEP PROCESS**

#### 4.3.7.1 Step 1 – Familiarisation phase

The familiarisation step was incorporated into the transcription process. Transcripts were downloaded from Zoom then formatted in Microsoft Word and pseudo-anonymised by providing a participant number. The documents were transcribed line by line using video recordings of the session to correct errors and fill gaps missed by Zoom software. Re-reading transcripts and repeated listening of discussions took place which encouraged familiarisation. The transcripts were reviewed again to ensure they were anonymous and no reference to participants' names were included in text.

#### 4.3.7.2 Step 2 – Coding phase

Transcripts were reviewed line by line and items of interest to the research topic were identified. Initial codes were created for each item of interest. Figure 27 displays a screenshot of this phase taken from NVivo software.

**Codes**

Name	Files	References	Created on	Created by	Modified on	Modified by
body image	1	1	28/09/2023 15:36	KC	28/09/2023 15:36	KC
clinic environment and practices	2	8	27/09/2023 16:49	KC	28/09/2023 14:56	KC
clinician experience and knowledge	2	14	27/09/2023 15:24	KC	28/09/2023 16:08	KC
clinician morals in not ill-prescribing	1	1	27/09/2023 15:49	KC	27/09/2023 15:49	KC
clinician seeing specific cases	2	8	27/09/2023 15:27	KC	28/09/2023 15:31	KC
cost of devices	2	5	27/09/2023 15:28	KC	28/09/2023 16:09	KC
cultural differences in practice	2	16	27/09/2023 16:33	KC	28/09/2023 16:08	KC
decision-making tool	1	2	27/09/2023 16:50	KC	28/09/2023 16:13	KC
designability	1	5	27/09/2023 15:59	KC	27/09/2023 17:16	KC
differences in practice	2	11	27/09/2023 17:10	KC	28/09/2023 15:46	KC
educating the patient	2	22	27/09/2023 15:26	KC	28/09/2023 16:12	KC
funding	1	7	28/09/2023 14:22	KC	28/09/2023 16:09	KC
future technologies	1	1	28/09/2023 15:56	KC	28/09/2023 15:56	KC
gender	2	2	27/09/2023 15:29	KC	28/09/2023 15:17	KC
giving patient autonomy	1	5	28/09/2023 14:51	KC	28/09/2023 16:12	KC
insurance type	2	5	27/09/2023 15:28	KC	28/09/2023 16:09	KC
involving patient in process	2	33	27/09/2023 15:27	KC	28/09/2023 16:12	KC
involving support group in process	2	7	27/09/2023 15:51	KC	28/09/2023 14:43	KC
multidisciplinary	2	21	27/09/2023 16:05	KC	28/09/2023 16:13	KC
objectivity	2	2	27/09/2023 16:46	KC	28/09/2023 14:41	KC

KC 55 Items

FIGURE 27 - SCREENSHOT OF NVIVO SOFTWARE DURING CODING PHASE

New codes were continually created throughout this process if no suitable code existed in the codebook. It was noted at this stage that some codes were difficult to interpret out of context (i.e. 'clinician morals in not ill-prescribing') and there were crossovers between existing initial codes at this stage. This step resulted in 54 first-order codes being introduced to the codebook for further analysis as shown in Table 8.

TABLE 8 - FIRST-ORDER CODES

Codes	
1 : body image	28 : outcome measures
2 : clinic environment and practices	29 : partial hand has more considerations than upper limb
3 : clinician experience and knowledge	30 : patient attitude to adopting a device
4 : clinician morals in not ill-prescribing	31 : patient expectations
5 : clinician seeing specific cases	32 : using appropriate language
6 : cultural differences in practice	33 : patient goal
7 : cultural differences in desired outcome	34 : patient research
8 : decision-making tool	35 : patient satisfaction
9 : format	36 : physical toolkit
10 : output	37 : prescribing multiple devices
11 : designability	38 : presentation
12 : differences in practice	39 : nature of injury
13 : educating the patient	40 : variability
14 : funding	41 : proof of previous device wear
15 : future technologies	42 : rehabilitation
16 : gender	43 : training with device
17 : giving patient autonomy	44 : restoring aesthetics
18 : insurance type	45 : shift in patients ideas of aesthetics
19 : reimbursement policies	46 : shift in clinician idea of aesthetics
20 : involving patient in process	47 : showing patient device options
21 : involving support group in process	48 : showing pros and cons
22 : multidisciplinary	49 : socket design
23 : educating other professions	50 : specific to patient
24 : team based approach to prescription	51 : talking to patients
25 : trust	52 : trusting the clinician
26 : objectivity	53 : understanding patient expectations
27 : osseointegration	54 : value in a decision-making tool

#### 4.3.7.3 Step 3 – Generating initial themes

Initial codes that related to each other, and patterns in the data, were grouped to generate initial themes. Codes such as ‘multidisciplinary’, ‘involving support group in process’ and ‘involving patient in process’ were grouped together under the theme of ‘team-based approach’. Grouping was carried out for all codes that were deemed suitable, with some codes appearing under multiple themes. At this stage, it was clear that some codes should be discarded as they were not related to the research question and did not appear frequently enough in the data. This step resulted in the generation of 12 initial themes as shown in Table 9.

TABLE 9 - INITIAL THEMES

Initial themes
<i>Complexity of partial hand</i>
<i>Shared decision-making</i>
<i>Education</i>
<i>Aesthetics</i>
<i>Trust</i>
<i>Prescribing for the individual</i>
<i>Team-based approach</i>
<i>Methods of prescription vary</i>
<i>Expectations</i>
<i>Financial considerations</i>
<i>Exploring multiple device options</i>
<i>Usefulness of a decision-making tool</i>

#### 4.3.7.4 Step 4 – Reviewing themes

Initial themes were compared against the data to assess if they represented the data. This step involved looking at transcripts and codes as done in previous steps, but with consideration of the initial themes. First-order codes were reduced to second-order

codes through combining together in NVivo as parent and child codes. The review process was iterative and generated themes were reconsidered using transcripts, the updated codebook, and with reference to the initial themes. Potential subthemes were considered at this point as the themes were reduced (Table 10). Codebook version 2 was cross-checked by assessing the number and quality of references associated to each code. This process indicated whether the themes generated were backed up by quality evidence in the data and no strong pattern or theme was ignored. In addition, a set of overarching questions (Jones 2022) were used to assess codebook version 2 and themes:

- *Do the themes make sense?*
- *Does the data support the themes?*
- *Is the theme too broad or too narrow?*
- *If themes overlap, are they really separate themes?*
- *Are there themes within themes?*
- *Am I missing any themes?*

Codebook version 3 was generated in response to the questions outlined above, and relevant quotes were added to confirm the presence of the emerging themes and subthemes. Codebook version 4 was then generated following review of version 3 and further reflection on the responses to the same questions. During the process, it became clear that subthemes required revision to align the evidence with the developing themes. In addition, new patterns were identified in the data during this stage of review. Some quotes were relevant to multiple themes and subthemes,

prompting a review of the codebook to assess how well the data supported each theme, and to ensure no key patterns had been overlooked.

**TABLE 10 - INITIAL THEMES AND SUBTHEMES**

<b>Initial themes</b>	<b>Subtheme</b>
<i>Shared decision-making</i>	<i>Giving the patient autonomy</i>
	<i>Communication</i>
	<i>Physical samples</i>
	<i>Trust</i>
<i>Education</i>	<i>Educating the patient</i>
	<i>Educating the workforce</i>
<i>Patient expectations</i>	<i>Understanding patient expectations</i>
	<i>Managing patient expectations</i>
	<i>Using patient goals as an outcome measure</i>
<i>Complexity of the prescription process</i>	<i>Variations in Practice</i>
	<i>Each case is unique</i>
	<i>Rehabilitation journey</i>
	<i>Multidisciplinary approach</i>
	<i>Funding</i>
<i>Considering multiple device options</i>	<i>Weighing up pros and cons</i>
	<i>Prescribing more than one device</i>

#### 4.3.7.5 Step 5 – Defining and naming themes

Final development of the themes was an iterative process to ensure they were strongly grounded in the data and subthemes were valid, but not independent enough to stand alone. At this stage, all transcripts were re-read in full. All relevant quotations had already been extracted, and it was confirmed that no additional quotes were overlooked. Themes were found to be valid, coherent, distinct and comprehensive. Therefore, themes and subthemes at this stage were defined as final (Table 11). Following this re-reading, some themes and subthemes were renamed to more accurately reflect the narrative emerging from the data. A thematic map was produced to illustrate themes and subthemes in visual format as shown in Figure 28.

TABLE 11 - FINAL THEMES AND SUBTHEMES

<b>Final themes</b>	<b>Subtheme</b>
<i>Shared decision-making</i>	<i>Giving the patient autonomy</i>
	<i>Communication</i>
	<i>Physical samples</i>
	<i>Trust</i>
<i>Education</i>	<i>Educating the patient</i>
	<i>Educating the workforce</i>
<i>Patient expectations</i>	<i>Understanding patient expectations</i>
	<i>Managing patient expectations</i>
	<i>Using patient goals as an outcome measure</i>
<i>Multidisciplinary</i>	<i>Team based approach</i>
	<i>Rehabilitation journey</i>
	<i>Involving other patients</i>
<i>Complexity of partial hand prescription</i>	<i>Weighing up pros and cons</i>
	<i>Prescribing more than one device</i>
	<i>Each case is unique</i>
	<i>Variations in practice</i>
	<i>Funding</i>

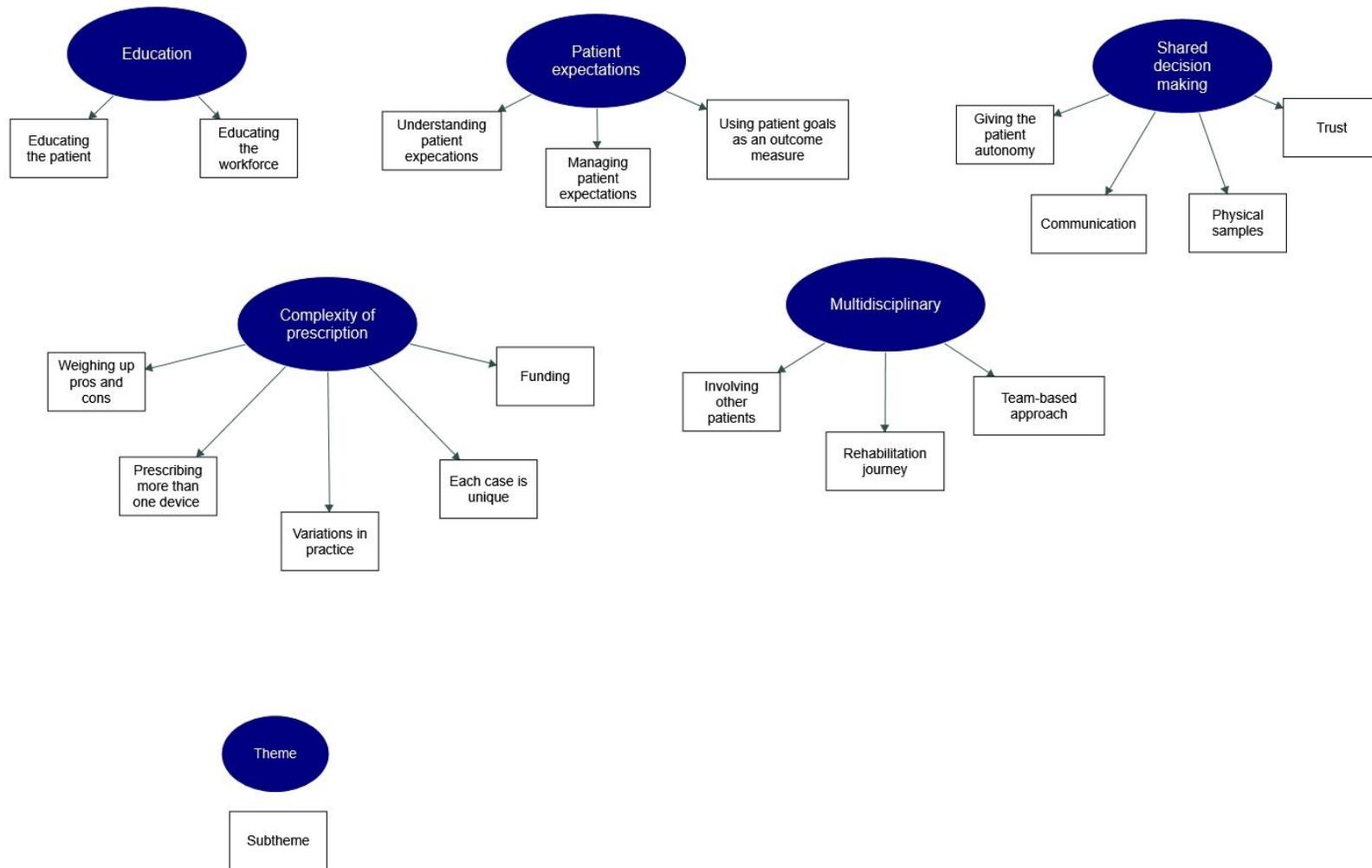


FIGURE 28 - THEMATIC MAP OF THEMES AND SUBTHEMES

#### 4.3.7.6 Step 6 – Writing up

Writing up involved selecting the most relevant quotes extracted from transcripts and placing themes in an order so that a narrative that tells the story of the focus group discussions could be constructed.

#### 4.3.8 Quality control

A two-day external NVivo training course titled ‘Complete NVivo Training for Windows’ (Elizabeth Training) was carried out by the author to ensure the software could be used effectively and correctly in preparation for data collection and analysis (Appendix K). The author generated initial codes and themes then consulted with other researchers on the findings throughout the iterative process of generating results.

### 4.4 Results

A total of 13 participants took part in the study – eight of whom took part in the first group session and the remaining five in the second session. Six participants did not attend the session despite confirming via consent form submission. Participants indicated having experience working in the field of partial hand prosthetics in the following countries: US (n=6), Canada (n=2), UK (n=1), Ireland (n=1), South Africa (n=1), UAE (n=2) and Sweden (n=1). One participant noted working in both the UAE and South Africa. Most participants were actively working in the field and one was retired. Participant occupations included prosthetist, therapist, consultant and technician.

Five themes and associated subthemes were generated. Themes are summarised in Table 12.



TABLE 12 - THEMES AND SUBTHEMES AS PRESENTED IN RESULTS

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Themes and subthemes
Theme 1: Shared decision-making
<i>Subthemes:</i>
(1.1) Giving the patient autonomy
(1.2) Communication
(1.3) Physical samples
(1.4) Trust
Theme 2: Education
<i>Subthemes:</i>
(2.1) Educating the patient
(2.2) Educating the workforce
Theme 3: Patient expectations
<i>Subthemes:</i>
(3.1) Understanding patient expectations
(3.2) Managing patient expectations
(3.3) Using patient goals as an outcome measure
Theme 4: Multidisciplinary
<i>Subthemes:</i>
(4.1) Team-based approach
(4.2) Rehabilitation journey
(4.3) Involving other patients
Theme 5: Complexity of partial hand prescription
<i>Subthemes:</i>
(5.1) Weighing up pros and cons
(5.2) Prescribing more than one device
(5.3) Each case is unique
(5.4) Variations in practice
(5.5) Funding

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#### 4.4.1 Theme 1 – Shared decision-making

The participants in this study were unified in their view of the importance of shared decision-making in prescription of partial hands.

##### 4.4.1.1 Subtheme 1.1 – Giving the patient autonomy

Participants described strategies that supported patient autonomy by relating the decision to acquire a prosthesis to familiar scenarios, such as purchasing a car or a house. Framing the decision in this way encouraged patients to take ownership, positioning the prosthesis as a personalised choice based on their individual needs.

*“And I listen briefly, and I state: ‘let's think about this as purchasing a large item, like a car or a house...you want to get what's best for you... so let's talk about you.” – P1.6*

*“They can connect with something that they perceive as their own need” - P1.3*

Participants also noted the responsibility of the patient in recognising their needs and being active in the decision-making process.

*“If they [want to] put a toothbrush on it it's their choice, you know. I cannot decide what's best for them, and that's the person's responsibility to pursue the right thing.” - P1.5*

##### 4.4.1.2 Subtheme 1.2 – Communication

Communication was a common discussion topic raised by participants. In addition to encouraging autonomy, participants indicated that communication is vital throughout follow-up procedures, such as evaluation and measuring outcomes.

*“...they're like ‘I joined band and I [want to] play the French horn’ and you're like, okay, how do we make this work? And so they need to be involved*

*because you're going to make something, and then they're going to come back and they're going to say: 'this is working, this is not'" -P1.1*

Nonetheless, participants discussed the importance of providing accurate and appropriate communication. There is potential to hinder the patient by presenting unrealistic, unachievable or unattainable ideas if you are not cautious with how you deliver.

*"you have to be very careful [with] when and how you present [patients] with things because they'll run with it" - P1.4*

#### 4.4.1.3 Subtheme 1.3 – Physical samples

To support decision-making, participants highlighted the value of using physical samples, allowing patients to touch and feel the available device options. While photographs were considered as helpful, physical samples were viewed as superior and essential tool in facilitating informed choices.

*"most people that are coming in have never interfaced with prosthetics before so they have ZERO idea what we're saying. So, having photos helps, but having things to touch and hold, really helps." – P1.1*

*"to see and have that hands-on experience is really critical" – P1.2*

Participants also noted that the characteristics of physical samples closely align with real-life experiences patients will encounter after receiving a prosthesis. The opportunity to interact with tactile models was seen as essential in preparing patients for the sensory and functional realities of using the device:

*“the decision-making process is a lot better if it's tactile, at the end of the day, it's going to be a tactile replacement” – P2.1*

#### 4.4.1.4 Subtheme 1.4 – Trust

Trust emerged as a key component of shared decision-making. Participants emphasised that involving patients throughout the process enhances their understanding of how and why decisions were made, which in turn builds trust in the final outcome.

*“if you include them in the decision-making process then they'll, you know, at least they understand where everything's coming from” – P2.4*

Trust was described as being important to many of the participants in the decision-making process. Trust was discussed in terms of trusting that the device selected is appropriate for the user. It was noted that it is important but can be difficult to establish trust with all parties.

*“one of the things that I think we find challenging with any relationship, whether it's with the patient, with the physician, with a with a payer is that there's a level of trust that needs to be established - trust in the in the fact that the recommendation that's being made is appropriate. The patient wants to know that. The physician wants to know that. The payer wants to know that.”*

**– P1.3**

#### 4.4.2 Theme 2 – Education

Participants in the study talked about the requirement for education and increased awareness across various aspects of partial hand prosthetics.

##### 4.4.2.1 Subtheme 2.1 - Educating the patient

Firstly, patient education was discussed as being valuable and necessary. Participants talked about patients not knowing what is available for their level of amputation. Moreover, advertisements and social media were raised as platforms that could educate or mis-educate a patient.

*“Another thing I think we need to value is patient education, because a lot of times a patient doesn't know what's available for their level of finger amputation. They just see an advertisement and think that maybe that would work for them, but may maybe it wouldn't” – P2.2*

Education was seen as being beneficial in terms of providing knowledge about prosthetic technology. Participants talked about education being required for the patient in terms of managing their expectations after being exposed to devices.

*“So it's [a] full scale education effort to make sure that they understand what the devices can and cannot do.” – P1.3*

##### 4.4.2.2 Subtheme 2.2 - Educating the workforce

As well as the patient, the workforce was highlighted as in need of education. As well as patients requiring education on limitations of devices, therapists were highlighted

as often being unaware. Gaps in therapist knowledge can be detrimental to the patient.

*“Many hand therapists are unaware of the different brands, the different options, and what they can do. So there's a gap for the therapist side that needs to be filled, but then, if the therapist doesn't know, the patient certainly doesn't know. So both people need the education and the understanding so that a great match can be made.” – P1.5*

As well as therapists, prosthetists who may interact with the patient at an earlier stage in the process also need to have thorough knowledge of partial hand devices. An understanding of the role another professional, such as a prosthetist or therapist, plays throughout prescription and rehabilitation is necessary.

*“I can't stress enough how important it is for the prosthetist to have the adequate background to even begin this conversation as well as the therapist”  
– P1.2*

In addition, surgeons were identified as a key member of the partial hand prosthetic workforce who also require education. Participants recognised that surgeons may not be aware of the options available to someone with partial hand amputation, and therefore unaware of the role they play in determining the prosthetic options available to the patient.

*“hand surgeons as we all know clearly, do not have a lot of insight into this, and they need to be educated” – P1.2*

*“[Surgeons] certainly need to be aware of [prosthetics] because obviously, what they're doing in the operating room significantly impacts what options exist for the patient. And so how in the world can we optimise what's appropriate for the patient unless the surgeon is doing the appropriate surgery.” – P1.2*

#### 4.4.3 Theme 3 – Patient expectations

When discussing the prescription procedure, participants often discussed the impact of patient expectations on their professional choices as well as the outcomes experienced by the patient. Patients come with varying levels of expectation and needs, which can influence the decisions made by the professional. Likewise, the expectations that patients have themselves can impact their satisfaction with the outcome of their prescription.

##### 4.4.3.1 Subtheme 3.1 – Understanding patient expectations

Participants emphasised that patient expectations are highly individual, yet they also observed common patterns influenced by factors such as culture and funding sources. For example, patients who self-fund their prostheses, sometimes paying significant sums, often have heightened expectations around both the process and the final product. This was again likened to purchasing a car, where a major investment shapes the desire for value and satisfaction.

*“90% of our patients are cash paying so the expectations and the outcomes need to match” – P2.1*

The variability of expectations around cosmetic appearance was also a key discussion point. Some participants noted a shift in perceptions of what makes a device

aesthetically pleasing, with some patients being attracted to more of a robotic look than a realistic appearance.

*“someone might find more value in an entirely non-functional, prosthetic MCP Driver as they would do in a cosmetic silicon finger” – P2.4*

Patients also reported that cultural attitudes can strongly influence aesthetic preferences, which in turn can limit acceptable device options. Understanding these preferences early in the process allows professionals to rule out prescriptions that patients are unlikely to accept.

*“some cultures will not tolerate a device that looks obvious, and others wouldn't tolerate having a device that they were trying to hide” – P1.3*

Despite understanding and communicating expectations and needs with the patient, it was also noted that patient expectations could limit their success with prosthetic provision. Patients often see devices in the media and set that as their expectation level. However, upon trialling a device they realise it does not meet their needs and thus their expectations about how their needs will be met can change.

*“[Patients] might say: ‘I absolutely want my hand to look like a hand’, and then as you start describing that, then what they see is pictures right?... we all know that pictures do a great job of showing custom painted silicone devices that look very nice but as soon as you grab a hold of a cup of coffee, and your fingers are sticking straight out because they don't bend... your cosmetic level is going to drop very quickly.” -P1.3*

#### 4.4.3.2 Subtheme 3.2 – Managing patient expectations

Patient expectations must be managed to provide a satisfactory outcome. As previously mentioned, communication is a key parameter in the decision-making process that can drive appropriate conversations around what to expect from a prosthetic device.

*“helping [patients] understand that this isn't a replacement of the hand and helping us, at least, set the table on having a good discussion with the person... so that six weeks later they're not putting that in the drawer because it didn't meet their expectations” – P1.4*

Participants also noted managing patient expectations by under-promising outcomes which ultimately negates risk of disappointment or upset.

*“I'm constantly under promising and over delivering. As soon as you turn that around and you over and over promise and under deliver, there's disgruntlement.” – P2.1*

In addition, participants acknowledged that the internet portrays devices with unrealistic expectations and this is important to address with patients.

*“The one REAL ingredient I think that's important for anyone in this space is to align their expectations with realistic expectations, with what these devices are actually designed to do and have the ability to do, because many unfortunately, approach this topic with what they see on the Internet, which sometimes is not as realistic.” - P1.2*

Relating device prescription to other activities was noted, again with the car purchase analogy. This time, the patient is informed of the longitudinal requirements or responsibilities associated with prosthetic device acquisition. Informing the patient that replacements, failures, and maintenance are normal is critical in avoiding surprise or upset further down the line. In doing so, the professional is giving the patient an insight into what to expect in the future as a prosthesis user.

*“[Patients] understand that there, or at least, I explained to them, just like maintaining a car - you're going to have maintenance issues, you're going need to replacements, and many of them (almost all of them) are totally surprised.” – P1.6*

#### 4.4.3.3 Subtheme 3.3 – Using patient goals as an outcome measure

When considering success and satisfaction, participants considered this as something specific to the patient. Sometimes, it is as simple as in-clinic assessments not being a true representation of the real world. Patient goals can be used as an outcome measure to assess success or satisfaction.

*“I've had patients that function amazingly. They really do well on the test and we're having a little celebration. We go out for a beer in the evening, and I see how they struggle to eat directly like a piece of barbecuing. You take these small things for granted, and I mean, we fitted so many patients. In the real world things are just different.” – P2.1*

To ensure chance of patient satisfaction, the professional can consider the patient's goals before the prescription. For some patients, they may want to return to one specific task, for example.

*“if the patient's like ‘I don't care about anything, all I want to do, the only thing I care about, I want to be able to go fishing again’... Then that's your outcome measure.” – P2.4*

#### 4.4.4 Theme 4 – Multidisciplinary

Participants in the study had varying job roles, and discussed the prescription process and user journey as involving a team. This team involves various occupations.

##### 4.4.4.1 Subtheme 4.1 – Team-based approach

Some participants noted that they work as a team in prescription and assessment, as well as making decisions.

*“we would always see the primary patients as part of our multidisciplinary team like it was kind of every three months we had a meeting with them and discuss stuff there” – P2.4*

*“We have to get the agreement of the team” – P2.3*

In a team-based approach, one participant indicated the importance of clear communication so the patient is given clear communication based off team discussions.

*“I think we have to be very careful about, and make sure that we're tagging appropriately with, the OT or the prosthetist, because sometimes we don't always relay the same information to the end user.” – P1.4*

#### 4.4.4.2 Subtheme 4.2 – Rehabilitation journey

There are many different people involved in rehabilitation for someone who has undergone partial hand amputation. Professions including social work were noted as important in the journey.

*“a reality that I think brings in the surgeon, the [physician], the prosthetist, the therapist, the rehabilitation nurse, the social worker, and then obviously the patient.” – P1.2*

*“we also work with an amputee clinic out of our regional rehabilitation hospital, [physicians], physios, occupational therapists [are] working on the whole teams there.” – P2.2*

#### 4.4.4.3 Subtheme 4.3 – Involving other patients

Incorporating other individuals with similar limb difference throughout the prescription process was encouraged by participants. Participants recognised that no two presentations are identical, however, this approach was seen as a positive method by participants.

*“if it's possible to include an opportunity for the individual to meet with another individual who has been fit with a similar device - that is very, very helpful” – P1.2*

More specifically, meeting other patients can expose the individual to limitations and set expectations.

*“if possible, have them meet another amputee, that's using that device so they can see the limitations” – P2.1*

While partial hand presentations are varied, someone with a similar presentation could be brought into the team to aid the decision-making process.

*“Two individuals who have similar hand presentations will never find the exact, or seldom do you find the exact same. But matching that interaction with two individuals can be very effective in the decision-making process for them to be aligned again with realistic expectations.” – P1.2*

#### 4.4.5 Theme 5 – Complexity of partial hand prescription

Participants discussed how complex partial hand prescription can be for a number of reasons including, but not limited to, various presentations, user expectations, device limitations and funding.

##### 4.4.5.1 Subtheme 5.1 – Weighing up pros and cons

Participants discussed weighing up pros and cons of devices to enable realistic expectations to be set. They suggested comparing different types of device, such as myoelectric versus body powered, to educate the patient on how the device functions.

*“It's not just the category education, but the pros and the cons of each one of those, and the realistic expectations of how do these different devices actually function in everyday life? Not just how do they look on paper.” - P1.3*

*“Try and show them [the] performance of a body power device versus a myoelectric device – what the pros and cons of each is.” – P2.1*

Showing the different options that exist was also suggested as a way to weigh up pros and cons.

*“Whether it's a passive device, or if it's cosmetic, or if it's a functional high activity, activity specific, myoelectric, give [patients] a baseline understanding of all the category of options that are available and then show them some examples with patients using them.” -P1.3*

*“I strongly believe in showing the options that exist.” – P1.2*

#### 4.4.5.2 Subtheme 5.2 – Prescribing more than one device

Participants recognised that not one device can provide solutions for the patient and often they will require multiple devices for their needs. They recognised that additional devices can be prescribed later in the rehabilitation journey.

*“not one device can can replace all of what a human hand can do. So that being said...starting with one and giving the patient the confidence that this is the one that's going to get you to your goals the fastest and the most efficiently, and then you may need to add on those additional options later on down the road” – P1.3*

It was noted that it may not always be feasible to provide all of the devices that the patient could benefit from and that this practice is an ideal-world scenario. However, it was reiterated that multiple devices are often needed for different presentations or needs.

*“Nobody can receive one device. Every amputee deserves, in the perfect world, to get several devices because they are functional, specific, the hand is multi functional [and] you can't expect a single device to to meet all their needs. They need activity specific devices. They need climate specific devices. They have different temperature of radiations, they have different sensations, they depending on what sport, what recreation, where they do it...in the perfect world they need all those devices.” – P2.1*

#### 4.4.5.3 Subtheme 5.3 – Each case is unique

Participants talked about partial hand as unique and varied. They used positive language to convey that the uniqueness of this type of limb difference makes it fun and opens up opportunities to get creative with designs and prescriptions. Nonetheless, this was caveated with the fact that it makes it difficult to generalise and therefore work can be experimental.

*“The challenging thing with partial hands is that every presentation is so unique and different. And that's what makes it so fun, but also really hard to create a generalisation.” – P1.1*

*“Every partial hand is different.” – P1.7*

*“Everybody enjoys the partial hand fitting because there's not two partial hands that look the same, and that creates an opportunity for us to be adventurous. That's great. It gives us a lot of satisfaction as clinicians...but for*

*the patients it can be often frustrating because we're experimenting 100% of the time” – P1.3*

With partial hand prescription being unique and sometimes experimental for the clinician, it was noted that experience comes in to play in terms of providing successful outcomes.

*“[In] manufacturing below elbow prostheses...you have the socket and you have a hand, and you have so many myoelectric hands. But in the partial hand field, you need experience. That is important.” – P1.7*

#### 4.4.5.4 Subtheme 5.4 – Variations in practice

With the participants having experience of prescribing partial hand devices in various countries, the differences in practice across the globe was noted in discussions. Participants in Canada and the United Kingdom stated that multidisciplinary practice is not common, despite previous discussions highlighting the different disciplines involved in the full pathway from amputation to rehabilitation.

*“In Canada prosthetic prescription falls within the prosthetist realm. There's usually discussions with [physicians] but a surgeon (as far as I know) would never do a surgery, and then say ‘Hey, fit this person with this device’ or an OT would never do an assessment and then say ‘Hey, fit this person with this device’.” – P1.1*

*“There wouldn't really be much input from any sort of multi-disciplinary team approach. [UK]” – P2.4*

Variations in practice across the globe can also come down to the environment in terms of resources, which impacts the decision made by the clinician.

*“Sometimes the environment in which you find yourself, the availability of the technology, the equipment... limits you in your decision-making when it comes to partial [hand] design.” – P1.8*

#### 4.4.5.5 Subtheme 5.5 – Funding

One of the participants stated that they work out what funding is available before proceeding to ask the patient specific questions about their goals.

*“Once we figure out what kind of funding we have in place then we'll start asking the client what their goals are. We also take into consideration, obviously the injury... how bad is the injury, what devices are available for the level of communication, and then collectively with the client we'll make a decision on what is going to be best for their lifestyle.” – P2.2*

Funding can limit what is possible to prescribe and this can be due to the country in which the patient and clinician are based and associated healthcare practices specific to the geographical area.

*“It might be possible to do an activity specific one as well as a day to day ... and in some places is not.” – P2.4*

*“it's not that someone might or might not have funding, because it's within the NHS, but we can only access certain products” – P2.3*

Not only can funding limit the devices available, it can change the experience for the clinician due to additional pressures applied in cash paying scenarios. Patients who are paying for their device may hold higher standards for the product and service.

*[on cash paying patients] "At times it's exhilarating, and other times it's exhausting. You gotta be on your toes. It's everything down to even the finest finishing of scratch marks or everything. – P2.1*

#### 4.5 Discussion

Focus group sessions generated interesting discussions between experienced clinicians across the globe. From the findings and participant discussions, it can be said that a decision aid for partial hand prescription in the form of a shared decision aid may be valued and welcomed in practice. The positive feedback and interaction from participants solidified the need for such a tool to support both clinicians and users alike. This intertwines with the themes of education and patient expectations, as such an aid may address some shortcomings seen by the participants. For example, a shared decision aid could set expectations prior to prescription and educate the patient on the devices available. Further, this could benefit the workforce that participants recognised as needing education as they would have an informative aid and guideline for use in their practice. A shared decision aid also may enable patient autonomy with the individual able to understand the reason for their prescription and have their say on the device prescribed.

The multidisciplinary theme throughout discussions highlighted that there are various perspectives that should be accounted for when developing a decision aid for prescription. Various people, including surgeons, therapists, social work and the patient, are all involved in the prescription process. Rehabilitation and training should also be considered at the prescription stage. Despite multidisciplinary working being a positive theme and many professions recognised as key roles, some participants recognised that this is not part of their practice due to the environment in which they work.

While partial hand prescription can be complex for the clinician for reasons such as funding, variations in practice, and the need for multiple devices to fulfil patient needs, participants also made positive comments. The uniqueness of partial hand presentation comes with opportunities to be creative and try new approaches, which may not be the case for other types of limb difference. For some clinicians in the field, lack of experience may limit their success with creating unique solutions and this can impact the patient if their practitioner is not aware of devices or adaptations that could be made. Despite being complex, it was indicated that partial hand prescription presents opportunities for creativity and variation in techniques applied by the clinicians.

.Themes were present in both of the focus group sessions, indicating that experiences and opinions were generally shared across both groups despite geographical differences. Participants voiced their experiences, opinions and ideas about partial hand prosthetic prescription. In addition, participants made use of the chat function during the focus group sessions to affirm their agreement and support for points that

other members of the group were making. Feedback within the chat was positive, and demonstrated that participants were interested and experienced in the topic being discussed. The study highlighted the need for shared decision-making, education across the board and recognition for patient expectations. While themes are separate, there may be relationships across themes. For example, involving other patients may relate to managing expectations, which could feed into education.

#### 4.5.1 Limitations

Due to the method of convenience sampling used to recruit participants, it is unknown who chose not to take part in the study despite being eligible and seeing the advertisement. The researchers did not collect information on where participants had seen the study, for example through social media or referral from someone in their network.

NVivo software was temperamental at times during the study causing crashes and work to be lost early on in the project. This meant that some time at the beginning of the data analysis period was spent on troubleshooting rather than data analysis itself. However, this issue was rectified and did not impact data analysis after the coding phase. No personal data except contact details were collected from participants during the recruitment phase. This meant that FG1 was predominantly made up of people who work in the United States. FG2 was more mixed. Not knowing this information meant that participants were allocated to groups based on their availability and response to emails. Further, some participants knew each other,

however, these participants did not overrule the group or facilitate discussions between one another directly during the session. No action had to be taken and the group dynamics across both sessions were similar. Nonetheless, both sessions provided similar outcomes and the themes and subthemes generated were present across both sessions. Collecting personal or demographic data may have allowed groups to be designed to ensure groups were balanced prior to the sessions.

One researcher (KC) conducted the complete initial coding and generation of themes. This could have introduced bias, however, coding and themes were cross-checked with other researchers SD and MDH who agreed that the codes and themes generated were sound representations of the data. MDH was present in the focus group sessions and SD watched recordings. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist could have been used in this study to ensure methods and analysis were clear, transparent and of sound quality.

It should be noted that this study was qualitative and therefore findings are the views and opinions of participants so these could be viewed as subjective rather than objective. Findings may not represent the general opinions of people working in the field of partial hand prosthetics due to the relatively small sample of participants. Recruitment was conducted using online methods such as social media. This could mean that an entire population of 'offline' researchers who are not active social media users are unlikely to have been aware of this study. Further, the PIS was sent to 35 potential participants, 19 of whom were interested, returned consent forms and were assigned sessions. For PIS non-respondents, no reasons were given, but these could include not being interested, available or eligible to take part. From

confirmed participants, six people did not show up for the session. One participant had provided a consent form but during recruitment indicated that they may not be able to join due to work commitments. One participant had last minute work commitments and sent apologies prior to the session. One participant did not join the session with reason given as not having a Zoom account, despite this not being required for participation. One participant joined the call in the same room as their colleague, and did not appear on camera or audio but listened to the conversations. Reasons for other no-show participants are not known. It could be said that some people who were interested initially may have been discouraged or unable to take part in an online session due to factors such as technical difficulties, time differences, emergencies or work commitments taking priority.

#### 4.6 Conclusion

In conclusion, this Chapter highlighted the value of, and desire for, a shared decision aid from the perspective of clinicians who prescribe partial hand prostheses. Participants highlighted the many key roles and professions involved in the decision-making process, from prosthetists and therapists, to surgeons and social work, and even other people with partial hand limb difference also playing an important role as a multidisciplinary team approach. Further, education is required across the board, for both patients and the professionals who work in the partial hand field. Education can help prepare the user for what is ahead, and support professionals in the field who may not have vast experience in working specifically with partial hand. Managing the expectations of users can help lead to successful outcomes, although clinicians shared how expectations differ between individuals. Partial hand prescription is

complex due to the variation in presentations, pros and cons of different device types and funding implications. Nonetheless, the participants in the study spoke positively about creating solutions to enable good outcomes that matter to the individual.

#### 4.7 Chapter summary

This Chapter presented a focus group study involving clinicians who prescribe partial hand prostheses. This study explored decision-making from the perspective of clinicians and gained valuable insight into strengths and weaknesses in current prescription practices. The focus group format enabled clinicians to share their experiences and perspectives, which generated key themes related to shared decision-making, clinician education, and patient-centred considerations. Moreover, this Chapter concluded patients should be involved in the process which indicated the need for a user involvement study to aid development of a decision aid.

## 5 Decision-making for device prescription

### 5.1 Introduction

From evidence gathered in the studies described in Chapters 2, 3, and 4, it was decided that a decision aid for partial hand prescription would be valuable and desired (Figure 29). This Chapter introduces a preliminary version of a decision aid. This Chapter describes considerations for the aid including adherence to standards and guidelines. Existing decision aids for similar applications are referenced.

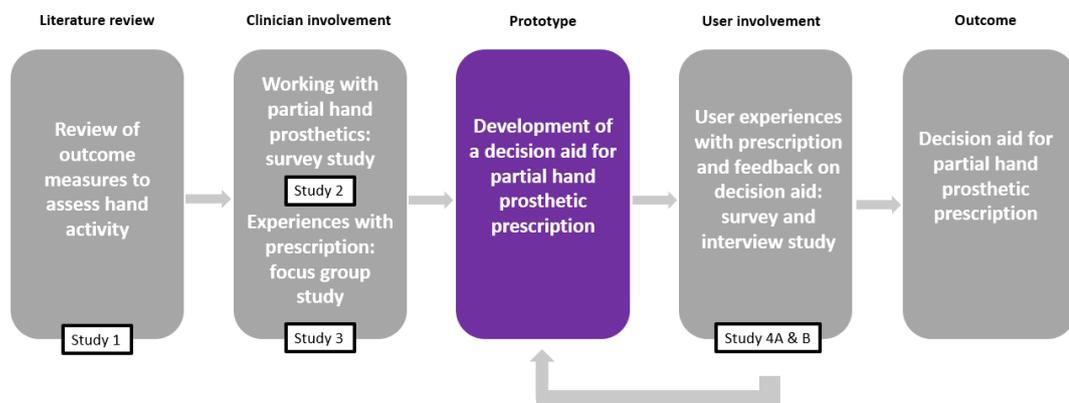


FIGURE 29 - FLOWCHART SHOWING RESEARCH STAGE DESCRIBED IN CHAPTER 5 IN PURPLE

## 5.2 Background

### 5.2.1 Decision tools in prosthetics

Research has been conducted to develop a decision-making tool for prescription of prosthetic and orthotic devices for persons with partial foot amputation (Saravanan 2020). While this research is focused on the lower limb, the methods used can be considered. The researchers identified themes in decision-making processes through semi structured interviews with clinicians in physiotherapy, prosthetics and rehabilitation medicine. The results of interviews were combined with existing literature to develop a decision-making protocol in the form of a branching decision tree. The decision tree was validated by surveying health care providers who prescribe partial foot prostheses. The results of this research reinforced the need for standardising the prescription process for partial foot. The researchers recommended future work involves validating the model using machine learning and with a larger pool of participants. It was also suggested that the tool should be further developed to consider low-resource markets in mind, as the current tool was based on prescription in the United States.

### 5.2.2 Patient decision aids

Patient decision aids aim to involve the patient in decisions related to healthcare. Such decisions include treatment, care and prescription options. They contain information about the decision in lay person language and help the patient to come to their own conclusion about what they want, based off the information and options displayed to them. Patient decision aids do not exist to persuade someone to choose one option over another, and instead account for different scenarios in an unbiased way (IPDAS 2025).

Patient decision aids can be used in healthcare decisions which are complex and require careful consideration. The advantages and disadvantages, or benefits and harms, of different options may allow the patient to decide which path to take based off what they value most. This can allow the patient to practice autonomy and feel empowered by their decision at what could be a difficult time.

The International Patient Decision Aid Standards (IPDAS) claims that there are over five hundred Patient Decision Aids (PDA) developed or under development. Nonetheless, the accuracy and effectiveness of PDA will impact whether they are sought, used, or appropriate for patients themselves. It has been said that PDA are difficult to create and not used widely (Agoritsas, Heen et al. 2015)

A patient decision aid for terminal device options for people with upper limb absence (PDA-TULA) has been developed by a group who specialise in upper limb in the Netherlands (Kerver, Boerema et al. 2023). The PDA-TULA was developed based on IPDAS and aimed to challenge device rejection rates in adult unilateral upper limb difference. The three-part aid was developed using findings from studies including literature review, surveys and focus groups which were specifically designed for development of the PDA. The development of the PDA-TULA differs from the work described in this thesis, as this thesis describes a set of studies which conclude the need for a PDA for partial hand. Nonetheless, the PDA-TULA was developed using a steering group consisting of 12 members. This relatively low number was deemed acceptable and allowed for the development of a tool to assist prescription.

### 5.2.3 Standards

#### 5.2.3.1 NICE framework

National Institute for Health and Care Excellence (NICE) developed a framework which contains a series of standards for patient decision aids. The purpose of the framework is to support developers to produce quality aids with all required elements and to enable assessment throughout development and use (NICE 2021). The NICE standards framework for shared decision-making support tools, including patient decision aids, was used to support development. The framework is open access and can be used to assess decision aid development using a 3-point assessment scale. The scale asks the developer to consider whether each listed aspect been met (2), partially met (1) or not met (0). It also asks developers to suggest where to find evidence of standards having been met and offers a column for further notes.

#### 5.2.3.2 IPDAS

The IPDAS has been developed by a collaboration consisting of researchers, practitioners and stakeholders. The IPDAS encourages development of reputable and recognisable decision aids by means of an established set of criteria to assess PDA quality (IPDAS 2005). A consensus approach was used to develop the standards, with input from 122 people from 14 countries. The standards manifest in the form of a checklist for users which can be used to monitor and assist in development and assessment of PDA. The checklist is divided into three sections with varying levels of subsections. Section I titled 'Content' asks if the PDA:

1. Provides information about options in sufficient detail
2. Presents probabilities of outcomes in an unbiased and understandable way

3. Includes methods for clarifying and expressing patients' values
4. Includes structured guidance in deliberation and communication

Section II titled 'Development Process' asks if the PDA:

5. Presents information in a balanced manner
6. Has a systematic development process
7. Uses up to date scientific evidence which is cited
8. Discloses conflicts of interest
9. Uses plain language

Section III titled 'Effectiveness' asks if the PDA:

10. Ensures decision-making is informed and based on values.

#### 5.2.4 Aims

The aim of the work in this Chapter was to develop a draft decision aid for prescription of partial hand prostheses. The aim of the decision aid is to support the decision-making process, rather than replacing the user-clinician discussion. The aim is for the decision aid to be provided to the user during the prescription process, either alongside an invitation to clinic or during the first visit. The final version of the decision aid is contained in Chapter 6.

### 5.3 Method

#### 5.3.1 Development

The IPDAS Original Patient Decision Aid Checklist was used as a guideline to create a template for the decision aid. This version contained sections and subsections as shown in Table 13. The content of the decision aid draft was based on findings from

Chapters 2-4 as well as standards and guidelines. The design process was iterative, with improved versions shown in Table 14 and text extract in Section 5.3.1.3.

5.3.1.1 Stage 1

TABLE 13 - STAGE 1 OF DECISION AID DEVELOPMENT WITH SECTIONS AND SUBSECTIONS

<b>Section</b>	<b>Subsection</b>
<b>Introduction to PDA</b>	<p>This decision aid is for you if...</p> <p>What are prosthetics</p> <p>Why am I being asked about prosthetics</p> <p>What are the prosthetic options for my condition</p> <p>What other health factors may influence your choice (scar tissue, future surgeries planned...)</p> <p>How to proceed with the decision aid</p>
<b>What does the research show?</b>	<p>Benefits</p> <p>Harms</p>
<b>What matters most to you?</b>	<p>Reasons to use __ prosthesis</p> <p>Reasons to decline __ prosthesis</p>
<b>Funding</b>	<p>Discuss with provider</p>
<b>Check your understanding</b>	
<b>How comfortable are you about making this decision?</b>	
<b>What are your next steps?</b>	

5.3.1.2 Stage 2

TABLE 14 - STAGE 2 OF DECISION AID DEVELOPMENT WITH SECTIONS, SUBSECTIONS AND NOTES

Section	Subsection	Notes
<b>Introduction to PDA</b>	This decision aid is for you if...	Partial hand limb difference, congenital or amputation, age
	What are prosthetics	Define prosthetics
	Why am I being asked about prosthetics	Making a decision about what device is best for you
	What are the prosthetic options for my condition	Information about device types, functions, features and limitations. Include brands.
	What other health factors may influence your choice (scar tissue, future surgeries planned...)	Future surgeries planned, scar tissue for burns,
	How to proceed with the decision aid	Instructions on how to complete
<b>What does the research show?</b>	Benefits	Benefits of using a device
	Harms	
<b>What matters most to you?</b>	Reasons to use __ prosthesis	Reasons to use each different type of device
	Reasons to decline __ prosthesis	
	Goal setting	
<b>Funding</b>	Discuss with provider	Include links to various websites
<b>Check your understanding</b>		
<b>How comfortable are you about making this decision?</b>		
<b>What are your next steps?</b>		Include links to support groups/websites

### *Section 1 – Introduction to PDA*

*Patient decision aids are designed to help people participate in decision making about options. The purpose of a patient decision aid is to prepare the patient by providing information to make an informed decision with their personal values at the forefront and to prompt discussions with their healthcare provider. (International Patient Decision Aids Standards (IPDAS) Collaboration (ohri.ca))*

*The purpose of a patient decision aid is not to persuade people to choose one option over another or replace interactions with health professionals.*

#### *1. This decision aid is for you if...*

*This document is to help you to make decisions about partial hand prosthetic prescription. It contains information about partial hand limb difference and options for this condition. You may be a candidate for some, or all, of the prosthetic options. Talk to your provider to find out what is available for you.*

#### *2. What is partial hand limb difference?*

*Partial hand limb difference refers to a residual limb with a functional wrist with only a portion of the hand. People with partial hand limb difference may have some fingers, a thumb, or a portion of the palm only.*

*Partial hand limb difference can be the result of amputation or congenital difference. Amputation is the surgical removal of a limb segment due to trauma or disease. Congenital hand difference occurs when a child is born with a hand that has formed differently, and a portion of the hand is absent.*

#### *3. What are prostheses?*

*Prostheses are artificial body parts which can be useful if someone is missing a body part, such as a limb. Such body parts could be missing for reasons such as amputation, trauma and congenital difference. A prosthesis may be designed to replace function, restore appearance, or a combination of both, in terms of the missing body part.*

*Prostheses can be high or low cost. They may also be fully, partly or not at all covered by funding depending on your situation.*

*Prosthetists are people who design, fit and assess prostheses.*

#### 4. Why am I being asked about prostheses?

*There are different types of prosthetic device available. Each option has its own benefits and limitations. Whether a device is suitable for you or not can depend on factors including (but not limited to) your existing function, presentation of your hand, occupational needs, hobbies, or aesthetic desires.*

*Your prosthesis will require maintenance and replacement. Frequency of maintenance and replacement may depend on factors such as prosthesis type, amount of use, and after care.*

#### 5. How to proceed with the decision aid

#### 6. What are the prosthetic options for my condition?

<b>Type</b>	<b>Examples</b>
<i>Body-powered</i>	<i>Naked Prosthetics</i>
<i>Myoelectric</i>	<i>Ossur (I Digits)</i>
<i>Mechanical</i>	<i>Points Design</i>
<i>Activity-specific</i>	<i>e.g.</i>
<i>Silicone/passive</i>	<i>e.g.</i>

*Myoelectric devices use signals from muscles to communicate with the device. The device responds to different muscle signals by creating various grip patterns.*

*Mechanical devices use ....*

*Activity specific devices could be used for sports or activities of daily living. The device is designed for a particular task. Activity specific devices include tools for sports such as swimming.*

*Silicone/passive devices are designed to look like the absent body part, and may feature hair and nails. These devices are not designed with a functional purpose.*

## *Section 2 – What does the research show?*

*A review article first published in 2022 explored and compared prosthetic options for partial hand (Kim 2023).*

### *1. Benefits*

*Research shows that using a prosthesis can increase quality of life and help people to adapt after amputation (Kuret 2019). Benefits also include increased independence in carrying out activities of daily living (ADL) (Biddiss and Chau 2007).*

*Benefits of not using:*

- Sensation*
- Avoid reliance*
- Adaptation?*
- This can be true for prosthesis wearers, who choose not to wear for periods e.g. sleeping/rest – can use it as much as you want*

### *2. Harms*

*Some people choose not to use a prosthesis. This option can result in over-use injuries if you rely on your other hand, or other body parts, to perform functions. If you choose not to use a prosthesis, you can consult with your provider to ensure you do not encounter problems such as overuse injury or postural issues.*

*Socket fit/sweat/thermal discomfort – speak to prosthetist, correct the issue*

*Training – what you bring to it, learning and practicing*

*Hygiene*

Section 3 – What matters most to me?

*Y – device might match the requirement very well*

*M – device might match the requirement*

*N – device might not match the requirement*

Requirement	Myoelectr ic	Body- powere d	Mechanic al	Activity - specific	Silicone/passi ve	Hybri d
Heavy physical activity		Y	Y	M	N	
Fine motor skills	Y			M	N	
Sports		M		Y		
Life-like appearanc e	N	N	N		Y	

1. Goal setting

*What you would like to do | difficulty | how important is it to be able to do this*

*For example, if you*

Task	Difficult					Not at all difficult					Not important					Very important				
Cutting food	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Dressing	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Washing	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Add your own...	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

#### *Section 4 – Funding*

1. *Discuss with provider*

#### *Section 5 - Check your understanding*

#### *Section 6 – How comfortable are you about making this decision?*

#### *Section 7 – What are your next steps?*

- *Links to support groups*
- *Resources*
- *Videos*

#### *Section 8 - References*

1. *Kim, G.M.P., J E.: Lacey, S A.: Butkus, J A.: Smith, D G., Current and emerging prostheses for partial hand amputation: A narrative review. PM&R, 2023. 15(3): p. 392-401.*
2. *Kuret, Z.B., H.: Vidmar, G.: Maver, T, Adjustment to finger amputation and silicone finger prosthesis use. . Disability and Rehabilitation, 2019. 41(11): p. 1307-1312.*
3. *Biddiss, E. and T. Chau, Upper-Limb Prosthetics: Critical Factors in Device Abandonment. American Journal of Physical Medicine & Rehabilitation, 2007. 86(12): p. 977-987.*

## 5.4 Chapter summary

This Chapter introduced a draft version of a decision aid for partial hand prosthetic prescription and outlined the iterative design process that guided its development. Relevant background on decision-making theory and existing tools used in healthcare and prosthetics was presented. The decision aid draft served as a foundation document for the user involvement study described in Chapter 6.

## 6 Study 4: User-involvement in the development of a decision aid

### 6.1 Introduction

Chapter 4 identified that a shared decision aid for supporting prescription of partial hand prostheses would be valued. Clinicians provided their input, however, no direct user involvement had been sought. Chapter 5 described the development of a decision aid draft. Chapter 6 presents Study 4, a two-part investigation consisting of a screening survey and interviews involving individuals who have been prescribed a partial hand prosthesis (Figure 30). Work in this Chapter aimed to gather information about the prescription process from the perspective of individuals who have undergone the process and provide an opportunity for co-creating further iterations of the decision aid contained in Chapter 5.

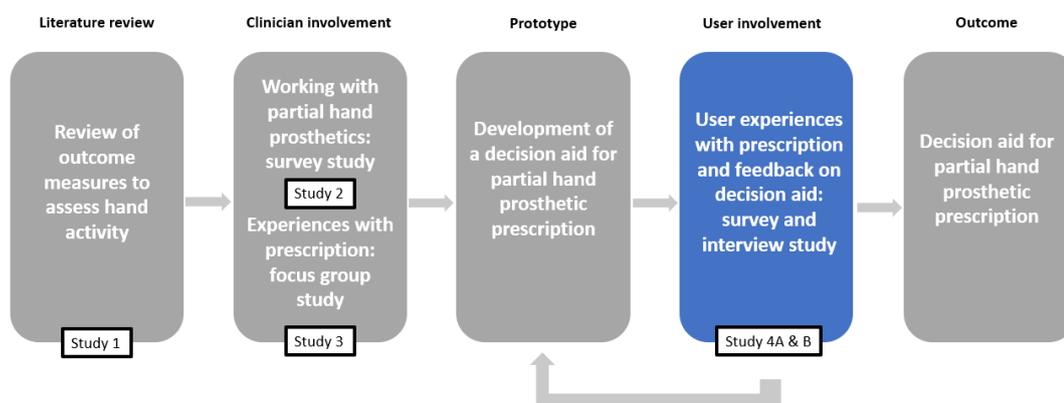


FIGURE 30 – FLOWCHART HIGHLIGHTING STUDIES DESCRIBED IN CHAPTER 6 IN BLUE

## 6.2 Background

### 6.2.1 Patient and Public Involvement and Engagement

Patient and Public Involvement and Engagement (PPIE) is a method used to involve stakeholders, in particular patients or users, in research and development. Members of the public, including patients, are active members of the team in PPIE studies and help to shape and engage with research (Health Data Research UK 2025). The aim of PPIE work is to ensure work is communicated effectively to patients and members of the public, and is driven towards meaningful outcomes. Research and development of health-related technologies requires PPIE to ensure outputs are desired, necessary, and target key problems related to the field. Users are key stakeholders in research and development of devices and tools and can provide insights which can drive iterative design. Examples of PPIE include user trials and research studies such as questionnaires or discussions (NIHR Great Ormond Street Hospital Biomedical Research Centre 2025).

PPIE studies are used in this thesis to facilitate understanding of use of devices in the real world, and the challenges encountered by stakeholders involved in partial hand prosthesis prescription.

### 6.2.2 User involvement studies

User involvement studies are methods of research in which a user plays an active role in the study, for example co-creating, developing work and contributing ideas (Kylberg, Haak et al. 2018). User involvement is useful in research and can result in success for developers and satisfaction of users of such developments. Studies have shown that user involvement studies can improve accuracy of user requirements for

developers (Kujala 2003). In terms of healthcare, user involvement in research can provide beneficial insights and knowledge as well as potentially improving relevance and quality of research (Kaltoft, Nielsen et al. 2014).

#### 6.2.3 Survey methodology

The survey described in this Chapter differs from the previous survey described in Chapter 3 in that the participants are individuals with limb difference rather than healthcare professionals. These participants may be described as 'patients' or 'users'. Surveys involving these types of groups should be designed using appropriate language and sensitivity around certain topics. Surveys can be used as scoping tools to gather quantitative and qualitative data from participants who may or may not take part in a future study, in this case being a follow-up interview.

#### 6.2.4 Interview methodology

Interviews in research are planned discussions between a researcher and interviewee to gather in-depth information about a topic. Interviews are commonly chosen as a qualitative research method as the participants may find this natural, private and comfortable (Taherdoost 2022). Interviews may be structured in varying levels, each level involving different amounts of guidance from the researcher conducting interviews. They may be structured, unstructured or somewhere in between known as semi-structured (Taherdoost 2022). Structured interviews have similar questions for each participant, which may be time efficient and allow for comparison across participants. This may aid data analysis as data gathered may be quantitative, but reduces the opportunity for the participant to delve further in depth in parts of the discussion they may feel strongly about, which can result in some experiences or views remaining unexplored (DiCicco-Bloom and Crabtree 2006). Unstructured

interviews take a different approach in that they allow the participant to speak more freely, and questions may follow responses. As this method is more loose than structured, data analysis can be more time-consuming, although data may be more in-depth and personalised (Mueller and Segal 2015). Semi-structured interviews are common for qualitative data collection (Harvey-Jordan and Long 2001). This method involves a set of questions from the researcher, which may be funnelled down to more specific questions and/or further probing questions based on responses (Moser and Korstjens 2018). Semi-structured interviews allow in-depth data to be gathered, but with the aid of pre-determined questions to ensure no key data is missed in the collection.

Interviews may take place online or in-person depending on the nature of the study. For example, online interviews may allow participants from across the globe to take part. Online interviews using software such as Zoom can allow for recordings and transcripts to be downloaded easily, whereas in-person interviews may require specialist recording equipment. Phone interviews may also be conducted, however, also require recording equipment and remove any visual data such as facial expressions or gestures which may be of interest in data analysis.

Benefits of conducting interviews over focus groups for this study include the intimate nature of the one-to-one discussion around what may be a sensitive or emotional topic. Additionally, online interviews allow participants to take part from the comfort of their own chosen space which may ensure they are comfortable in opening up about emotions or experiences, and encouraging participation from those who may not be able to travel to an in-person session which subsequently

opens up the pool of potential candidates (Morgan, Krueger et al. 1998). Nonetheless, interviews can take longer to transcribe than focus group data due to the volume of data gathered.

#### 6.2.5 Study aims

This study aimed to inform the development of the decision aid for partial hand prosthetic prescription by gathering user feedback on the draft presented in Chapter 5. It also sought to explore experiences of the prescription process and to understand what users' want and need from decision aids more generally. The objectives of the study were to gather feedback on, and co-create further iterations of the decision aid for use in partial hand prosthetic prescription. An additional objective was to gain insight into the lived experiences of people who have undergone the partial hand prosthetic prescription process.

### 6.3 Method

#### 6.3.1 Research design

The study comprised two parts. Part one was a screening survey referred to as "Study 4A", and part two was a semi-structured interview study referred to as "Study 4B". The aim of Study 4A was to gather quantitative and qualitative information from people with partial hand limb difference. Study 4B was designed to delve deeper through interview methods. A two-part study was also selected as it was anticipated that sample size may be small, and it may be time-effective to gather information through surveying people in their own time. In addition, some individuals may not wish or be able to take part in a one-to-one interview. A flowchart of Study 4A and 4B stages from recruitment to write up is depicted in Figure 31. Ethical approval for

the study was granted by the University Ethics Committee, University of Strathclyde (UEC 2409).

#### 6.3.1.1 Study 4A

An anonymous screening survey was designed in Qualtrics software and distributed online (Appendix L). The survey included a selection of multiple choice, Likert-type scale, closed and open-ended questions. The survey was divided into two main sections titled 'About You' and 'Device Prescription'. The 'About You' section featured questions about participant characteristics, cause of limb difference, amputation information (if applicable), hand presentation and occupation. The 'Device Prescription' section featured questions about when and where the participant received their first and last, or only, prosthesis. This section also featured questions on the type of prosthesis prescribed, information provided to the participant during prescription and opinions about the process. The participants were given the opportunity to voluntarily upload a photo of their affected hand(s) to enable the researchers to see their presentation.

#### 6.3.1.2 Study 4B

Online one-to-one interviews were conducted online using Zoom software and each lasted one hour. A semi-structured interview guide was designed by the researchers which included an introduction and reminder of the research purpose, followed by three main sections and an opportunity for participants to raise additional thoughts (Appendix M). The three main sections were 1) prosthesis prescription, 2) decision aid development, and 3) decision aid draft. The questions within these sections were open-ended and delved deeper into the questions asked in the screening survey. Participants were asked to share their experiences with prescription, as well as their

thoughts and opinions. Participants were also asked about what they thought the decision aid should contain, the format in which it should be presented and what resources would be useful for this tool. Further, participants were shown examples of decision aids for other applications as well as a draft of the decision aid in development (Appendix N). They were then asked their thoughts about the document, opinions on the content, and to reflect on their own experience and imagine if this tool would have impacted the outcome of their prescription. The interview guide was amended slightly for each participant based on the information they provided in the screening survey. For example, 'Joe' indicated he has only been prescribed one device, whereas 'Tom' has been prescribed six, therefore they were asked questions specific to their situation.

#### 6.3.2 Sampling and participants

Participants were individuals with partial hand limb difference who are, or have been, prosthesis users. The inclusion criteria were as follows: currently uses or has used a partial hand prosthesis within the past five years, English language speaker, over 18 years old, has access to a device which enables them to take part in an online survey (Study 4A) and online Zoom meeting with audio and video (Study 4B). The only exclusion criteria were individuals who have never acquired a partial hand prosthesis through prescription by a healthcare professional.

Convenience sampling was used to recruit Study 4A participants. The investigation was advertised on social media using a poster. Participants from Study 4A were invited to provide contact details should they wish to participate in Study 4B.

### 6.3.3 Recruitment

Participants were recruited via a link to the online survey. The link was distributed on social media channels – Twitter, LinkedIn, and Instagram – with a poster (Appendix O) and relevant tags used to increase visibility within the target population. A PIS and consent form were provided on the first page of the survey for the participant to provide informed consent before continuing on to survey questions (Appendix P). The PIS contained information about both studies and highlighted that it may not be feasible for all participants to take part in Study 4B. If a participant consented to providing contact details to be invited to take part in Study 4B, their name and email address were collected. However, no identifiable data were used in data analysis. Email invitations and PIS specific to Study 4B were sent directly to participants who indicated interest in Study 4B (Appendix Q and R). This PIS contained information about the one-to-one interview, a review of the study aims and details specific to the online session. Participants who returned a signed consent form were contacted individually to arrange a suitable time to conduct the interview. Participants were recruited globally. Recruitment by referral could also be used in this study as the advertisement was shared on social media. No monetary incentives were offered for taking part in either study.

### 6.3.4 Data collection

For Study 4A, data were collected between 8<sup>th</sup> April 2024 and 31<sup>st</sup> May 2024. For Study 4B, interviews were carried out between 31<sup>st</sup> May 2024 and 5<sup>th</sup> June 2024. Interview recordings were downloaded from Zoom and pseudo-anonymised. Data were pseudo-anonymised to enhance the security of the personal data obtained from the participants, and to encourage participation by sharing personal experiences

while safeguarding participants so they cannot be identified by any resulting publications. This was carried out by replacing each participant's name with a code name. Pseudo-anonymisation was selected over anonymisation as the researcher was present in the interview and was required to identify participants during data analysis.

As participants were shown a draft of the decision aid, codes related to these parts of the discussion were identified separately from discussions about experience and opinions on the general prescription process. Semantic and latent codes were produced.



FIGURE 31 - FLOWCHART OF STUDY 4A AND 4B STAGES

### 6.3.5 Data analysis

For Study 4A, analysis was performed using in-built Qualtrics tools such as graphic displays. In addition, data were exported to Microsoft Excel where descriptive statistics were calculated.

For Study 4B, analysis was carried out using NVivo for analysis of unstructured text, audio and video data collected from the interview sessions. Thematic analysis was performed by means of an inductive, data-driven approach in accordance with Braun and Clarke's six step process for reflexive thematic analysis as previously described in Chapter 4. The six step process is described in further detail in Chapter 4, however, was adapted to suit the semi structured interview method used in this particular study as described below.

#### 6.3.5.1 Step 1 – Familiarisation phase

This step was incorporated into the transcription process. Transcripts were downloaded from Zoom then formatted in Microsoft Word and participant names were pseudo-anonymised. The documents were transcribed line by line using video recordings of the session to correct errors and fill gaps missed by Zoom software. Re-reading transcripts and repeated viewing of interview recordings took place which encouraged familiarisation.

#### 6.3.5.2 Step 2 – Coding phase

This step took place in NVivo software and involved going through each transcript line by line and identifying items which were of interest to the research question (Figure 32). Initial codes were created and additional codes created throughout this process if no suitable code existed in the codebook. There were crossovers between existing initial codes at this stage. This step resulted in 48 first-order codes being

introduced to the codebook for further analysis as shown in Table 15. As participants were shown a draft of the decision aid, codes related to these parts of the discussion were identified separately from discussions about experience and opinions on the general prescription process. Codes in *italic font* in Table 15 relate specifically to the decision aid draft shown to participants. Semantic and latent codes were produced.

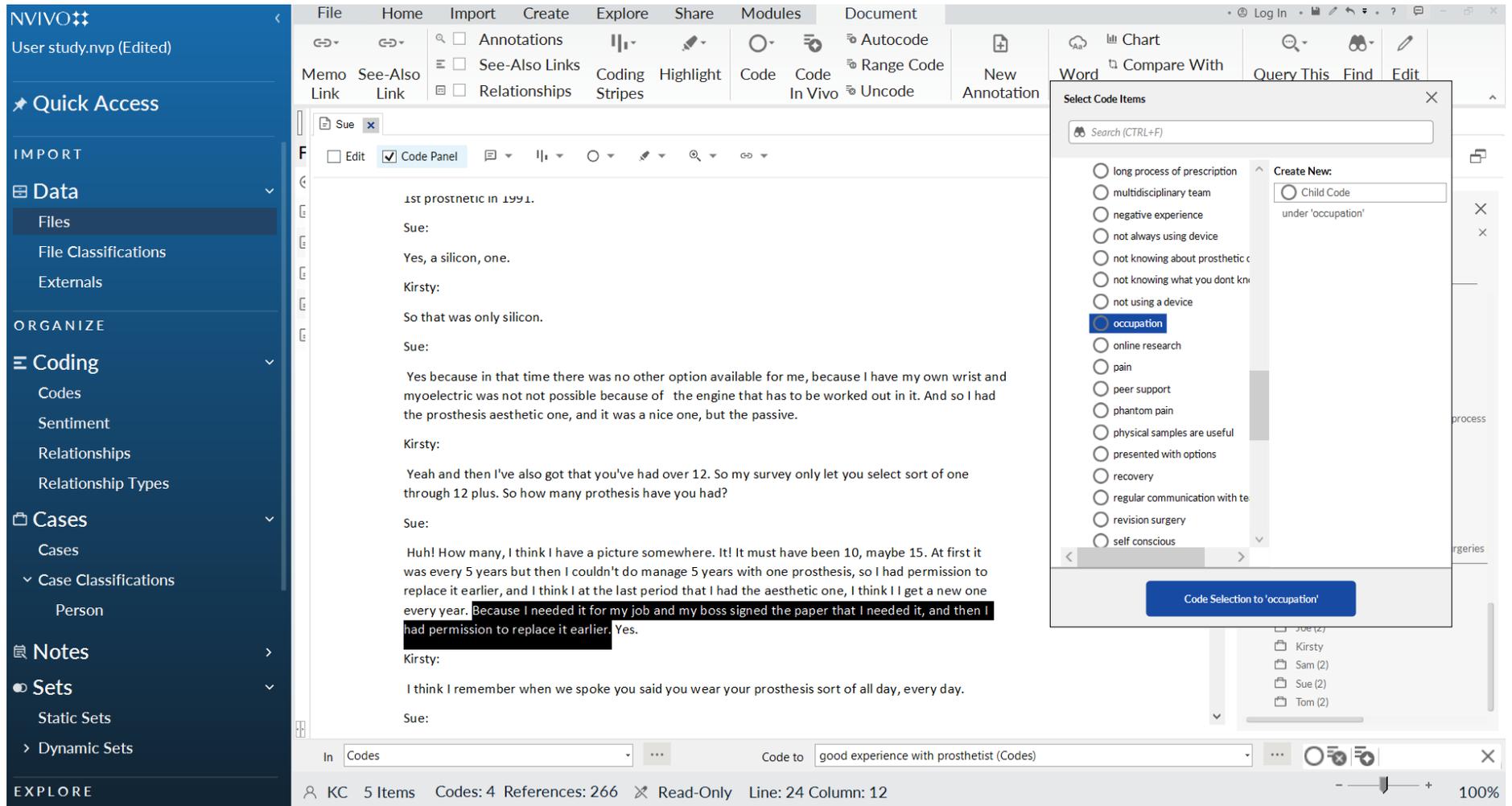


FIGURE 32 – SCREENSHOT OF NVIVO SOFTWARE DURING CODING PHASE

TABLE 15 - FIRST ORDER CODES

<b>Codes</b>	
1 : activity specific	25 : good experience with prosthetist
2 : advocating for ones self	26 : had input on decision
3 : aware of options	27 : having multiple devices
4 : being open minded	28 : impressed by the prosthetic
5 : change in priorities	29 : improvements in technology
6 : comfort and fit	30 : interested in prosthetic design
7 : comfortable in public	31 : knowing what was wanted at prescription stage
8 : compensatory movements	32 : learning about hand function
9 : cost	33 : learning curve
10 : device options	34 : limitations
11 : device requirements	35 : long process of prescription
12 : education	36 : maintenance
13 : general thoughts	37 : negative experience
14 : goal setting	38 : not knowing about prosthetic options
15 : visuals	39 : not using a device
16 : device is not useful	40 : occupation
17 : device is useful	41 : online research
18 : didn't know what to expect	42 : peer support
19 : each person is different	43 : physical samples are useful
20 : education from professionals	44 : presented with options
21 : emotional about condition	45 : recovery
22 : everyday activities	46 : regular communication with team
23 : expectations about process	47 : tactile feedback
24 : frustration	48 : training

#### 6.3.5.3 Step 3 – Generating initial themes

Initial codes which were related to each other were grouped together to generate initial themes, with some codes appearing under multiple themes. At this stage, it was apparent that some codes should be discarded as they were not supported strongly by the data. This step resulted in the generation of 10 initial themes as shown in Table 16.

TABLE 16 - INITIAL THEMES

---

Initial themes
<i>Expectations about process</i>
<i>Prosthetic device is useful</i>
<i>Limitations</i>
<i>Independent research</i>
<i>A learning curve is involved</i>
<i>Prescription process had negatives</i>
<i>Positive experience with professionals</i>
<i>Emotional aspects</i>
<i>Individual process</i>
<i>Knowing what lies ahead is important</i>

---

#### 6.3.5.4 Step 4 – Reviewing themes

Initial themes were compared against the transcript data to assess if they represented the data and whether they should be amended or discarded. The review process was iterative and generated themes were reconsidered using transcripts, the updated codebook, and with reference to the initial themes. Potential sub-themes were considered at this point as the themes were reduced. As described in Chapter 4, a set of overarching questions was used to assess the codebook. Examples of themes and subthemes generated at this stage are shown in Table 17. At this stage, subthemes were continuously reviewed, edited and reviewed based on the data. Visual charts were used to aid this process as shown in Figure 33.

TABLE 17 - POTENTIAL THEMES AND SUBTHEMES

Potential themes	Potential subthemes
1) <i>The journey</i>	Recovery Learning curve Knowing what lies ahead
2) <i>The individual</i>	Everyone is different Self advocacy Psychosocial
3) <i>Support</i>	Peer support Professional support
4) <i>Knowledge</i>	Awareness Online research
-	Education from healthcare professionals
5) <i>Limitations</i>	Living with partial hand limb difference Device limitations

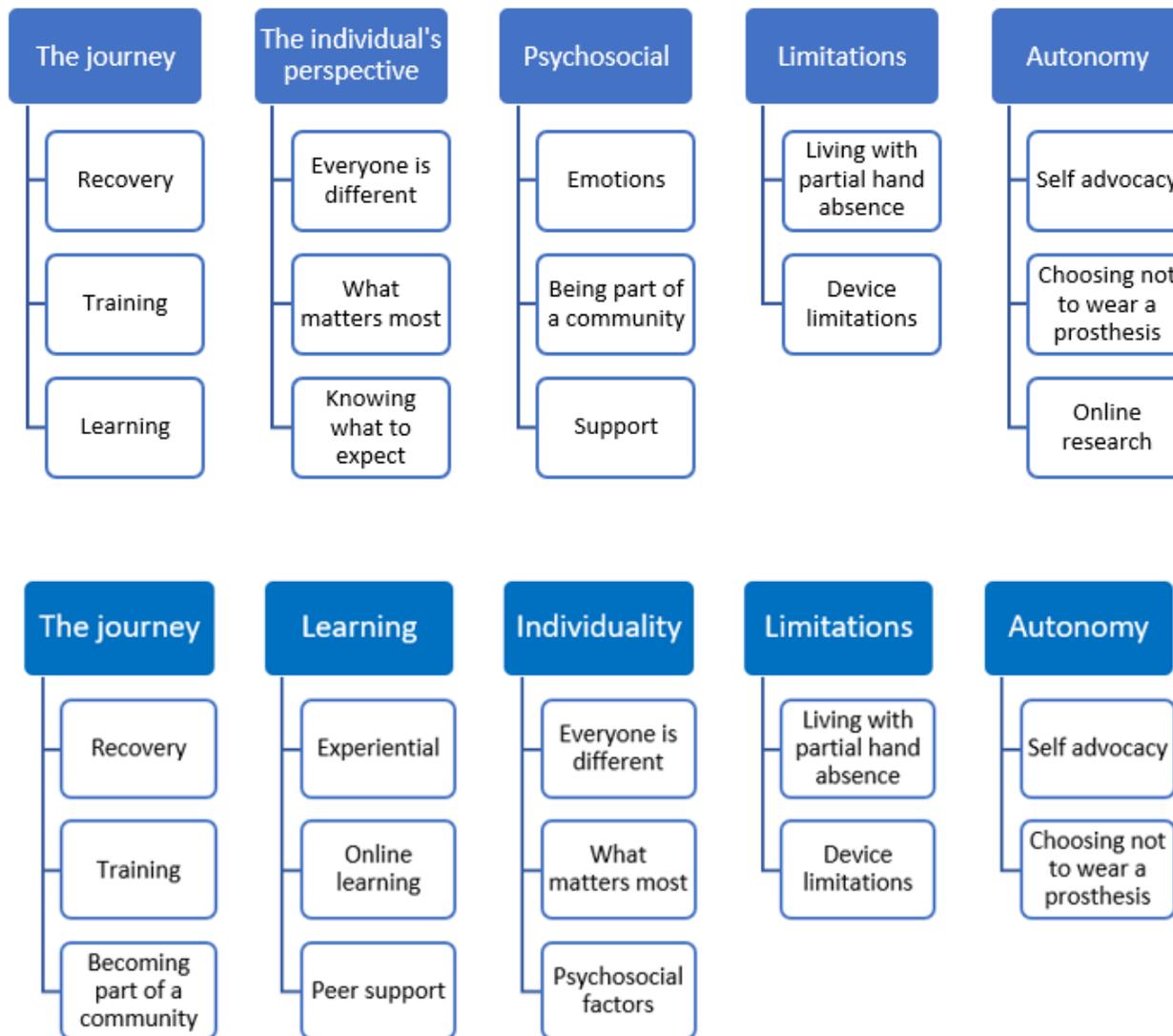


FIGURE 33 - THEMATIC MAPS SHOWING DIFFERENT THEMES AND SUBTHEMES GENERATED DURING THE REVIEWING PHASE

#### 6.3.5.5 Step 5 – Defining and naming themes

Themes were defined by considering the evidence in the form of quotes assigned to each subtheme. This was an iterative process to ensure the themes were backed up strongly by the evidence and that subthemes were true but also not standalone themes. Themes and subthemes were renamed to ensure they represented the evidence and message they portrayed. Full transcripts were read again, with patterns recognised during re-reading cross-checked against the themes and subthemes generated. All relevant quotations had been extracted from the transcripts and it was decided that no themes had been missed. Therefore, themes and subthemes at this stage were defined (Table 18). Following re-reading of transcripts, some themes and subthemes were renamed to better illustrate the story told through the data. A thematic map was produced to illustrate themes and subthemes in visual format (Figure 34).

**TABLE 18 - FINAL THEMES AND SUBTHEMES**

<b>Final themes</b>	<b>Subtheme</b>
<i>Ongoing journey with limb difference</i>	<i>Training to use a partial hand prosthesis</i>
	<i>Recovery</i>
	<i>Adaptation</i>
	<i>Adjustment</i>
<i>Acknowledging situation of limb difference</i>	<i>Emotions</i>
	<i>Goal setting</i>
	<i>What matters most</i>
<i>Understanding limitations of partial hand</i>	<i>Physical limitations</i>
	<i>Periods of non-use</i>
	<i>Using multiple devices</i>
<i>Learning and advocating</i>	<i>Research</i>
	<i>Outreach</i>
	<i>Self-advocacy</i>

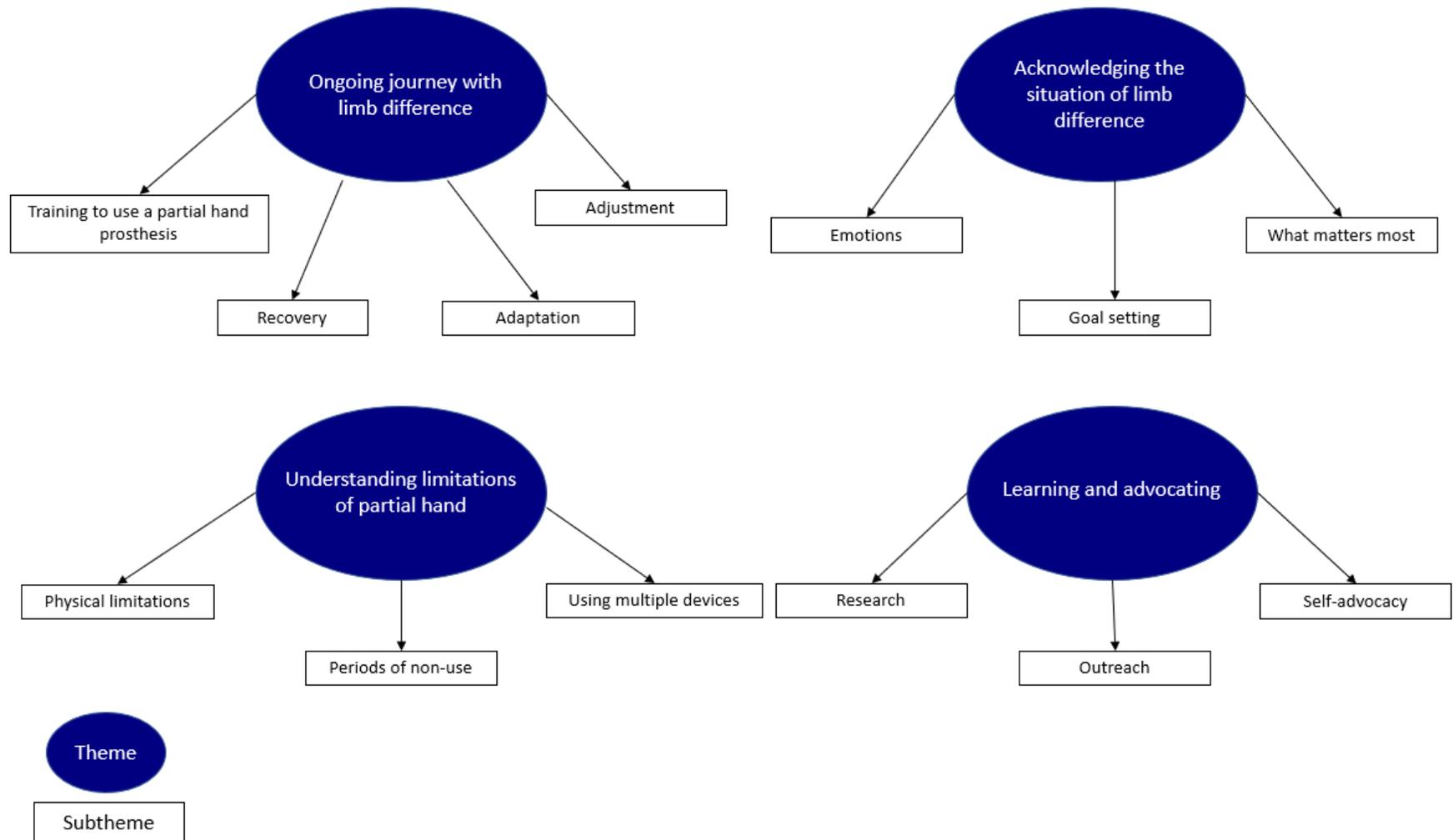


FIGURE 34 – THEMATIC MAP OF THEMES AND SUBTHEMES

#### 6.3.5.6 Step 6 – Writing up

Writing up involved selecting the most relevant quotes extracted from transcripts to provide evidence to build the results section. Findings which were in the form of feedback specific to the decision aid draft were segregated and contained in a separate table.

## 6.4 Results

### 6.4.1 Study 4A

A total of 17 participants completed the survey. Most of the participants were from the United States of America (n=10), followed by the United Kingdom (n=2), Canada (n=2), Austria (n=1), Belgium (n=1), the Philippines (n=1), Thailand (n=1) and Germany (n=1). One participant listed multiple countries (the Philippines, Thailand and Bangkok). Figure 35 shows that most participants who took part identified as male (n=12) and the remainder as female (n=5). Participants selected an age bracket in which they belonged, resulting in a spread of representation from the 18-24 range to 65–74-years old.

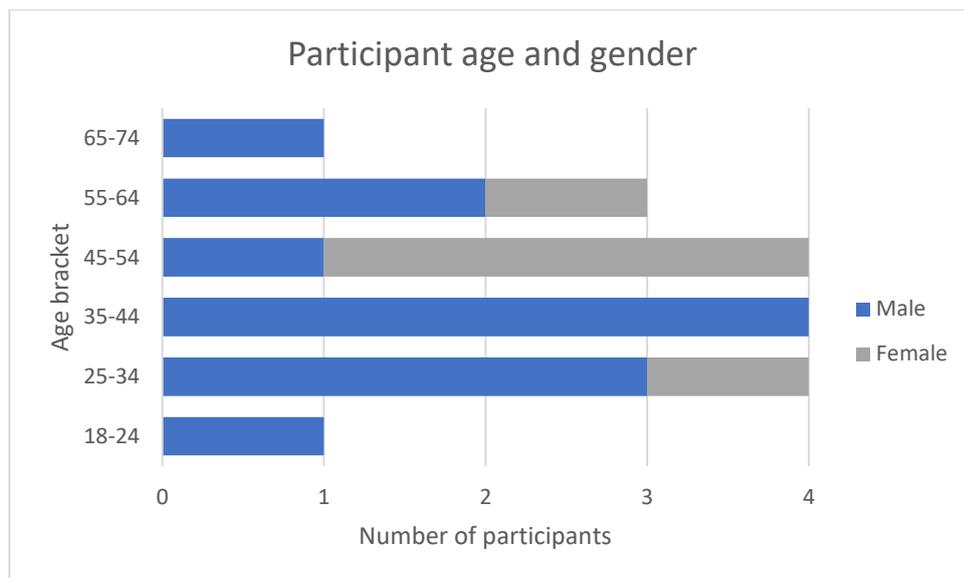


FIGURE 35 - GRAPH SHOWING NUMBER OF PARTICIPANTS IN DIFFERENT AGE BRACKETS AND BY GENDER

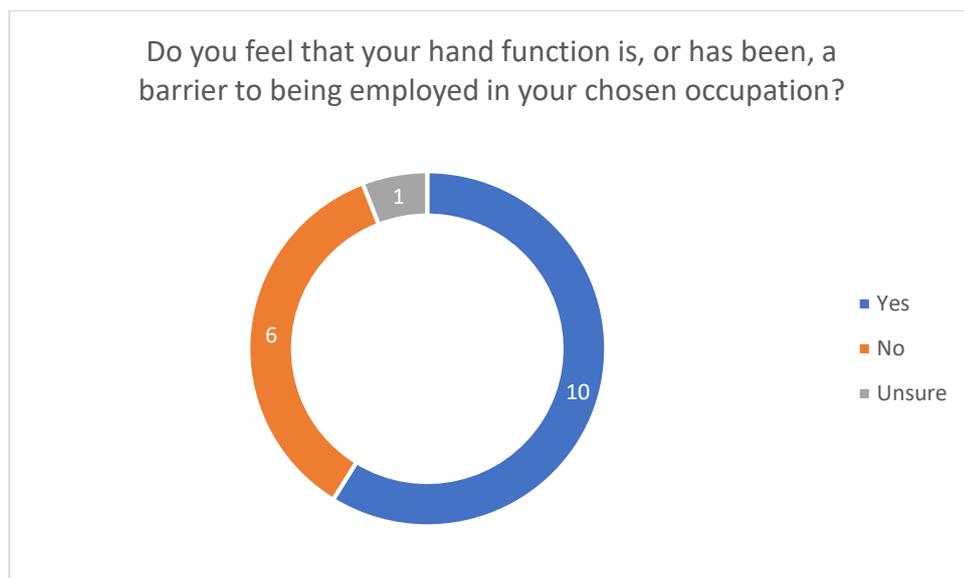
The majority of participants (n=15) had partial hand amputation, and the remaining two had congenital limb difference. The majority of the reasons provided for amputation were work-related (Table 19). The term 'workplace accident' was applied to variations of text-based inputs that included 'work' in the description. Other

reasons, such as 'traumatic' and 'farm machinery' accidents, may have also been work-related. Many of the participants have received one prosthesis, therefore the year of 'most recent prosthesis' row in Table 19 is empty in such cases.

**TABLE 19 - REASON FOR AND YEAR OF PARTICIPANTS' AMPUTATION ALONGSIDE YEAR OF FIRST PROSTHESIS PRESCRIPTION**

<b>Reason for amputation</b>	<b>Year of amputation</b>	<b>Year of first prosthesis prescription</b>	<b>Year of most recent prosthesis prescription</b>
Firecracker accident	1990	2018	2024
Workplace accident	1999	2000	2021
Workplace accident	1999	2019	
Traumatic accident	2016	2017	2024
Farm machinery accident	2017	2018	2024
Workplace accident	2018	2020	2024
Hand got caught in a factory machine	2020	2021	
Workplace accident	2020	2024	
Table saw accident	2021	2022	
Trauma	2021	2022	2023
Explosion	2022	2023	2023
Hunting accident using crossbow	2022	2023	
Covid	2022	2023	
Workplace accident	2023	2023	
Traumatic	2024	2024	

When asked about current employment status, 70% (n=12) of participants stated they were employed at the time of taking the survey, and the remaining 30% (n=5) were not employed. The range of occupations held by the employed participants varied, including but not limited to manual labour work and office-style occupations. The majority of participants said that their hand function is, or has been, a barrier to employment in their chosen occupation (Figure 36).



**FIGURE 36 - PIE CHART SHOWING THE MAJORITY OF PARTICIPANTS FEEL THAT HAND FUNCTION IS A BARRIER TO EMPLOYMENT IN CHOSEN OCCUPATIONS**

Five participants noted being employed in the same occupation at the time of the survey as their occupation at the time of amputation (Table 20). Five participants stated that they were not in employment at the time of completing the survey. Three of these individuals reported that their hand function is, or has been, a barrier to employment in their chosen career. Reasons why participants' hand function is, or has been, a barrier include limited use of hand, slower work, difficulty, and inability to perform certain tasks. Reasons why some participants said hand function is not a

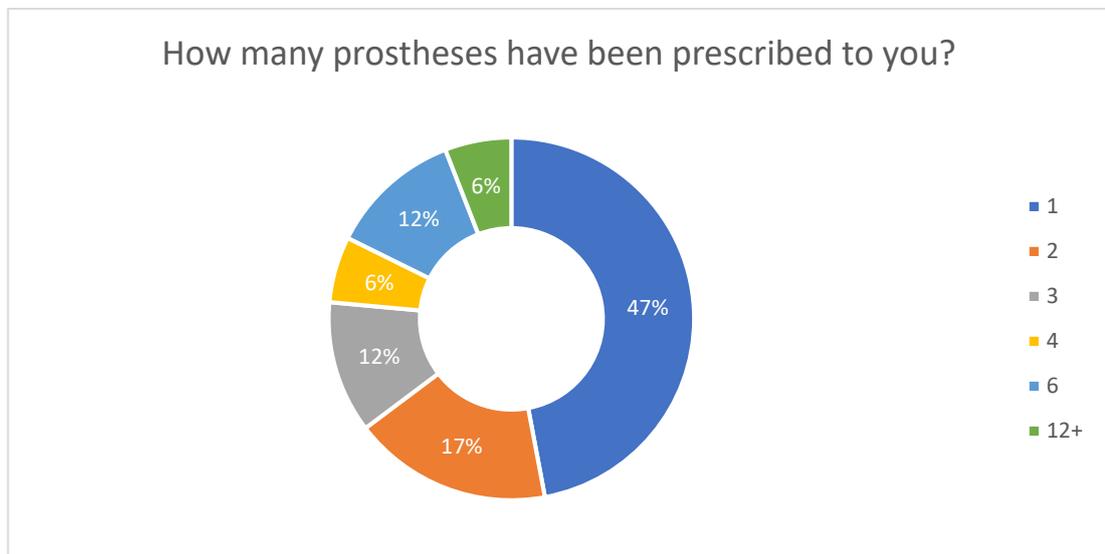
barrier to employment included the role not coming with physical demands, being able to do what they did before, and support for limb difference.

**TABLE 20 - PARTICIPANTS EMPLOYMENT STATUS, HISTORY AND OPINIONS ON HAND FUNCTION IMPACT ON EMPLOYMENT**

<b>Employed</b>	<b>Current occupation</b>	<b>Occupation at time of amputation (if applicable)</b>	<b>Is/has hand function (been) a barrier to employment in chosen occupation?</b>	<b>If yes, why?</b>	<b>If no, why?</b>
Yes	Retailer	N/A	Yes	"It prevents me from doing my primary duties in my desired field"	
Yes	Machinist	Machinist	Yes	"Limited use and feeling"	
Yes	Business development manager	Technician	Yes	"It is hard to do the day to day task that would be required of me"	
Yes	Teacher	N/A	No		"I could do what I had to do"
Yes	Vice President	Student	No		"Our work is in the entertainment industry. It's not dependent on technical hand movements"
Yes	Senior Project Analyst	Warehouse Technician	Unsure		
Yes	Public relations and communications	College student full time, working in sawmill part time.	No		"the physicality of my work is not that extreme. The largest inconvenience for me is typing, but after all these years I capably type with just my thumb on my left hand, and my full right hand."
Yes	Artist	Artist	Yes	"I work much slower, and am more reticent to do intellectual hand work"	
Yes	Waterjet operator/ entrepreneur	Pipe fitter	Yes	"Can't hold steady to pass weld test"	
Yes	Farmer	Farmer	Yes	"Current hand function makes almost all require tasks more difficult to accomplish"	
Yes	Brewmaster	Brewmaster	No		<i>*no response provided</i>
Yes	Waitress	Waitress	Yes	"Difficult carrying/serving food to customers"	
No	N/A	Elevator mechanic	Yes	"Need all ten fingers"	
No	N/A	Admin	Yes	"It would be difficult to use a computer"	

No	N/A	Machinist	No	"Do almost everything I did before. Just differently"
No	N/A	Veterinarian	Yes	"well, duh. besides the obvious I am at much great danger for infection in the repaired hand and scratches and bites happen"
No	N/A	Juice and smoothie bar worker	No	"I work in childcare now, where differences are celebrated"

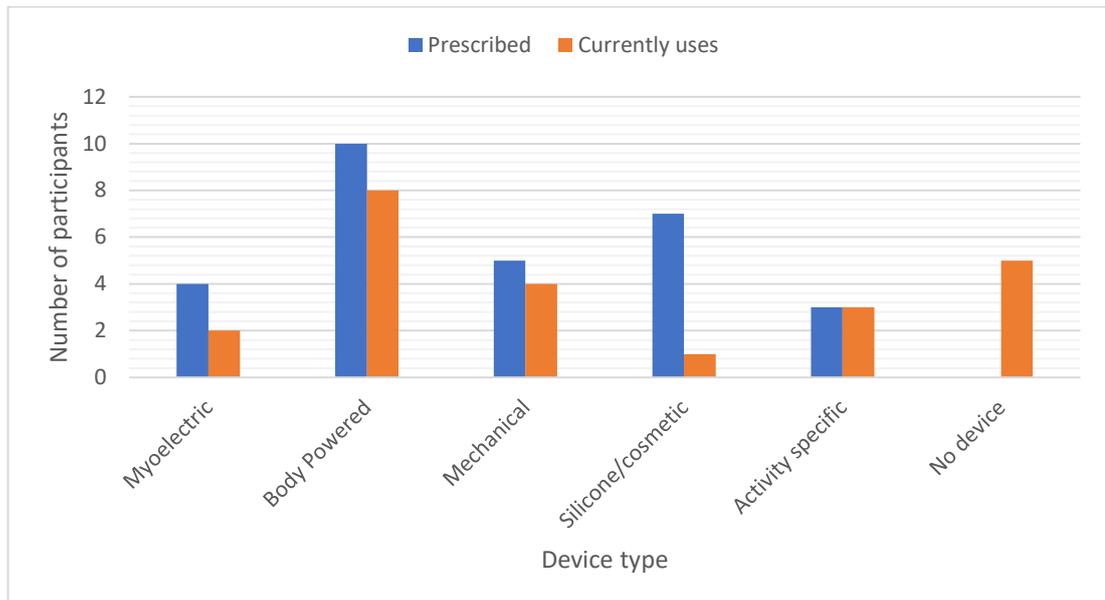
The number of prosthetic devices prescribed to participants varied (Figure 37). The number of prostheses is shown in the legend on the right side of the chart. The percentage of participants who have been prescribed each number of prostheses is shown in the chart as a percentage of total participants.



**FIGURE 37 - PIE CHART SHOWING THAT THE MAJORITY OF PARTICIPANTS HAVE BEEN ASSIGNED ONE PROSTHESIS AND PERCENTAGE OF PARTICIPANTS WHO HAVE BEEN PRESCRIBED MULTIPLE, UP TO 12+**

The majority (n=8) of participants had been prescribed only one prosthesis. One participant, however, had been prescribed over 12 prostheses at the time of the survey. Participants were provided with a list of device types described as follows: Myoelectric (driven by signals from residual limb to the device), Body-powered (driven by residual function), Mechanical (e.g. a ratcheting device which can be manipulated by an opposing limb or a surface), Silicone/cosmetic (appearance like skin, some with nails and hair), Activity specific (designed for a specific activity e.g. a swimming prosthesis). Participants were given an option labelled 'Other' where they could specify in text, but none took this option. Participants were asked which devices

from the list they had been prescribed, then were asked which they currently used and given the option of 'No device' for this question (Figure 38).



**FIGURE 38 - GRAPH SHOWING HOW MANY PARTICIPANTS HAVE BEEN PRESCRIBED, AND CURRENTLY USE, EACH DEVICE TYPE LISTED**

One of the participants who selected 'No device' also indicated currently using body-powered, mechanical, and activity-specific. Therefore, this participant appears to choose not to use a device at times, and the selection of 'No device' does not necessarily indicate abandonment of prostheses. The participants who selected 'No device' and indicated they do not currently use a prosthesis were previously prescribed body powered (n=2), silicone/cosmetic (n=2), and mechanical (n=1). Three of these participants were not given any physical information packs (e.g., leaflets). General comments and suggestions from the participants who no longer use a prosthesis included:

*“more help dealing with insurance”*

*“very unrealistic to wear and not practical [to] have eight partial amputations”*

*“it needs to be more individualised”*

*“Give some options. I was not given any choice or information. Very little questioning of my daily activities to make sure my device was specifically appropriate for me as an individual.”*

In total, five participants were given physical information packs at the time of prosthesis prescription and provided the following descriptions of what this contained:

*“how to care for prosthesis”*

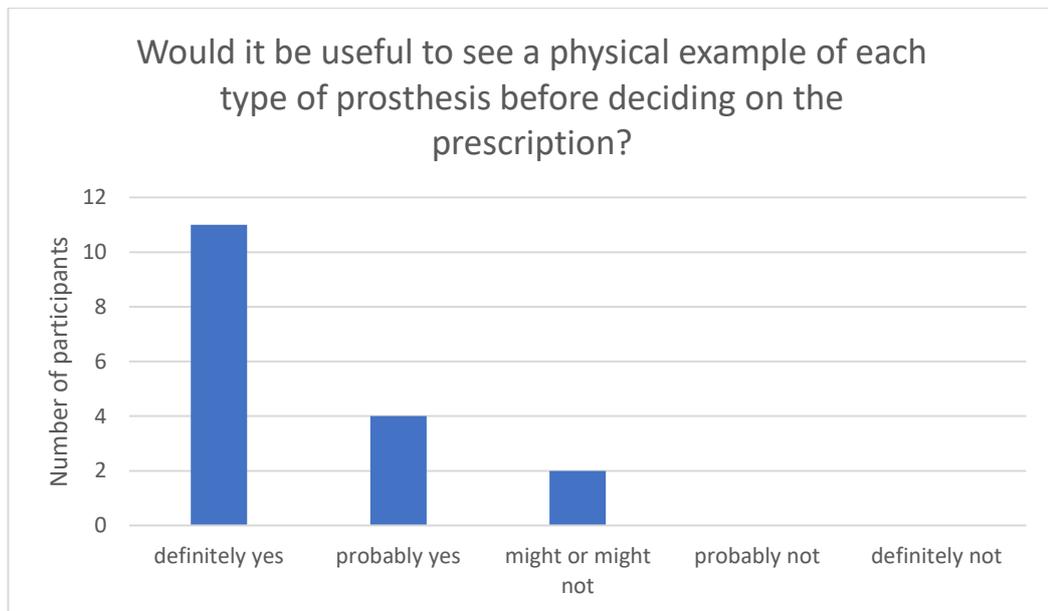
*“about how it can change your life”*

*“I was given information booklets”*

*“Don’t remember. But seem to remember there was printed matter.”*

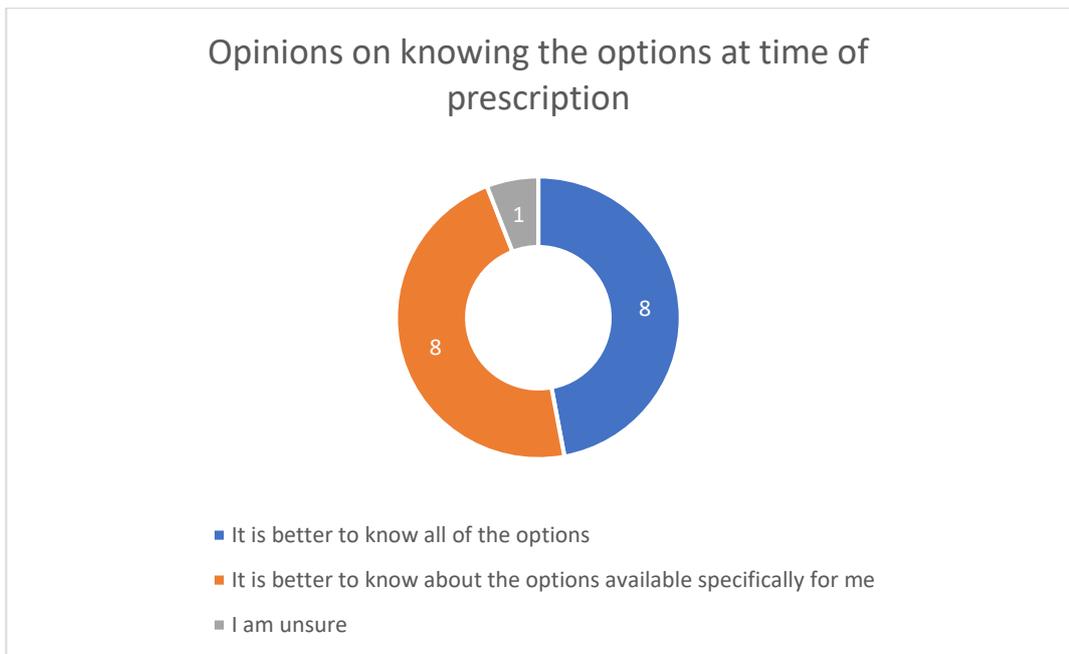
*“It was just for basic upkeep and if I needed any modifications, to bring the device to the clinic”.*

The majority (n=13) of participants were shown a physical example of the prosthesis before their measurements were taken. One participant could not remember, and the remainder (n=3) were not shown a physical example. All participants were asked about the usefulness of seeing physical examples at time of prescription (Figure 39).



**FIGURE 39 - GRAPH SHOWING PARTICIPANTS AGREE, OR ARE UNSURE, WHETHER A PHYSICAL EXAMPLE WOULD BE USEFUL**

Participants were asked to think about when they were prescribed their prosthesis and if they would have liked to know about all the different prosthetic options available for partial hand limb difference, or just about the options available to them. Opinions on this question were conflicting, as shown in Figure 40.



**FIGURE 40 - GRAPH SHOWING PARTICIPANTS WERE DIVIDED IN OPINION REGARDING KNOWING THE OPTIONS AT TIME OF PRESCRIPTION**

#### 6.4.2 Study 4B

Five participants took part in an individual interview lasting approximately 1 hour.

Participant characteristics are summarised in Table 21.

**TABLE 21 - STUDY 4B PARTICIPANT CHARACTERISTICS AND INFORMATION**

Pseudonym	Joe	Tom	Sam	David	Sue
Age range	45-54	55-64	35-44	35-44	45-54
Gender	Male	Male	Male	Male	Female
Country	USA	USA	Canada	USA	Belgium
Reason for limb difference	Amputation (table saw accident)	Amputation (traumatic accident)	Amputation (workplace traumatic accident)	Amputation (workplace accident)	Congenital
Year of amputation	2021	2016	1999	2020	N/A
Presentation (as described by participant)	Absent thumb and ring finger	Absent 2, 3, 4 digits at MCP – right dominant hand	Absent half index, 4/5 middle, ring and baby above MCP/Phalangeal joints – left hand	Absent tip to first joint, right index finger	No fingers, one hand
Employment status	Employed	Employed	Employed	Employed	Employed
Is limb difference a barrier to employment?	N/A – same occupation	Definitely yes	No	Yes	No
Number of prostheses prescribed	1	6	6	1	12+
First prosthesis	2022	2017	2000	N/A	1991
Most recently prescribed prosthesis	N/A	2024	2021	2024	2023
Type of device	Body powered	Myoelectric and mechanical	Body powered, silicon, activity specific	Mechanical	Myoelectric and silicone
Given information packs	Yes	No	No	No	No
Shown physical example	Yes	No	Yes	Do not remember	No
Was physical example useful?	Definitely yes	N/A	Definitely yes	N/A	N/A

Four themes and associated subthemes were generated and summarised in Table 22.

TABLE 22 - THEMES AND SUBTHEMES

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Themes and subthemes
Theme 1. Ongoing journey with limb difference
<i>Subthemes:</i>
(1.1) Recovery
(1.2) Training to use a partial hand prosthesis
(1.3) Adaptation
(1.4) Adjustment
Theme 2. Acknowledging the situation of limb difference
<i>Subthemes:</i>
(2.1) Emotions
(2.2) What matters most
(2.3) Goal setting
Theme 3: Understanding limitations of partial hand
<i>Subthemes:</i>
(3.1) Physical limitations
(3.2) Periods of non-use
(3.3) Using multiple devices
Theme 4: Learning and advocating
<i>Subthemes:</i>
(4.1) Research
(4.2) Outreach
(4.3) Self-advocacy

#### 6.4.2.1 Theme 1 – Ongoing journey

Participants described the journey they had been on since amputation, or through childhood in Sue's case having congenital limb difference, and described different phases they had encountered.

*“it took me like four tries or five tries till we finally got one that fit. So that was a little bit of a of a mess there.” - David*

##### 6.4.2.1.1 Subtheme 1.1 - Recovery

Participants who had amputations talked about recovering from their injury. They highlighted that recovery is a process and their hand changed over time before settling into a final shape. Level of trauma, pain, sensitivity, and scar tissue may all be factors that impact recovery time, which, in turn, impacts time taken for prescription. This is important in prescription to set expectations and help patients understand that prosthesis acquisition may not be immediate due to injury recovery.

*‘you might not want to get a prosthetic done right away...because your hand is so sensitive it might be painful, and also your hand might not look like that six months from now.’ – Sam*

In addition, the timing of prosthesis prescription within an individual's journey of recovery can influence decisions. For example, Joe considered his residual function before selecting a hand.

*‘my hand was still wrapped at bandages, and so on, and I wanted the chance to see what kind of function the paw had before I chose a hand.’ – Joe*

#### 6.4.2.1.2 Subtheme 1.2 - Training to use a partial hand prosthesis

The importance of training to use a partial hand prosthesis was noted by participants.

From discussions with clinicians, Joe's view was that people who have practical jobs such as carpenters or plumbers are suited to training to use devices or tools:

*'they say, like, tell me what I need to do, and then they do it versus people who don't, you know, hold up their injury and say 'fix it'.'* – **Joe**

Training is something to be invested in, rather than a healing process. Participants felt it would be beneficial for new prosthesis users to be educated on what is required from them throughout their rehabilitation journey ahead, and to be inducted in a training plan before trying to use a prosthesis. A training plan could look like physical exercises or a selection of tasks to complete using a device over a period of time. This process could be staged, for example, encouraging users to use their device more over each set time period. It was voiced that this would help manage expectations and support new users in effectively using their device, potentially reducing the risk of abandonment in the longer term. Sue described her experience of training with a prosthesis as someone with congenital limb difference. She discussed being trained on myoelectric control by someone who did not have limb difference.

*So if people tell me you have to do like this [clicks fingers] with your left hand for co contraction, I don't understand, because I have never given the signal on the left side, so I don't remember. I don't know what I have to do.* – **Sue**

This experience could be frustrating and result in users abandoning their device or falsely believing they are unable to use such a device. Following this, Sue spoke with a myoelectric prosthesis user who explained differently, and Sue was able to produce

the signals required. Incorporating lived experience into training for prosthesis use could be beneficial in producing successful outcomes.

#### 6.4.2.1.3 Subtheme 1.3 - Adaptation

For congenital users, it is important to consider adjustments to prosthesis control and performing functions which the individual may not have used on their affected side. Sue noted that in some cases it is preferential for her to continue with how she conducts tasks like typing with a myoelectric prosthesis rather than adapting to using a prosthesis for the task:

*‘So, for example, something like typing, for me, 20 years of adapting to just using my thumb is more advantageous than bothering to try and wear this while I type like that. That’s a complete retraining of what my brain has been doing for the last two decades.’ – Sue*

As well as adapting to prosthesis use, participants discussed making additional adaptations, such as using supplementary tools or modifying existing equipment, to enable participation in society. Joe noted that he sought adaptations for his house and car, as well as gym equipment.

*‘You have the prosthetic, but then you also have, like adaptation, like you know, things that you do around the house like when I first started working out, I was afraid I wouldn’t be able to grip a dumbbell. So I bought, like, you know, lifting straps and other stuff and messed around with that.’ – Joe*

Such adaptations are not necessarily off-the-shelf products, and their need may be learned throughout the journey.

#### 6.4.2.1.4 Subtheme 1.4 - Adjustment

Participants discussed how the journey of adjustment is not an overnight process. The hand can change during the period of recovery, therefore a prosthesis may not be prescribed and fitted immediately after amputation. Participants noted adjusting to their new presentation. Joe described adjusting to having no thumb:

*'So I went from reaching for things as if I had a thumb to, by the time I got the prosthetic, (because it took nine months by the time I got the prosthetic), that when I had the prosthetic on, I was reaching for things as if I didn't have a thumb' – Joe*

For new prosthesis users, it may be useful to explain that their function, anatomy and proprioception could change during the time in between amputation and receiving a device. Navigating adjustment can mean becoming familiar with wearing and donning the prosthetic device. By not persevering and getting used to wearing a device, as Sam quoted below, could lead to abandonment or non-use.

*'at the beginning it was very heavy...I had to get used to it.'* – Sam

An understanding of what prosthesis use can feel like could be useful in helping the user to prepare for their prescription. In addition, guidance on how to get used to it and how long that process can take could assist a user in preparing for using a device. Some people may have never worn a prosthesis, and it could be hard to imagine what one would feel like until it is in use.

#### 6.4.2.2 Theme 2 – Acknowledging the situation of limb difference

Participants discussed their journey in a way that was individual, personal, and driven by experience. Acknowledging the situation that they were in, the participants

discussed prescriptions from their own lens, with some experiences being different from others.

*“I think I probably had a more consistent journey than a lot of other people have. That's for sure.” - Sam*

#### 6.4.2.2.1 Subtheme 2.1 – Emotions

Both positive and negative emotions can arise from partial hand amputation and congenital limb difference. Participants recognised the emotional aspects of their journey. Sue shared how she felt about giving back the loaner hand she received at the beginning of her myoelectric prosthesis journey.

*“they called me and they said ‘You have to give the hand back because some other person in Germany (I think) wants to test it.’ And I cried. I said, ‘Oh, I don't want to give my hand back, I want to keep it’. And then I knew I have to buy it.” - Sue*

Sue recognised the device as something she felt she needed and cried tears when returning it. For David, returning to his workplace and seeing the specific machine in which his trauma took place sparked a range of emotions including anger:

*“I was taking pictures to show them and I saw bits of my finger in there so I grab my favourite hammer and went to work on it - smashed it up, and they fired me.” - David*

In terms of revision surgery, Tom reflected on his experience and noted the difference between surgeries as he viewed the process differently:

*“The 1st one was very emotional because at that time I was given up a part of my body that I sat and thought about for a couple of weeks before the surgery. The second one was not emotional, because I knew what I was gaining.” –*

**Tom**

Being a prosthesis user may also come with feelings of attachment, and fear of losing their prosthesis or having it taken away from them.

*“I’m just scared to death always of losing it.” – David*

Each participant discussed emotions from their lens, specific to their situation. The emotional aspect of prescription should not be overlooked. Some aspects of prescription could trigger negative emotions, and individuals may experience evolving emotions depending on their situation. Whether it be negative emotions that arise during discussing future revision surgeries, distress when seeing their limb difference, or positive emotions when fitted with a device they are satisfied with, or regaining functional ability which allows them to participate in society or activity.

#### 6.4.2.2.2 Subtheme 2.2 – What matters most

It was evident from conversations that what matters to one person going through the prescription process may vary from others in a similar situation. Joe described that he did not want to disguise his injury.

*“I knew for myself that I didn't want to disguise it, and I also didn't want something useless on my hand.” - Joe*

On the contrary, in Sue’s case, she initially didn’t want her prosthesis to be visible and attract attention.

*“I thought, everyone is going to see... and I didn't want it” – Sue*

However, for Joe, using a visible prosthesis was important to him because he felt that it attracted less attention to his injury:

*“I see it as a hand, and that's very important to me. Because of the way it moves, very few people recognise the fact that there's something missing.” –*

**Joe**

At the point of discussing prosthesis options, both Sue and Joe took ownership in what mattered to them at the time. Each of them considered the views of other people and how they view them as a prosthesis user. Some people may wish to conceal their visible limb difference, and others may wish to have function that subsequently conceals the absence of function due to limb difference. They acknowledged this and used this to drive what they were looking for in a prosthesis. In addition, acknowledging help and support to carry out activities that are important was also raised.

*“it's very humbling because I had to ask for a lot more help at times. And you know it, within our world, and we're gonna get honest there, try wiping your behind with a fist, it just doesn't work, you know” – Tom*

It would be advantageous to provide guidance on how to seek support at times when the individual is unable to perform activities due to limb difference or recovery. Some individuals may recognise the difficulties that could lie ahead, and for other activities, such difficulties may not arise until it comes the time to carry them out. Prosthesis users should be supported even after the point of prescription.

#### 6.4.2.2.3 Subtheme 2.3 – Goal setting

Setting goals is beneficial in multiple ways. For example, the individual with limb difference can look to the future and reverse engineer their device selection based on activities they wish to pursue. For the professional prescribing the device, goal setting can aid in selecting what is most appropriate for the individual to be satisfied with their prosthesis. Additionally, in the longer term, goal setting can be used to help measure progress with training and adaptation. If the individual achieves their goals with their prosthesis, it could be seen as a successful outcome. In terms of goals, it is critical to consider aspects of activities of daily living such as materials, weight and configuration. This can vary between individuals.

*“I found it very helpful to take my time before I went into the clinic, and to really think about what I do all day, and what I need.” – Joe*

In Joe’s case, he took time prior to the prescription to think about his needs and goals. This may not be the case for all individuals entering a prosthesis prescription facility, and professionals could facilitate discussions to encourage such people to consider what matters most to them.

#### 6.4.2.3 Theme 3: Understanding limitations

Participants noted understanding both their own physical limitations as well as limitations that exist within partial hand prosthetic devices.

##### 6.4.2.3.1 Subtheme 3.1 – Physical limitations

Participants recognised the physical limitations that can exist as an individual with partial hand limb difference. Overuse injuries can occur if individuals perform tasks

with their unaffected side or certain movement patterns. Tom shared his experience with injuring his unaffected side due to overcompensation which led him to become cautious of overuse injury:

*“Another part of that education is not pushing through learning your limitations because you gotta protect what's left as much as possible.” - Tom*

Additionally, participants discussed the physical limitations they experience due to their limb difference. Device limitations were also noted by participants.

*“This thing is, gonna get you let's say, 80% of the way or 90% of the way. Like there is that, like 10 or 20% that it's not going to do and that's fine. You just don't wear it for those things.” - Joe*

Understanding that prostheses have limitations may aid in setting realistic expectations. Some people may not be aware of this before they receive their prosthesis, which could lead to dissatisfaction and/or abandonment.

#### 6.4.2.3.2 Subtheme 3.2 – Periods of non-use

As highlighted by Joe in subtheme 3.1, there are situations where a prosthesis may not be worn. Therefore, not all prosthesis users are constant device wearers; devices are not necessarily worn 24 hours, seven days a week. For some, there are periods of non-use for reasons such as comfort, and the prosthesis not aiding their ability.

*“It's okay to not use a prosthetic at times” - Tom*

For participants, there are activities in which using a prosthesis can hinder function, and it may be easier to perform the task without their prosthesis.

*“putting sun cream or something on, it's more easy without the prosthesis” –*

**Sue**

Not only for the user, but this may be important for insurers to note, as wear time is not necessarily a measure of how useful and necessary the prosthesis is. In addition, when performing outcome measurement assessments, clinicians should note that the individual may prefer to perform tasks without their prosthesis and should discuss how they carry out such tasks outside the clinic.

#### 6.4.2.3.3 Subtheme 3.3 – Using multiple devices

Use of multiple devices to meet needs was apparent from participants sharing their experiences and opinions. Multiple devices can be used for different tasks or situations, and this was likened to having multiple pairs of shoes:

*“Don't tell me just one pair of shoes is good for everything. It is not. So they got to be accepting that you need multiple and stuff” – Tom*

As well as using multiple devices, some people may use activity specific devices, such as for sport.

*“I have a cosmetic hand. I use some strapping systems for weights. And then I've got yeah, just other hands for canoe, kayak, and rowing otherwise. And then, of course, the Naked Prosthetic device... I use that one for fine detail work” – Sam*

Different types of device can offer unique benefits. Individuals shouldn't be categorised by device types, such as a 'silicone passive prosthesis user'. People with partial hand limb difference can benefit from a device that they may only wear for a

short period of time, for a specific task. In addition, the ability to participate in or return to activities such as sports could lead to subsequent improved quality of life, and in turn positively impact adaptation and mental wellbeing.

#### 6.4.2.4 Theme 4 – Learning and advocating

It was apparent across the interviews that each individual has gone through a process of learning and some are passionate about sharing their knowledge and experiences with others with partial hand limb difference.

##### 6.4.2.4.1 Subtheme 4.1 – Research

The internet is a valuable source of information for people with partial hand limb difference. For specific tasks, prosthesis users may seek videos of someone with similar presentation performing the task so they can learn from them.

*“So I, for instance, I'm knitting, and crocheting, I do that and sometimes I look for a movie from how do they do that? But then I have to adjust it” – Sue*

Nonetheless, such videos come without qualified clinical guidance and the onus is on the user to seek what other people may have voluntarily shared. In addition to seeking information from other prosthesis users about completing tasks, Sam noted searching online to keep up to date about prosthetic devices for his presentation.

*“I'm always casually looking around to just because you know, sometimes I'll just do a Youtube or a Google search to see, you know, partial limb impairment prosthesis.” – Sam*

While the internet is a valuable resource, not every person will be successful in finding answers to questions via these means:

*“we don't know what we don't know, so we just don't know what questions to always ask” – Tom*

As well as not knowing what to search, people could be misinformed by incorrect information available online. Further, information online could contradict advice or prescriptions provided by a clinician. It would be beneficial for the clinician to steer the individual towards what to research, and where, should the individual have further questions or curiosities about their limb difference. Moreover, research can also come in the form of speaking directly to someone with partial hand limb difference.

*“I got to talk to an individual that had a myo hand and could ask him questions and stuff and that was very good and kind of confusing at the same time, in the sense that you, you come in naïve, expecting you're gonna have this cool thing replace your fingers and it's just gonna work perfectly, and everything”  
– Tom*

Finding out about what to expect, or seeking advice, directly from a prosthesis user can be advantageous particularly for someone who has undergone amputation. Speaking to someone who has undergone a similar journey could help one to relate and buy in to advice.

#### 6.4.2.4.2 Subtheme 4.2 – Outreach

Participants use social media platforms to share their experiences, knowledge and support with the partial hand limb difference community. The impact of social media

is global and there is a clear interest in and space for educational, informative content about a prosthesis users' experience.

*“When I first got this prosthetic, I did a full video about that, and I got, I don't know thousands of likes, couple of 100 comments from all over the world, too.” - Sam*

In addition to benefitting the community, social media advocacy can be constructive for the content creator. For Sam, sharing his lived experiences with others on an online support group brings positive emotions:

*“with a quarter century (almost) experience being a partial hand amputee I can lend a voice of experience to that type of environment as well, which is nice.” – Sam*

Professionals may ask individuals with partial hand limb difference to speak directly to others with similar presentations to educate them about prosthetic options.

*“they ask me different times to go with them to an amputee center and to talk to people to show them what exists.” – Sue*

As well as sharing experiences and knowledge of devices, some requests can be more specific, such as Tom's example of advocating for other people with partial hand limb difference by providing recommendations on who to see to acquire a prosthesis:

*“I, try and steer them to the better locations for a better chance up front” – Tom*

#### 6.4.2.4.3 Subtheme 4.3 – Self advocacy

As well as advocating for the partial hand limb difference community, participants also shared their experiences with advocating for themselves.

*“no one ever came to me and said ‘Hey, Sue, there’s something new on the market. Maybe it’s fits you’. No, I had to figure out myself.” – Sue*

Not all people with limb difference will seek out treatments or solutions for themselves, which means that without adequate support and information, some people may not acquire a prosthetic device which could improve their function and quality of life. This is highlighted by Sam:

*“I needed to do more advocacy for myself, to make sure that I would end up with something that’s comfortable.” – Sam*

As well as prosthesis prescription, self-advocacy was noted in terms of surgery and care.

*“8 years of going through all of this my advocacy is towards the least number of surgeries as possible at anything because learning the scar tissue, and we don’t realize how much it affects us.” – Tom*

Advocating for oneself is often required for prescription of appropriate devices and treatment. Eliminating the need for such advocacy through educating professionals and providing informative decision support materials may improve the process and outcomes for the end user.

#### 6.4.2.5 Feedback on decision aid:

In addition to sharing experiences, thoughts and opinions on the prescription process and life as a prosthesis user, participants also shared feedback on the draft decision

aid. General feedback on the concept of the decision aid was positive overall, and constructive feedback provided by participants around format, content and language. Participants commended the use of examples, pictures and incorporation of psychosocial aspects within the draft. Considerations, evidence and implications for the decision aid are contained in Table 23.

TABLE 23 - CONSIDERATIONS FOR DECISION AID INCLUDING EVIDENCE FROM STUDY 4B

Considerations	Evidence	Implications for decision aid
<b>Colour selection</b>	<p>“I'd say it's a little off. But with the, you know, 'cause you got the red and the greens.” – David</p> <p>“I thought, if you use colors, green, yellow, and red, then you don't need the letters.”- Sue</p>	<ul style="list-style-type: none"> <li>- Change colours to represent message</li> <li>- Simplify presentation of information</li> </ul>
<b>Language</b>	<p>“Part of life like appearance, is movement. And so, while something doesn't look like a hand, or an arm or a leg, if it moves like one, it disappears.” – Joe</p> <p>“Okay, cause in terms of a material base like this is my canoe [holds up sports device] there's a lot of silicon in there as well.”– Sam</p> <p>“so the silicon passive is that the, the touch like for using like a touch screen? Is that what that means, or?” – David</p> <p>“Guess maybe a, maybe dumbing down any of the words. Some of some of the stuff like, this sounds stupid, but I I don't know what congenital means.” - David</p>	<ul style="list-style-type: none"> <li>- Use lay person language</li> <li>- Remove 'life like appearance'</li> <li>- Consider descriptions of different device types</li> </ul>

<b>Device wear times</b>	<p>“cutting food, dressing, washing. These are like these are REALLY important things to think about. Really, you know, washing your body like... I don't take this thing in the bath.” - Joe</p> <p>“you can let people know like, ‘Hey, this is...you know, you're not sewing this thing to your body. You can use it as much as you want, you know, and in the circumstances that you want it.” - Joe</p>	<ul style="list-style-type: none"> <li>- Inform readers that they don't need to use their prosthesis constantly</li> </ul>
<b>Educate on limitations</b>	<p>“think there are things that they provide and there are gaps, you know, you can think about that 20% of like, yeah, it's not really gonna do it. And that 3% of like, it's really gonna interfere” - Joe</p>	<ul style="list-style-type: none"> <li>- Inform readers that a device will not replicate the hand</li> </ul>
<b>Choose language that is recognised</b>	<p>“That's, yeah...when you got the your, your silicone/passive category. I'm just gonna hold up an example [holds up cosmetic device] Is this what you're referring to.”- Sam</p>	<ul style="list-style-type: none"> <li>- Review text and language to ensure no jargon is used and can be read by the lay person</li> </ul>
<b>Open-ended and inclusive questions</b>	<p>“maybe, rather than asking, you know - do you lift heavy objects or what not? - ask more tasks specific type questions, because what I feel is heavy and what you feel is heavy is two different relationships and so that could change a little bit” - Tom</p>	<ul style="list-style-type: none"> <li>- Ask task-specific questions</li> </ul>
<b>Inclusion of pictures</b>	<p>“But for me it would be important that they are pictures.” - Sue</p>	<ul style="list-style-type: none"> <li>- Use images as aids</li> </ul>

<b>Manufacturer-specific</b>	“the clinic where I was, they are connected with BeBionic, so they wouldn't be happy if you only have Ossur and not BeBionic” - Sue	- Make the decision aid non-biased in terms of manufacturers
<b>Links to digital/online resources</b>	“the one thing I would suggest is links to like Youtube videos or something of that sort” – Tom  “if you have a printed version, you can add a QR code.” - Sue	- Provide links to external resources
<b>Explain stakeholders and occupations</b>	“maybe a quick little description of like, what what a hand therapist would do/does.” – David  “my occupational therapist had a lot of good advice about what a prosthetic might look like for me through the hand therapy process, so that might be someone else that may or may not be part of someone's team and would be useful to introduce as well.” - Sam	- Introduce different occupations – consider that these roles may be described differently across the globe
<b>Interactive elements</b>	“Space for people fill in their own ideas. I think that's great.” - Sam	- Allow reader to input via checking boxes or writing/typing answers to questions

---

**Break down sections to allow reader to digest**

“I'm pretty cerebral, and I wanted as much information as I get. Other people might not be. [uses hands to demonstrate a flow/decision process] It's like, are you interested in knowing the ways in which your hand may change over the course of time -Yes - click here to read more information about the physiology side of this. If no, okay, here's what you need to know about just getting a prosthetic done.” - Sam

- Use summaries and images to help readers who do not wish to read large paragraphs of text, and vice versa

## 6.5 Discussion

### 6.5.1 Study 4A

Participants who took part in the survey were predominantly from the United States.

This was also seen in the survey study described in Chapter 3 with clinicians. This could be an indicator that there are more people in the United States who use partial hand prostheses. Another reason may be the advertising methods used for the studies which may have reached audiences in this region through word of mouth or social media.

Most of the participants had partial hand amputation. Little is known about how individuals with congenital limb difference are referred to clinics for prostheses. Individuals with congenital limb difference, for example Sue who took part in the interview study, may approach a clinic with some knowledge about prostheses due to their own research. People who have undergone amputations may be provided information by their medical team, and may be referred directly to a clinic. There may be differences in existing knowledge and expectations between people with congenital limb difference and amputation as a result.

Workplace accidents made up the majority of reasons for amputation. Workplace accidents may have resulted in insurance pay outs which could allow individuals to receive funding for their prosthesis, which in turn increase the likelihood of using prostheses. However, participants were not asked about how their device was funded. Time between year of amputation and year of first prosthesis prescription varied. Some participants received their first prosthesis the same year as their amputation, and others did not receive a prosthesis prescription for up to 22 years.

The majority indicated a gap of around one year between amputation and first prescription. Quantifying the average wait between amputation and prosthesis prescription may aid in setting timeline expectations.

Most participants said that their hand function is, or has been, a barrier to employment in their chosen occupation. Three of these participants noted not being employed at the time of taking the survey. Only five participants responded that they were employed in the same occupation as time of amputation. It could be said that hand function can limit the types of work people can do due to difficulty in performing specific functional tasks and slow work. One participant also noted risk of infection being a factor due to the nature of their previous work as a veterinarian. However, the principle of hand function limiting work cannot be generalised for all types of work as some participants noted that their roles were not highly physical and some participants claimed they could perform as they did before their amputation. This was also supported by the participants who worked in the same occupation as time of amputation. These occupations included machinist, artist, brewmaster and farmer. These roles all require physical function and a level of dexterity. Prosthesis use or adaptation for these individuals may or may not have contributed to their ability to perform the same work-related tasks. Some participants also noted being employed at the time of the survey, but not employed at time of amputation. Reasons for this could include unemployment due to being unwell or injured. Additionally, individuals may have undergone a career change following amputation. Some participants used multiple prostheses up to and including over 12 devices. The majority used only one. It is unknown whether participants who use one device did

so through choice and having a preferred device, or if they only had access to one prescribed device. Of the devices which were prescribed and no longer used, silicone was the most abandoned device type. Five participants noted that at the time of the interviews they used no device. This may suggest that they chose not to wear their prosthesis at times.

The only device type in which the same number of prescribed and currently used devices were recorded was activity specific. These types of prostheses are prescribed for specific tasks, and therefore may be less likely to be abandoned due to the user requiring them for their goals. Many of the participants used devices at the time of interview. This may be due to the inclusion criteria of the study which allowed current or recent prosthesis users to take part and may not be reflective of the partial hand limb difference population as a whole. Other device types which were no longer being used may not have been fit for purpose, or required to meet an individuals' goals. There is also a possibility that they were ill-prescribed. Participants who no longer used a prosthesis provided varied feedback that suggests reasons for abandonment included funding, prosthesis not meeting their individual needs and ill-prescription.

The majority of participants did not receive a form of physical information pack. Those who did provided feedback which included information about caring for a prosthesis and maintenance. There were no reports of physical information including setting expectations, training or what to expect on their journey as a prosthesis user. None of the participants stated that physical examples probably or definitely would not be useful. The majority were shown physical samples, therefore this opinion on physical examples being useful may be driven by positive experiences for many of the

participants. Participants were conflicted, however, on being aware of partial hand prosthesis options at time of prescription. It is unknown whether it is better for individuals to know all of the options, or their specific options. Therefore, it may be down to the individual and prescribers could offer either option of full or partial information about options at time of prescription.

#### 6.5.2 Study 4B

In the interview study, participants discussed a period of recovery which may be considered in terms of time taken to receive the first prescribed prosthesis. Joe described the period of waiting for a prosthesis as a time of adaptation and that he adapted to not having a thumb, which then leads to another period of adaptation following prosthesis acquisition. The residuum may change in shape and size, and some may wish to see what function they have post-amputation before making a decision about what they require from a prosthesis. As well as this, training with a prosthesis takes time. While individuals may wait to receive their first prosthesis, it would be advantageous to provide a timeline including recovery, training and adaptation to set expectations. Likewise, from a congenital point of view, Sue highlighted in interview that training and adaptation is required for people with congenital limb difference to become familiar with producing muscle signals or movement patterns with their affected side as they may have spent the majority of their life not using that side. This could be considered when creating training plans for individuals who are going to receive their first prosthesis. Setting expectations in terms of a timeline may increase satisfaction and buy-in to the process, which could lead to successful outcomes and reduce prosthesis abandonment.

In the interview study, participants who used multiple devices noted using prostheses for specific tasks. One participant, Tom, likened this to owning multiple pairs of shoes as often people require different functions for different scenarios. Sam discussed different sports prostheses and using a body powered prosthesis for dextrous work. Participants discussed the visibility of their prosthesis and functionality. At first, Sue didn't want a device that everyone would 'see' whereas Joe noted the importance of functionality in appearance. Some people may wish to conceal or disguise their limb difference, but move towards other functional goals as time progresses. They may adjust and adapt to their limb difference and no longer prioritise cosmetic appearance over functionality, which could result in abandonment of silicone prostheses. Additionally, a silicone prosthesis may be prescribed at the beginning of the prosthetic journey before the individual learns to control a different type of device, which may go on to be a preferred device.

Owning a prosthesis does not mean that the individual is a constant and consistent prosthesis user. This could be considered when shaping policy and requirements for funding. An individual who uses a prosthesis for one hour a day may receive the same benefits and satisfaction as another person who uses it for 16 hours per day depending on their individual needs and goals.

Expectations are critical in various formats. Expectations about the journey ahead are important. Expectations about how a prosthesis may look or feel can help prepare the individual to adapt once they receive their prosthesis. This may apply not only to

first prosthesis prescription, but any additional prostheses that are prescribed down the line.

The survey questions did not specifically ask about emotions and feelings towards amputation, prescription or prostheses. However, a theme across interviews was acknowledging the situation; encompassing emotions, priorities and setting goals. Participants felt differently about their limb difference, with some wishing to conceal and disguise at the beginning of their prosthesis journey and others actively seeking functional options. This is important for healthcare professionals to consider when discussing prosthetic options. Additionally, professionals should consider that goals can change over time and reviewing goals over time and reassessing the suitability of prescription should be carried out. It is also important to consider emotions particularly in cases where the individual has experienced traumatic injury. One participant was going through a period of anger when he returned to his workplace following injury. Preparing the individual for feelings of anger, grief, loss and sadness, for example, through counselling or other therapies could ease the process of adjustment to life with limb difference. In doing so, the journey towards prosthesis prescription could be more successful if negative emotions are managed.

Learning about prostheses, advantages and limitations was a theme across the interviews. Participants often learned through experience, and some advocate for prosthesis users and people with limb difference through various online platforms. The internet and online communities can serve as a useful resource for people with partial hand limb difference. However, this could be an indication that this population is not provided with useful information and tools at prescription. Nonetheless,

engaging with people who have similar limb difference can be valuable as lived experience can resonate with participants. Similarly, the participants in this study give back in the form of outreach and advocacy for the partial hand limb difference community. Participants recognised this as positive and valuable work which generates engagement. On the other hand, some of the participants had to find information and advocate for themselves, which may influence their desire to help others within the partial hand limb difference community. Advocating for themselves could have led to successful prosthesis prescription and satisfaction with surgical care. There is a possibility that people in this population are unable to advocate for themselves for a variety of reasons, and therefore may be disadvantaged in terms of their treatment and prescription.

#### 6.5.3 Implications for decision aid

Feedback on the decision aid draft from interview participants was positive. The decision aid was well received. Co-creation of the decision aid occurred during each interview as feedback from participants was documented live while showing the document during the interview via a shared screen. Participants contributed to the design and development of the decision aid by inputting their ideas and feedback on aspects including content, structure, terminology and presentation. Retrospective co-creation occurred after analysing transcripts when further changes and additions were made to the document. This formed a period of iteratively co-creating further improved iterations of the decision aid with user involvement.

#### 6.5.4 Limitations

Due to the method of convenience sampling used to recruit Study 4A participants, participation was relatively low. It is unknown who chose not to take part in the study despite being eligible. The researchers did not collect information on where participants had seen the study, for example through social media or referral from someone in their network. In addition, it is unknown who may have clicked on the survey link and started the survey without completing until the end. Reasons for non-completion remain unknown. The sample size may reflect the difficulty in reaching the partial hand limb difference community. While the researchers have built up a network of professionals in the community, end users/patients are not necessarily connected with the researchers on social media. Therefore, it was hoped that word of mouth could illicit more responses. In addition, a leading partial hand prosthesis manufacturer was contacted for support and agreed to send the study information to some of their users who they thought would be interested in taking part. As this manufacturer is based in the United States, this could illicit bias in the demographic of participants. Further, the survey recruitment closed at the time of the interviews closing. This was to allow for a period of data analysis before implementing findings into the next iteration of the decision aid in development. Nonetheless, a longer recruitment period may have allowed for more participants which in turn would provide more data which would add new information or enrich existing information gathered.

Deriving the theme of learning and outreach from the data could have been influenced by the nature of the participants. Participants volunteered their time, and

advertising was conducted online. Therefore, it could be said that the participants are representative of the more active members of the partial hand community who conduct outreach and use online platforms to research and learn. Future work could involve reaching out directly to clinics or support groups to ask for their support in advertising studies for this population. However, time required to gain ethical approval for this sampling method should be considered.

Ten invitations were sent out to participants who indicated interest in taking part in Study 4B. Four did not respond. One participant replied then later withdrew participation. No reason was given for withdrawal, however, the participant previously asked if a gift voucher or compensation would be given. This information was included in the PIS, however, it could be possible that this was not clearly understood.

Due to the semi-structured approach, the participants were not asked exactly the same set of questions, however core questions and topics were included across all interviews. Additionally, only one participant was female (Sue) and was also the only person with congenital limb difference who took part in Study 4B. Therefore, may not be wholly representative of the female or congenital community with partial hand limb difference. Similarly to Study 3, the COREQ checklist could have been used in this study to ensure methods and analysis were clear, transparent and of sound quality.

## 6.6 Conclusion

In conclusion, this Chapter involved prosthesis users to find out about their opinions and experiences as well as co-create further iterations of the decision aid in development. Participants in Study 4A shared information about their experiences and situation, which showed that people have varying outcomes in terms of prescriptions, and opinions on how options should be presented. Some people remain in the same occupation, and others find their limb difference to be a barrier. In Study 4B, five participants discussed their opinions, thoughts and feelings about navigating life as a partial hand prosthesis user. Participants in this study gave feedback on the decision aid, which was positive overall and indicated desire and need for the tool. Findings from this study highlighted the importance of educating people with limb difference about what to expect on their journey through life with limb difference. While outreach and advocacy is positive, and participants are actively involved in such activities, there is space for research-based evidence sharing to allow people with limb difference to take ownership in the decision-making process regarding prosthesis prescription.

## 6.7 Chapter summary

This Chapter described a two-part user involvement study comprising of a screening survey and interviews. Participants shared their experiences with prescription and partial hand limb difference, as well as their opinions on the prescription process. Participants provided feedback on the proposed decision aid, which was generally positive.

## 7 Decision aid for partial hand prosthetic prescription

### 7.1 Introduction

This Chapter presents the final version of the decision aid for partial hand prosthetic prescription (Figure 41). This version was iteratively refined based on insights gained from preceding studies described in this thesis. The decision aid presented in this chapter will be available via the University of Strathclyde thesis repository page. Links to the thesis and a publicly accessible version of the decision aid will be available on the researcher's Pure webpages.

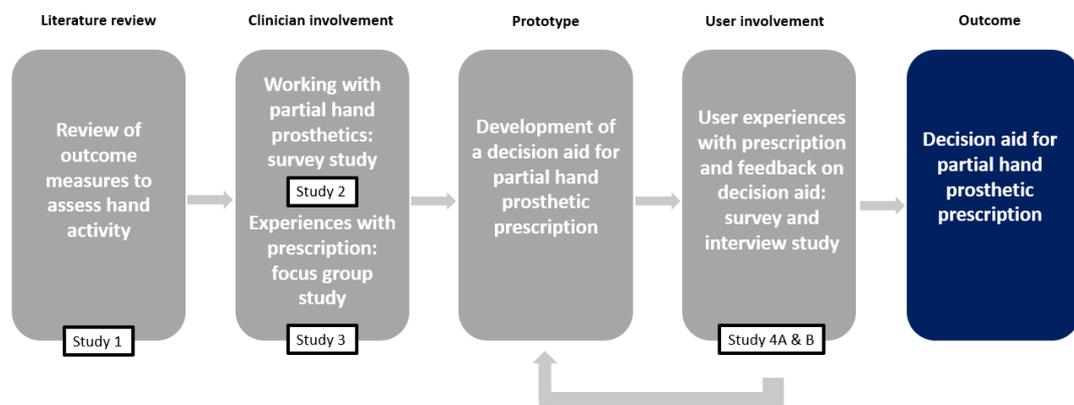


FIGURE 41 – FLOWCHART HIGHLIGHTING WORK DESCRIBED IN CHAPTER 7 IN BLUE

## 7.2 Iterative development of decision aid

The draft decision aid described in Chapter 5 was further developed in an iterative manner. Iterations were made during and/or after each individual interview in Study 4B (Chapter 6) as participants were shown the document during the session. Changes were made to the document live during the interview, amended after the interview, then shown to the next interviewee. This process was repeated for each interviewee.

Table 24 contains sections from the table presented in Chapter 6. This version of the table features an additional column which details the sections which were changed as a result of feedback from the participants in Study 4B. Figure 42 shows a segment of the draft decision aid with comments displayed to demonstrate how instructions for changes were recorded during and after interview sessions.

TABLE 24 - CONSIDERATIONS FOR DECISION AID AS DESCRIBED IN STUDY 4B INCLUDING DECISION AID PAGE REFERENCES FOR IMPLEMENTED CHANGE

Considerations	Evidence	Implications for decision aid	Section
<b>Colour selection</b>	“I'd say it's a little off. But with the, you know, 'cause you got the red and the greens.” – David	- Change colours to represent message	- All
	“I thought, if you use colors, green, yellow, and red, then you don't need the letters.”- Sue	- Simplify presentation of information	- All
<b>Language</b>	“Part of life like appearance, is movement. And so, while something doesn't look like a hand, or an arm or a leg, if it moves like one, it disappears.” – Joe	- Use lay person language	- All
	“Okay, cause in terms of a material base like this is my canoe [holds up sports device] there's a lot of silicon in there as well.”– Sam	- Remove 'life like appearance'	- Page 9
	“so the silicon passive is that the, the touch like for using like a touch screen? Is that what that means, or?” – David	- Consider descriptions of different device types	- Page 9

<b>Device wear times</b>	<p>“cutting food, dressing, washing. These are like these are REALLY important things to think about. Really, you know, washing your body like... I don't take this thing in the bath.”- Joe</p> <p>“you can let people know like, ‘Hey, this is...you know, you're not sewing this thing to your body. You can use it as much as you want, you know, and in the circumstances that you want it.” - Joe</p>	<p>- Inform readers that they don't need to use their prosthesis constantly</p>	- Page 10
<b>Educate on limitations</b>	<p>“think there are things that they provide and there are gaps, you know, you can think about that 20% of like, yeah, it's not really gonna do it. And that 3% of like, it's really gonna interfere” - Joe</p>	<p>- Inform readers that a device will not replicate the hand</p>	- Page 10
<b>Choose language that is recognised</b>	<p>“That's, yeah...when you got the your, your silicone/passive category. I'm just gonna hold up an example [holds up cosmetic device] Is this what you're referring to.”- Sam</p>	<p>- Review text and language to ensure no jargon is used and can be read by the lay person</p>	- All
<b>Open-ended and inclusive questions</b>	<p>“maybe, rather than asking, you know - do you lift heavy objects or what not? - ask more tasks specific type questions, because what I feel is heavy and what you feel is heavy is two different relationships and so that could change a little bit” - Tom</p>	<p>- Ask task-specific questions</p>	- Page 13 & 14

<b>Inclusion of pictures</b>	“But for me it would be important that they are pictures.” - Sue	- Use images as aids	- Page 8
<b>Manufacturer-specific</b>	“the clinic where I was, they are connected with BeBionic, so they wouldn't be happy if you only have Ossur and not BeBionic” - Sue	- Make the decision aid non-biased in terms of manufacturers	- Page 8
<b>Links to digital/online resources</b>	“the one thing I would suggest is links to like Youtube videos or something of that sort” – Tom “if you have a printed version, you can add a QR code.” - Sue	- Provide links to external resources	- Page 17
<b>Explain stakeholders and occupations</b>	“maybe a quick little description of like, what what a hand therapist would do/does.” – David “my occupational therapist had a lot of good advice about what a prosthetic might look like for me through the hand therapy process, so that might be someone else that may or may not be part of someone's team and would be useful to introduce as well.” - Sam	- Introduce different occupations – consider that these roles may be described differently across the globe	- Page 4

<b>Interactive elements</b>	"Space for people fill in their own ideas. I think that's great." - Sam	- Allow reader to input via checking boxes or writing/typing answers to questions	- Pages 12-16
<b>Break down sections to allow reader to digest</b>	"I'm pretty cerebral, and I wanted as much information as I get. Other people might not be. [uses hands to demonstrate a flow/decision process] It's like, are you interested in knowing the ways in which your hand may change over the course of time -Yes - click here to read more information about the physiology side of this. If no, okay, here's what you need to know about just getting a prosthetic done." - Sam	- Use summaries and images to help readers who do not wish to read large paragraphs of text, and vice versa	- Page 4, 9, 11

Section 3 – What matters most to me?

Y - Yes – device might match the requirement very well

M Maybe – device might match the requirement

N - No – device might not match the requirement

Colours only

Requirement	Myoelectri c	Body- powere d	Mechanica l	Activity - specific	Silicone/passiv e	Hybri d
Heavy physical activity		Y	Y	M	N	
Fine motor skills	Y			M	N	
Sports		M		Y		
Hobbies – think of examples						
Kitchen tasks						
Life-like appearance	N	N	N		Y	
Use in water						

1. Goal setting

What you would like to do | difficulty | how important is it to be able to do this

KC

**Kirsty Carlyle**

Add a note that this could change over time

KC

**Kirsty Carlyle**

Add section at the side for people to rank these in an order for their primary device

KC

**Kirsty Carlyle**

Add examples e.g. of heavy physical activity

KC

**Kirsty Carlyle**

Change colours

KC

**Kirsty Carlyle**

Change terminology

KC

**Kirsty Carlyle**

Add a note section – what else matters to you?

KC

**Kirsty Carlyle**

Add a note that you can revise this list to measure progress with training/adaptation

FIGURE 42 - SCREENSHOT OF DECISION AID DRAFT WITH COMMENTS FROM STUDY 4B FINDINGS

### 7.3 Collaborative development

Initial graphics were sketched by the author and realised by a graphic designer; Crunch Design, Southampton. Crunch Design were chosen based on recommendation from a PhD student conducting similar research. EPSRC funding was used to fund the service. Examples of sketches made are contained in Figures 43 to 45. Documents were sent to Crunch Design for formatting and development (Appendix S).

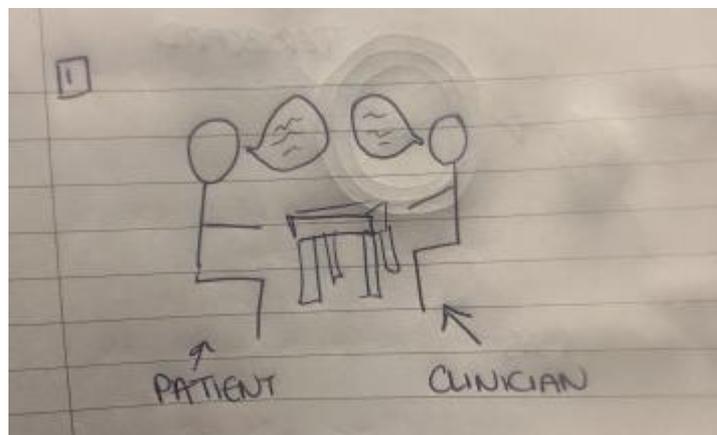


FIGURE 43 - SKETCH OF PATIENT AND CLINICIAN SPEAKING, DRAWN BY AUTHOR AND SENT TO CRUNCH DESIGN

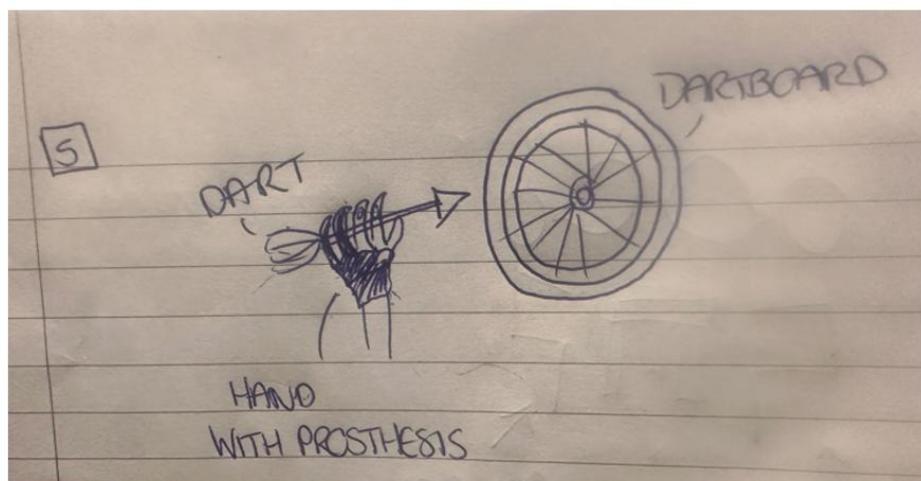


FIGURE 44 - SKETCH OF SOMEONE USING A PARTIAL HAND PROSTHESIS TO THROW A DART, DRAWN BY AUTHOR AND SENT TO CRUNCH DESIGN

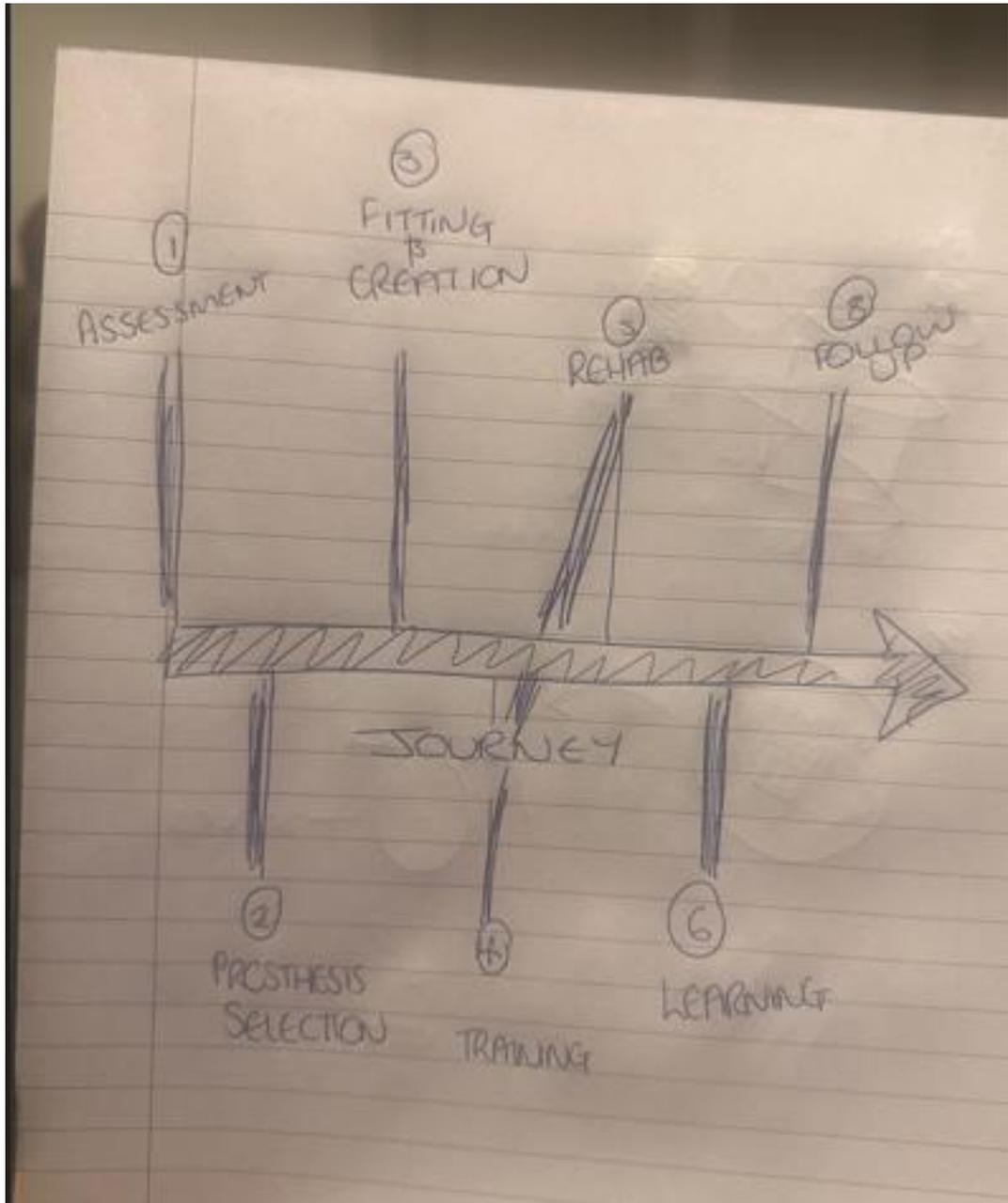


FIGURE 45 - SKETCH OF KEY STAGES IN THE PROSTHESIS PRESCRIPTION JOURNEY, DRAWN BY AUTHOR AND SENT TO CRUNCH DESIGN

Crunch Design translated the documents, including sketches, into a draft decision aid PDF and returned the first draft of the document (Appendix T). On receipt of drafts from Crunch Design, further instructions were sent back to Crunch Design with notes on formatting and updates to graphics or content. Revisions were sent between Crunch Design and the author and iteratively developed through written communication.

Red text was used to communicate instructions and yellow highlighting was used to identify changes to existing text. An example of this is shown in Figure 46. Illustrations were also used alongside sketches to describe the format and design desired for sections within the document. A total of 7 versions of the document were created before the final version agreed (Section 7.4).

**How comfortable are you about making this decision?**

Read the statements below and circle 'Y' if you agree or 'N' if you disagree with the statement.

Please can the 'Y/N' be put in a box to make it stand out? Or, like the example in this image:

### Things to check

I feel sure about the best choice for me	<input type="checkbox"/> Yes   <input type="checkbox"/> No
I know enough about the potential advantages and disadvantages of each option	<input type="checkbox"/> Yes   <input type="checkbox"/> No
I am clear about which potential advantages and disadvantages matter most to me	<input type="checkbox"/> Yes   <input type="checkbox"/> No
I have enough support and advice to make a choice	<input type="checkbox"/> Yes   <input type="checkbox"/> No

I know enough about the advantages and limitations of prostheses Y/N

I am clear about what matters most to me Y/N

I have support and advice to make a decision Y/N

FIGURE 46 - SCREENSHOT OF EXTRACT FROM DOCUMENT SENT TO CRUNCH DESIGN WITH HIGHLIGHTED CHANGES IN YELLOW AND INSTRUCTIONAL NOTES IN RED

## 7.4 Final decision aid

The final decision aid is presented on the following pages. This is an 18-page document split into three sections as indicated on the 'Contents' page (Page 2).

# Partial Hand Limb Difference: A Guide to Making a Decision About Prostheses

## ➤ Introduction to this guide

This guide is here to help you **make decisions about prosthetic options**. It gives you useful information and includes pages you can fill in. You can bring it with you to talk with your doctor or other healthcare professionals.

The goal of this guide is not to tell you what to choose, but to help you understand your options. The purpose of this guide is not supposed to replace talking with your healthcare team.

## This decision aid is for you if...

This guide focuses on **partial hand prosthetics**. It explains what partial hand limb difference is and the different options available. You may be a good fit for some or all of these prosthetic options.



# Contents

**1**

Information about partial hand limb difference and prostheses

Page  
**03**

**2**

Interactive sheets

Page  
**12**

**3**

Further support

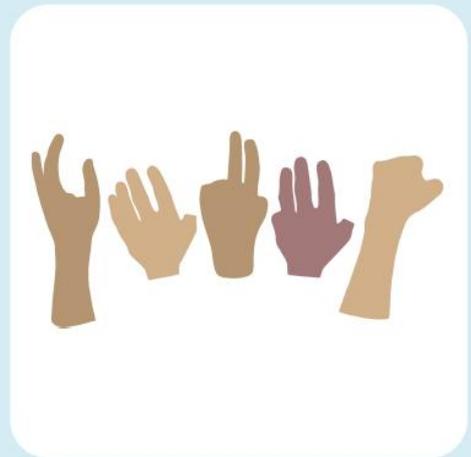
Page  
**16**

### What is partial hand limb difference?

**Partial hand limb difference** means someone only has part of their hand or is missing some or part of their fingers. Therefore, this could include having some fingers, a thumb, or part of the palm. You might also hear this called 'limb absence'.

Partial hand limb difference can be the result of either of the following:

- **Amputation:** This is when part of a limb is surgically removed because of an injury or illness.
- **Congenital difference:** This means a person is born with it. A congenital limb difference happens when a baby is born with a hand that hasn't fully formed, so part of the hand is missing.



### What are prostheses?

**Prostheses** are artificial body parts that can help people with limb differences. A prosthesis can be designed to replace the function of the missing body part, improve how it looks, or do both.

**Residual limb** or 'residuum' means the part of the limb that is still there. For example, if you are missing fingers, the rest of your hand is called your residual limb.

A **socket** is part of your prosthesis. The socket is the part that contacts with your residual limb. Sockets are custom made to the shape of your residual limb. Sockets are usually lightweight, comfortable, and can protect your residual limb.



# Who might I work with on my journey to being provided with a prosthesis?



There are many types of professionals who work in prosthetics for people with partial hand limb differences.

The team you meet can vary depending on where you live. Here are some common roles you might work with:



- **Prosthetist (CPO, clinician):** This person may prescribe, fit, and check your prosthesis.
- **Occupational Therapist (OT):** An OT can help you learn how to do daily tasks and activities. They may also teach you how to use your prosthesis.
- **Physiotherapist (physical therapist, PT):** A physiotherapist helps with rehabilitation and can give you exercises to improve your strength and movement.
- **Hand Therapist (HT):** A hand therapist specialises in the hand. They might assess your hand, give you exercises, and sometimes prescribe a prosthesis.
- **Mental Health Worker (psychologist, counsellor, nurse):** This person supports your mental health and helps you cope with any emotional challenges related to limb difference.
- **Social Worker:** A social worker may help with practical things like organising paperwork, applying for funding, or managing other parts of your care or treatment.
- **Surgeon:** If you need surgery, you may work with a surgeon. Some surgeons specialize in hands, orthopaedics (bones), trauma (accidents), or other areas. They may work closely with prosthetists or other team members.
- **Rehabilitation Physician (rehab doctor):** This doctor may help after surgery by referring you to other specialists, like a prosthetist or occupational therapist.



- Different occupations may be involved in your journey, from prosthesis assessment to post-prescription care.

## How much does a prosthesis cost?



The cost of prostheses may be fully, partially or not at all covered by funding depending on: your situation, reason for limb difference, geographical location and insurance coverage.

The price range for prostheses varies and may require consideration when choosing your device. You may wish to discuss funding with your provider.

## When would I get a prosthesis and what happens after?



### First prosthesis

People get their first prosthesis at different times. If you've had an amputation, you may start working with a team to help you get ready for a prosthesis. After surgery, your residual limb may change shape as it heals, so you may need to wait before getting fitted. Over time, your residual limb could keep changing shape, which means you might need new fittings and sockets. If you have congenital limb difference, you may need to build strength or train your residual limb to get ready for using a prosthesis.

### Training

All prostheses require a period of practice, training and adaptation. For example, a **myoelectric prosthesis** requires learning how to control it and perform different hand movements. Training usually starts with practice alongside your clinician and continues at home or work. **Passive devices** which do not have moving parts may need less training but may still require time to get used to. Depending on what stage of your journey you receive your prosthesis, you may have adapted to not having a hand, and it could take time to get comfortable with having the prosthesis attached to your residual limb.

### Learning

Learning is an important part of using a prosthesis. You may learn how to use your prosthesis through training or from other prosthesis users. You'll learn how your prosthesis works, what it can do, and what it can't do. You might also learn from other prosthesis users about their experiences. You may also learn how to perform tasks and achieve goals with your residual limb instead of a prosthesis.

Adjusting emotionally is part of the journey too. You may feel both positive and negative emotions as you get used to being a prosthesis user. Talking to support groups or others with limb differences can help you navigate and express these emotions.

## Maintenance

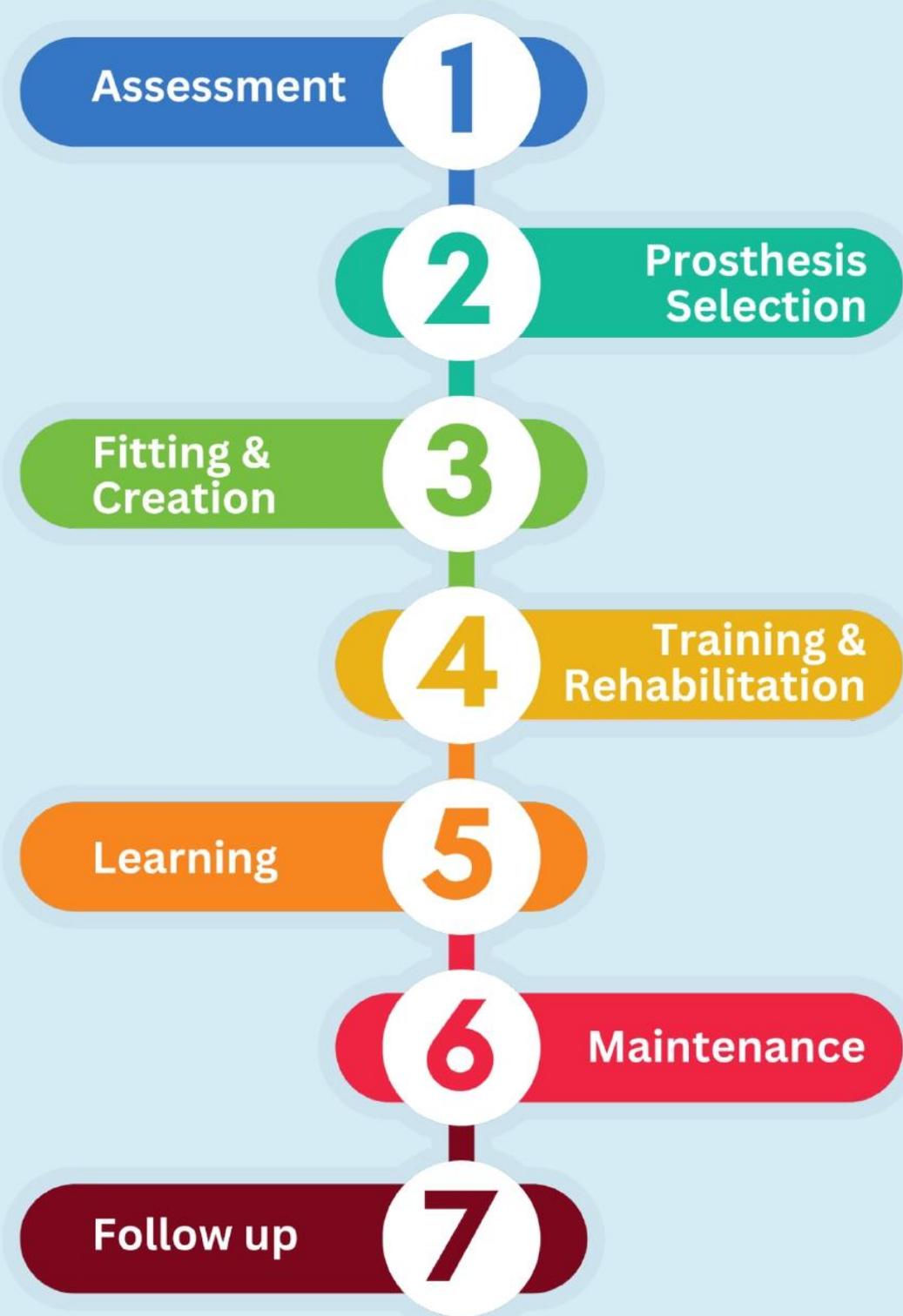
Your prosthesis will require care, maintenance and sometimes replacement. Frequency of maintenance and replacement may depend on factors such as prosthesis type, amount of use, changes to your residual limb and following after care instructions given to you by your provider. It is important to follow instructions for how to take care of and clean your prosthesis. Instructions may be given by your provider and/or the manufacturer of your prosthesis. Some prostheses may also require servicing.

## Why am I being asked about prostheses?



There are different types of prostheses available. Each option has its own benefits and limitations. Whether a device is right for you can depend on factors including - but not limited to - your existing function, the shape of your residual limb, occupational needs, hobbies, goals or preferences for how you want your device to look. The decision to use, or not use, a prosthesis is up to you.

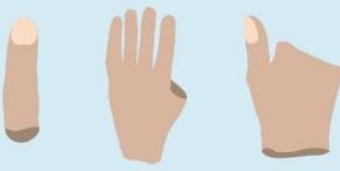
# What does the prescription process involve?



# What are the prosthetic options for my condition?



The table below summarises prosthesis types available for partial hand limb difference. This table is intended to introduce prosthesis types and manufacturers. Not all options or manufacturers are included in this table - you may wish to speak to your provider or research online to find out more.

Type	Alternative Terms	Image	Examples	
<b>Body-powered</b>	Body-driven		PIPDriver	Naked Prosthetics
<b>Myoelectric</b>	Muscle controlled, bionic, robotic		i-Digits	Ossur
<b>Mechanical</b>	Ratcheting		Point Digit	Point Designs
<b>Activity-specific</b>	Sports prosthesis		Weightlifting device	Various: custom made or off-the-shelf
<b>Passive</b>	Cosmetic, silicone		Custom silicone partial hand prostheses	Various
<b>Assistive device</b>	Opposition plate, tools		Toothbrushing tool	Various: custom made or off-the-shelf
<b>No prosthesis</b>	N/A		N/A	N/A

## Types of Prostheses:

**Body-powered** prostheses use the function you may already have in your fingers, hand or wrist to move the prosthesis.

**Myoelectric** prostheses use signals from muscles to control the prosthesis. The prosthesis responds to different muscle signals by creating various grips – such as pointing a finger or closing the device round an object.

**Mechanical** prostheses use mechanical systems, such as a ratcheting system, to move. You may use your other hand, or a surface such as a table, to move the fingers.

**Activity-specific** prostheses are designed for specific tasks like sports, work, hobbies or activities of daily living. Activity specific devices include tools for sports such as swimming or fixtures that allow you to hold objects such as hand tools.

**Passive** prostheses are designed to look like the missing body part can include details like hair and nails. These devices are not designed with a functional purpose. If your partial hand limb difference affects only one hand, this type of device may be modelled based on your other hand.

**Assistive** devices may not look like a hand and may not have fingers. Some attach to your residual limb and use features like plates or hooks. They may require you to use existing function in your residuum to press against an existing thumb or palm for example to create a grip.

**No prosthesis** is an option in which you choose not to use a device. You may perform tasks and feel satisfied without using a device.



- You may choose not to have a prosthesis
- You may use multiple devices

## What does the research show?



A review published in 2022 looked at and compared different prosthetic options for people with partial hand limb difference [1]. Another article from 2020 described types of partial hand prostheses available and explained options which might work best depending on the level of amputation [2].

## Advantages

Research shows that using a prosthesis regularly can improve health, increase quality of life and help people to adapt to life after amputation [3,4]. Some benefits of using a prosthesis include:

- **Increased independence:** Prosthesis use can help with carrying out daily activities, such as cooking, dressing and cleaning [5]
- **Returning to work and hobbies:** Being able to carry out such tasks independently can lead to better quality of life a higher level of satisfaction [6-8]
- **Pain and mental health:** Regularly using a prosthesis can also reduce pain and improve emotional wellbeing [9-11].

You don't have to wear a prosthesis all of the time to experience benefits. For example, you can remove it when you sleep or rest. Additionally, if you choose not to use a prosthesis, you may avoid relying on a device and be able to adapt to performing tasks with your residual limb.

## Challenges

### Limitations of prostheses

A prosthesis cannot replace a hand and can be limited in what it can do. A prosthesis is unlikely to achieve the same level of function as a hand. Additionally, you cannot feel objects through your prosthesis so may rely on other senses such as sight in order to use the device. You may find it easier to take off the prosthesis to perform some tasks, particularly tasks such as washing dishes or showering as some prostheses cannot get wet.

Training with a prosthesis may involve learning, practicing and assessing your progress which can take time. You may benefit from seeking support from other users or professionals to help you achieve your goals.

Wearing a prosthesis comes with some challenges. Sockets should be comfortable, but you may feel discomfort if your residual limb gets warm or sweaty inside. Your prosthetist may adjust or remake your socket, which can take time to get right.

### **Limitations due to partial hand limb difference**

If you have congenital limb difference, or receive your prosthesis after a long period following amputation, you may have become used to not having a hand. You may have adapted to life with limb difference, which could make it challenging to get used to wearing a prosthesis.

If you choose not to use a prosthesis, you might rely more on your other hand, or other body parts, to do tasks. Over time, this could cause overuse injuries or issues with your balance and posture. You can consult with your provider to avoid issues and find solutions.



- Learning and training to use a prosthesis can bring many benefits
- A prosthesis can't produce the same level of functions as a hand, so can be limited



## What matters most to me?

Thinking about what matters to you could help you choose which prosthesis could prove most beneficial to you. Additionally, what matters most to you could change over time. It may be useful to share this page with your provider. You may wish to use the 'date' columns to revisit this section after you receive a prosthesis and track your journey.



## What matters most to you right now?

Answer: \_\_\_\_\_  
date: \_\_\_/\_\_\_/\_\_\_\_\_

Answer: \_\_\_\_\_  
date: \_\_\_/\_\_\_/\_\_\_\_\_

Answer: \_\_\_\_\_  
date: \_\_\_/\_\_\_/\_\_\_\_\_

# Device Selection Guide



**Step 1:** Look at the examples provided and see which prosthesis type typically works well, or does not work well, to meet each requirement.

**Step 2:** Think about what you require support with and write these down in the blank rows. You may wish to think of a specific task or feature based on your answers on page 12.

**Step 3:** Speak to your provider to find out more about devices types which meet your requirements.

Use this table to consider how different prosthetic options might meet your requirements:

-  - device might match the requirement very well
-  - device might match the requirement
-  - device might not match the requirement

Requirement	Body-powered	Myoelectric	Mechanical	Activity specific	Passive	Assistive device	No prosthesis
Heavy physical activity e.g. weightlifting, farming	✓	?	✓	?	✗	?	?
Fine motor skills e.g. handwriting	✓	✓	?	?	✗	✗	?
Sports	?	?	?	✓	✗	?	?
Hobbies	?	?	?	?	?	?	?
Kitchen tasks e.g. chopping food	✓	✓	✓	✓	✗	?	?
Looks like a hand e.g. skin texture, nails	✗	✗	✗	✗	✓	✗	?
Use in water	✓	✗	?	?	?	?	?

# Goal Setting



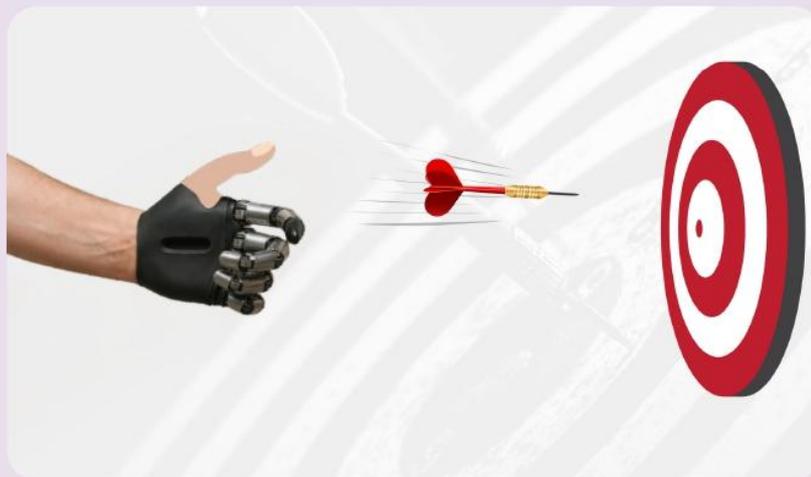
A prosthesis does not need to be worn for all tasks throughout the day. For example, you may use a prosthesis to carry out work, but find some tasks easier without the device.

**Step 1:** Think about how difficult it is to carry out the tasks listed and rate difficulty using the scale.

**Step 2:** Think about how important this task is to you and rate using the scale.

**Step 3:** Use the blank rows to list tasks that are specific to your daily life. Repeat steps 1 & 2.

**Step 4:** You may wish to revise this list to assess your progress as you adapt to life with or without a prosthesis.



Task	Difficulty	Importance
Cutting Food	1 2 3 4 5	1 2 3 4 5
Dressing	1 2 3 4 5	1 2 3 4 5
Washing	1 2 3 4 5	1 2 3 4 5
Tie Shoes	1 2 3 4 5	1 2 3 4 5
Driving a Car	1 2 3 4 5	1 2 3 4 5
Riding a Bike	1 2 3 4 5	1 2 3 4 5
	1 2 3 4 5	1 2 3 4 5
	1 2 3 4 5	1 2 3 4 5
	1 2 3 4 5	1 2 3 4 5
	1 2 3 4 5	1 2 3 4 5
	1 2 3 4 5	1 2 3 4 5
	1 2 3 4 5	1 2 3 4 5

Tip: Not at all difficult (1)  
Neither difficult or not difficult (3)  
Difficult (5)

Tip: Not important (1)  
Neither important or unimportant (3)  
Very important (5)

# Device Selection



You may wish to weigh up your decision based on your goals, preferences, wants and needs. The checklist below can be used as an aid to support your decision. The first row has been filled as an example.

**Step 1:** Write a device type (e.g. myoelectric) as an option across the top row. Speak to your provider about the prosthesis options available to you.

**Step 2:** Fill in the first column with a list of goals and/or preferences you would like help from with your prosthesis. You may wish to use your answers on pages 12-14 to support you.

**Step 3:** Consider if the device option will help you to perform tasks or achieve your goals by adding a  : Tick,  : cross, or  : question mark in the boxes. You may wish to speak to your provider or people who use this prosthesis if you are unsure.

**Step 4:** Count the number of ticks in each column and write total in the last row.

**Step 5:** Consider the number of ticks, crosses or question marks associated with each option. This may indicate which options are more likely to benefit you.



Goals and preferences	Option 1:	Option 2:	Option 3:	Option 4:
<i>e.g. Prosthesis can be used to paint artwork</i>				



## Check your understanding

Place a tick next to each key point to show you understand. Any key point(s) which you are unsure about should be discussed with your provider.

Key points	I understand
Partial hand prostheses can help people who have lost part of their fingers or hand	<input type="checkbox"/>
Prosthetists can fit and assess prostheses - other occupations may be involved too	<input type="checkbox"/>
You may benefit from having more than one prosthesis	<input type="checkbox"/>
You may choose not to use a prosthesis	<input type="checkbox"/>
Some people wear a prosthesis for a small part of the day, others may use it for long periods	<input type="checkbox"/>
Setting goals can help you and your provider choose the best prosthesis for you	<input type="checkbox"/>
You may not be a candidate for all prosthesis options	<input type="checkbox"/>
Funding varies between individuals – speak to your provider to find out your options	<input type="checkbox"/>
You can find support by joining online communities	<input type="checkbox"/>

## How comfortable are you about making this decision?

Read the statements below and circle 'Y' if you agree or 'N' if you disagree with the statement.

- Q: I know enough about the advantages and limitations of prostheses **Y / N**
- Q: I am clear about what matters most to me **Y / N**
- Q: I have support and advice to make a decision **Y / N**
- Q: I feel able to make the best decision for me **Y / N**
- Q: I would like more information to help make a decision **Y / N**

I have questions for my provider:

- Q: \_\_\_\_\_
- Q: \_\_\_\_\_
- Q: \_\_\_\_\_



## 1. Resources

- Arm Dynamics | “Finger and Partial Hand Prosthetic Options” [armdynamics.com/our-care/finger-and-partial-hand-prosthetic-options-1](https://armdynamics.com/our-care/finger-and-partial-hand-prosthetic-options-1)
- O&P Virtual Library | “7C: Aesthetic Restoration” [oandplibrary.org/alp/chap07-03.asp](https://oandplibrary.org/alp/chap07-03.asp)
- Advance Medical Care | “Prosthetic Hand: What is it, Types, and Life-Changing Benefits” [advancemedical.ae/prosthetic-hand-what-is-it-types-and-benefits/#What are the Benefits of Prosthetic Hands](https://advancemedical.ae/prosthetic-hand-what-is-it-types-and-benefits/#What%20are%20the%20Benefits%20of%20Prosthetic%20Hands)

## 2. YouTube channels and videos

- Manufacturers and clinics:
  - @ArmDynamics | [Arm Dynamics - YouTube](#)
  - @OssurAcademy | [Össur Academy - YouTube](#)
  - @HangerNews | [Hanger Clinic - Youtube](#)
  - @NakedProsthetics | [Naked Prosthetics - YouTube](#)
  - @PointDesignsProsthetics | [Point Designs - YouTube](#)
- Prosthesis users:
  - [Jeffgivingahand Soelberg - YouTube](#)
  - [Stuart Chase Videos - YouTube](#)

## 3. Charities and support groups

- Finger and Partial-Hand Amputee Peer + Support Group | Facebook | [facebook.com/groups/fingerandpartialhandamputees/](https://facebook.com/groups/fingerandpartialhandamputees/)
- Finding Your Feet | [findingyourfeet.net/local-amputee-support-groups-directory/](https://findingyourfeet.net/local-amputee-support-groups-directory/) (England and Scotland)
- Jeff Giving a Hand | Facebook | <https://www.facebook.com/groups/Jeffgivingahand.org/>
- Community Connections | Amputee Coalition | [amputee-coalition.org/limb-loss-resource-center/community-connections/](https://amputee-coalition.org/limb-loss-resource-center/community-connections/) (USA)

This decision aid was created to support people with partial hand limb difference in making a decision about prosthesis prescription. Content for the decision aid was developed with input from prosthesis users, healthcare professionals and researchers in the field of partial hand prosthetics. This decision aid was last updated in May 2025.

Content in this decision aid was written by Kirsty Carlyle MEng<sup>1</sup>(Biomedical Engineer), Sarah Day PhD<sup>1</sup> (Prosthetist) and Maggie Donovan-Hall PhD<sup>2</sup> (Health Psychologist). Graphics in this document were designed by Crunch Design, United Kingdom.

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## 7.5 Evaluation

The decision aid was evaluated by assessing the document against items contained in the NICE patient decision aid self-assessment framework (NICE 2021) for developers presented in Chapter 5. The NICE patient decision aid self-assessment framework was chosen to evaluate the decision aid developed. This framework was chosen over the IPDAS checklist as items in the IPDAS checklist were more suited to clinical applications. The results from the self-assessment are contained in Table 25.

TABLE 25 - EVALUATION OF DECISION AID USING THE NICE PATIENT DECISION AID SELF-ASSESSMENT FRAMEWORK

Health condition, decision and available options	Met (2), partially met (1), not met (0)	Where to find the evidence	Notes
<p>The patient decision aid (PDA) states:</p> <ul style="list-style-type: none"> <li>the symptom, condition, disease or illness the person is experiencing</li> <li>that a decision about treatment or investigation is needed, and indicates which aspect of care this relates to</li> <li>what evidence-based treatment or investigative options are available including all reasonable alternatives and the option of doing nothing.</li> </ul>	2	Page 3, 8, 9, 10, 11	<p>Partial hand limb difference and prostheses defined (p3). Prosthetic options are presented as well as the option to choose ‘no prosthesis’ (p8-9). Referenced research and limitations are described (p10-11)</p>
Details of the available options	Met (2), partially met (1), not met (0)	Where to find the evidence	Notes
<p>The PDA presents detailed information about the options to enable the person to make an informed decision, and does so in an unbiased way. This includes:</p> <ul style="list-style-type: none"> <li>detailed information about the potential consequences, benefits and harms of each option</li> <li>an even-handed approach to how the options are displayed and framed. For example, using the same sized font or neutral language</li> <li>the option of doing nothing new or different, for example, what happens if the person chooses to continue with their current treatment, does not have further treatment or has no treatment at all.</li> </ul>	2	Page 8, 9, 10, 11	<p>Different types of prosthesis are described using neutral language and with illustrations. The option of ‘no prosthesis’ is presented (p8-9). Limitations of prostheses are described as well as potential harms of not using a prosthesis (p10-11)</p>
Support for person’s values and preferences	Met (2), partially met (1), not met (0)	Where to find the evidence	Notes

<p>The PDA supports people’s understanding by:</p> <ul style="list-style-type: none"> <li>• helping people to prioritise what matters most to them in terms of the positive and negative features of the available options</li> <li>• supporting people to communicate these priorities with others, such as health professionals.</li> </ul>	2	Page 12, 13, 14, 15	An interactive ‘what matters most to you’ section aims to encourage the reader to think about their goals (p12) and carry this through to device selection (p13 & 15) and a goal setting exercise (p14).
<b>Use of language and numbers</b>	<b>Met (2), partially met (1), not met (0)</b>	<b>Where to find the evidence</b>	<b>Notes</b>
<p>The PDA is written in the most accessible way by:</p> <ul style="list-style-type: none"> <li>• using everyday language that is widely understood or simpler language where necessary</li> <li>• using language equivalent to a reading age of 9 to 11 confirmed by a validated instrument such as the readability statistics within Word, or the Flesch Kincaid tool. Where this is not possible, and the PDA is intended to be explained by a healthcare professional, a reading age of 11 to 14 should be used</li> <li>• explaining information in a way that is meaningful to people without a background in health</li> <li>• explaining quantitative information about risks, benefits, chance and uncertainty in a way that is understandable to people with low levels of numeracy.</li> </ul>	2	Page 3	The document could be read at home or by a professional. Language has been written for a reading age of 9-11. Statistics have not been heavily used in the document. Terminology such as ‘socket’ and ‘residuum’ as well as ‘amputation’ and ‘congenital difference’ has been defined (p3).
<b>For patient decision aids that include screening and diagnostic tests</b>	<b>Met (2), partially met (1), not met (0)</b>	<b>Where to find the evidence</b>	<b>Notes</b>
<p>Where the PDA relates to screening and diagnostic tests, it provides details about:</p> <ul style="list-style-type: none"> <li>• what the test is designed to measure</li> <li>• how likely the test is to accurately identify what is being tested for</li> </ul>	N/A	N/A	Not applicable as the document does not include screening or diagnostic tests.

<ul style="list-style-type: none"> <li>what (if any) intervention could follow from any result and the implications of that for example, further investigations or treatments</li> </ul> <p>the consequences of detecting a disease or condition that would not have caused any problems if the test had not been done.</p>			
<b>Formats and availability of patient decision aids aimed at patients</b>	<b>Met (2), partially met (1), not met (0)</b>	<b>Where to find the evidence</b>	<b>Notes</b>
<p>Where the patient decision aid (PDA) is intended for a patient audience it addresses the needs of the patient through:</p> <ul style="list-style-type: none"> <li>providing the PDA in a variety of sources such as websites, apps or by providing hard copies providing a step-by-step guide to making a decision, and then explaining how to discuss that decision with family, friends, carers and healthcare professionals, if they wish.</li> </ul>	1	Page 15	The document can be hosted online or printed. No app development has taken place for this document. Device selection on page 15 encourages the reader to select options and consider their goals and preferences. Readers are encouraged to speak to their provider or other people with limb difference.
<b>Evidence sources</b>	<b>Met (2), partially met (1), not met (0)</b>	<b>Where to find the evidence</b>	<b>Narrative</b>
<p>The patient decision aid (PDA) and supporting documentation provides information about:</p> <ul style="list-style-type: none"> <li>how evidence was found, appraised and summarised</li> <li>how certain the evidence is about the likelihood of the outcomes described</li> </ul> <p>the sources of evidence – citing NICE guidance where applicable</p>	1	Page 18	Sources of evidence are provided (p18). No information is given about the studies from this thesis which influenced the content of the decision-aid. This work is not published

			but could be referenced in the documents in further revisions.
<b>Patient involvement and co-production</b>	<b>Met (2), partially met (1), not met (0)</b>	<b>Where to find the evidence</b>	<b>Narrative</b>
<p>The supporting documentation demonstrates that the PDA focuses on the needs of the person. This is by confirming that:</p> <ul style="list-style-type: none"> <li>• a clear need for the PDA has been established through dialogue with relevant people with lived experience</li> <li>• the PDA has been co-produced with a range of people with lived experience and professionals to ensure the tone is acceptable to patients, and the information is presented in a balanced and easy-to-understand way</li> </ul> <p>a peer-review process with people with lived experience and professionals has been done.</p>	2	Page 17	The need for the decision aid was established through studies involving prosthesis users and prescribers (Chapters 4 and 6). Peer review was undertaken with prosthesis users in Study 4B in Chapter 6. This supporting documentation may be referenced in the document in further revisions.
<b>Neutral presentation of risks and benefits</b>	<b>Met (2), partially met (1), not met (0)</b>	<b>Where to find the evidence</b>	<b>Narrative</b>
<p>The developers have considered the presentation of risks and benefits to ensure they are neutral, consistent and unbiased. They ensure this by:</p> <ul style="list-style-type: none"> <li>• use of absolute risk rather than relative risk</li> <li>• use of natural frequency</li> <li>• consistent use of data</li> <li>• presenting risk over a defined period of time such as months or years, if appropriate</li> <li>• use of numerical data, where possible, to describe risk, not terms such as rare, unusual, common as these are open to interpretation</li> </ul>	2		The document presents various manufacturers and the option to choose not to use a prosthesis. The risks of not using a prosthesis, such as overuse injury, are outlined. No statistics regarding risk are included

inclusion of both positive and negative framing where possible			due to the nature of the document being focused on prostheses, rather than medicine or other higher-risk interventions.
<b>Review cycle and declaration of interests</b>	<b>Met (2), partially met (1), not met (0)</b>	<b>Where to find the evidence</b>	<b>Narrative</b>
The PDA includes: <ul style="list-style-type: none"> <li>the date that the PDA was last updated and the nature of the updating process in the future, for example, on a regular cycle or when new evidence emerges</li> <li>a declaration of the source of funding to develop the PDA and any potential conflicts of interest</li> </ul> the author and developers' qualifications.	2	Page 17	Information about authors and qualifications are detailed. Funding source for research is declared. Date of last update is detailed (p17)
<b>Experience of treatments</b>	<b>Met (2), partially met (1), not met (0)</b>	<b>Where to find the evidence</b>	<b>Narrative</b>
The PDA describes: what the person's experience might be depending on which option they choose.	2	Page 4, 5, 6, 7	Decision aid contains a description of the journey ahead should the person decide to receive a prosthesis, including training and the team involved.
<b>Presentation of data</b>	<b>Met (2), partially met (1), not met (0)</b>	<b>Where to find the evidence</b>	<b>Narrative</b>

<p>The supporting documentation demonstrates that the patient decision aid (PDA) focuses on the needs of the person. This is confirmed by:</p> <ul style="list-style-type: none"> <li>• using alternative formats such as audio and video format, as needed by the <a href="#">Accessible Information Standard</a></li> <li>• using a mixed approach to display data and multiple descriptive methods such as words, numbers, diagrams, pictograms and icon arrays</li> </ul> <p>including risks and benefits that are personalised where possible.</p>	1	Page 10, 11	Images, words and icons used to display information. Advantages and challenges included.
<p><b>Field testing and validation with users</b></p>	<p><b>Met (2), partially met (1), not met (0)</b></p>	<p><b>Where to find the evidence</b></p>	<p><b>Narrative</b></p>
<p>The supporting documentation verifies that through use of the PDA, people can:</p> <ul style="list-style-type: none"> <li>• recognise the need for a decision</li> <li>• know what options are available to them</li> <li>• understand how their preferences, values and circumstances affect their decisions</li> <li>• identify what matters most to them in terms of outcomes, and can choose the option most aligned with this</li> <li>• discuss their values and preferences with their healthcare professionals</li> </ul> <p>be involved in decision-making to the extent that they wish to.</p>	0	N/A	No field testing or validation has been conducted with users. Users have been involved in the iterative design of the decision aid.
<p><b>Equality, diversity and health inequalities</b></p>	<p><b>Met (2), partially met (1), not met (0)</b></p>	<p><b>Where to find the evidence</b></p>	<p><b>Narrative</b></p>
<p>The developers have taken into consideration equality, diversity and health inequalities, through:</p> <ul style="list-style-type: none"> <li>• a thorough equality impact assessment looking at the protected characteristics in the <a href="#">Equality Act 2010</a>, to avoid discrimination and promote equality</li> <li>• assessing whether the PDA could reduce health inequalities, or make them worse</li> </ul> <p>a consideration of cultural diversity in terms of decision-making and risk analysis.</p>	1	N/A	No equality impact assessment has been carried out. Studies preceding the development of the decision aid were ethically approved by relevant committees at the University of Strathclyde. The decision aid

			could reduce health inequalities if validated for use and used to provide justification for funding the most appropriate and/or multiple devices for those who are candidates.
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## 7.6 Chapter summary

This Chapter described the development and presented the final version of a decision aid for partial hand prosthetic prescription. The final version was shaped by findings from the studies described in this thesis. The decision aid was evaluated using the NICE self-assessment framework.

## 8 Discussion and conclusions

### 8.1 General discussion

This research set out to develop a deeper understanding of how partial hand prostheses are used and prescribed in real-world clinical contexts. The aim was to explore partial hand prosthesis use and prescription. The primary output of this research is a novel decision aid designed to support shared decision-making in the prescription of partial hand prostheses.

To achieve this aim, this thesis presents a series of interlinked studies that progressively build towards the development of the decision aid (Figure 47). The early stages of the research focused on examining existing practices in assessment and prescription of partial hand prostheses —first broadly in the literature review examining outcome measures for hand activity, and then towards specifically considering partial hand prostheses. Studies 1 and 2 helped to establish a baseline understanding of the clinical landscape, identifying gaps and inconsistencies. Such gaps included a lack of measures which consider both functional and quality of life measures, as well as no specific recommendations found for assessing partial hand outcomes. Further studies - 3, 4A and 4B - involved direct engagement with key stakeholders; clinicians and partial hand prosthesis users. This stakeholder-involvement approach involved co-creation which ensured that the development of the decision aid was going to be valued and desired by those who it was intended for. Additional work explored the role and structure of decision aids more generally, providing a theoretical and practical foundation for the design of the document.

### 8.1.1 Decision aid

The culmination of this research is the development and presentation of a decision aid for partial hand prosthetic prescription. This document is intended for use in clinical settings to facilitate a transparent, informed, shared decision-making prescription process. A decision-making tool for prescription of prosthetic and orthotic devices for partial foot amputations exists, which is a similar application albeit for lower limb and developed through a set of research studies. However, this tool differs in that it features branches and delivers outputs, rather than facilitating a shared decision-making approach. Further, the decision aid for partial hand described in this thesis is similar to the PDA-TULA which aims to challenge device rejection rates in adult unilateral upper limb difference. The PDA-TULA was developed using similar methods such as using findings from literature review, surveys and focus groups. However, development of the decision aid in this thesis differs in that the PDA-TULA studies were specifically designed for development of the aid, whereas the studies in this thesis lead towards defining the need for the aid. The decision aid developed in this thesis features text, graphics, charts and interactive sheets to make it visually appealing and practical. It was noted in Study 4B that some people benefit from informative sections of text, and others absorb more information through visuals. The skills of a graphic designer were sought to enable creating a visually appealing document that aligns with other decision aids available for similar applications. This decision aid has the potential to improve the prescription experience, both at time of prescription and thereafter, for individuals with partial hand limb difference. The work not only highlights the complexity of

decision-making in partial hand prosthetic prescription but also offers a pathway to improving it through structured support and shared understanding.

Findings from the user-involvement study reinforce the need for user-centred approaches to prescription and strongly support the development of the decision aid. Feedback on the draft was positive and indicated that the decision aid would be well received by the people whom it is intended to support. Study 4B found a number of themes which were incorporated into the decision aid, however, highlighted gaps and areas for attention. At the time of writing this thesis, literature which explores users' experiences of partial hand prescription was limited. Therefore, findings such as the themes of self-advocacy and outreach may inform further research and development of materials or recommendations to support people with partial hand limb difference in navigating the prescription process.

#### 8.1.2 Education and support for clinicians

Clinician experiences were examined in Studies 2 and 3. Findings from both studies highlighted the complexity and differences in practice in terms of prescription of partial hand prostheses. Study 2 found a range of outcome measures, and no clear conclusions were drawn which suggested a recommended group of outcome measures to assess this population. This lined up with Study 1 which found a lack of outcome measures specific to this population. A range of patients are seen at clinics as highlighted in Study 2 where some participants seen a high number in clinics, to some seeing zero in the past 12 months. This finding, alongside variations in practice discussed in Study 3 and the lack of recommended outcome measures for partial

hand found in Studies 1 and 2, also strengthen the need for tools to support clinicians' with prescription towards a more standardised process. Nonetheless, a decision aid alone may not close the gap as clinician's need a level of understanding to facilitate discussions. Additional educational and standardisation tools could be beneficial alongside the decision aid., as well as standardisation of terminology used among clinicians and end users.

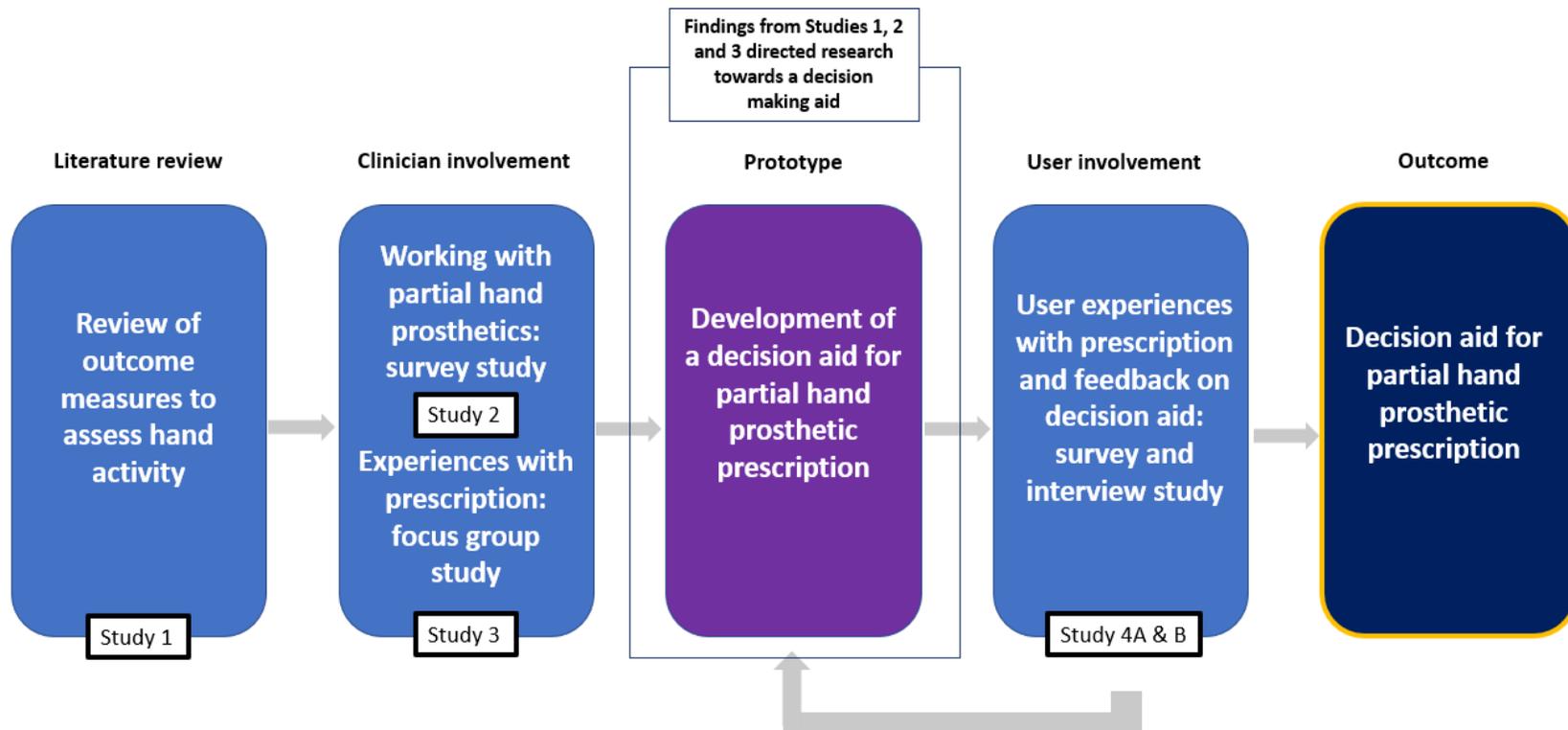


FIGURE 47 – FLOWCHART ILLUSTRATING THE STAGES OF RESEARCH CONDUCTED

### 8.1.3 Limitations

While this research provides valuable insights into partial hand prosthetic prescription and has resulted in the development of a novel decision aid, some limitations should be acknowledged.

#### 8.1.3.1 Sampling and generalisability

Sampling methods used in Studies 3, 4A and 4B may introduce uncertainty around how representative the findings are in terms of the partial hand limb difference community. It is unknown who chose not to participate despite being eligible and potentially seeing the advertisements for studies. Participants were primarily recruited via online platforms, including social media, professional networks, and through specific organisations based in the United States and the United Kingdom. This resulted in a high proportion of participants from the United States, which may introduce location bias and limit the global generalisability of the results. Additionally, stakeholders who are not active on social media were less likely to be reached, potentially excluding a notable portion of the partial limb difference population. Similarly, there is no information about individuals who started but did not complete the surveys, or those who may have disregarded the studies because they did not perceive it to be relevant to them.

#### 8.1.3.2 Participant characteristics

Demographic diversity within some parts of the study was limited. For example, Study 4B included only one female participant, who was also the sole participant with congenital limb difference. As a result, the findings from this study may not fully

reflect the views of women or those with congenital limb difference in the broader population. Moreover, some participants in the focus groups were known to one another, which may have subtly influenced group dynamics, although no obvious impact on the discussion was observed.

Allocation to focus group sessions was based on availability rather than demographic or experiential criteria due to the lack of demographic data collected during recruitment and low volume of participants expected to take part. This may have influenced the composition of focus groups and affected the range of perspectives captured.

#### 8.1.3.3 Recruitment and non-participation

Across multiple studies, non-response and participant withdrawal were noted, with some participants failing to attend scheduled sessions or withdrawing without providing reasons. While some reasons (for example scheduling conflicts, technical barriers, or lack of compensation) were noted, others remain unknown. This further contributes to potential selection bias and limits the ability to draw conclusions about the broader community of clinicians and prosthesis users.

#### 8.1.3.4 Data collection and analysis

In qualitative components of the study, semi-structured interviews and focus groups were carried out. While this approach allowed for rich, in-depth data collection, the fact that participants were not asked explicitly identical questions may affect the consistency and comparability of responses. In addition, technical issues with NVivo

software at the start of the analysis process resulted in some data being lost and had to be re-entered, although this did not impact the final coding or thematic analysis.

The initial coding for Studies 3 and 4B was conducted by a single researcher, which may have introduced individual bias. However, codes and themes were cross-checked by other members of the research team to enhance reliability. The qualitative nature of the studies also means that findings are interpretive and subjective, reflecting participant perspectives rather than objective measures.

#### 8.1.3.5 Representation of the partial hand limb different community

Reaching the partial hand prosthesis user community presented challenges. Despite efforts to recruit a diverse sample, including via word of mouth and through a manufacturer in the United States, sample sizes remained relatively small as anticipated, and participants were likely skewed toward those more active or engaged in outreach and online platforms. This may have influenced certain themes—such as “learning and outreach”—which could reflect the nature of this evidently engaged subgroup rather than the broader population.

#### 8.1.3.6 Decision aid

The decision aid was evaluated in section 7.5 which found that there are areas for improvement, such as the lack of testing of the tool in the field with users. The decision aid is expected to be used by members of the public who may potentially misuse it. Examples of misuse include using the tool as leverage for funding for a device that a user/clinician has pre-determined as their need, rather than allowing the tool to help them reach a conclusion about what device is best for the user. In

addition, the tool could set unrealistic expectations if not used in conjunction with clinical advice. The tool is also limited in that it does not list every professional who may interact with the user, such as a prosthetic technician, however it was deemed impossible to list all potential occupations within the document. A discussion guide to support clinicians in using the tool could alleviate some potential cases of misuse by clinicians or users.

## 8.2 Recommendations for future work

### 8.2.1 Knowledge mobilisation

The decision aid developed will be available via the University of Strathclyde thesis repository page. Links to the thesis and a publicly accessible version of the decision aid will be posted on the researcher's (KC, SD, AB) Pure webpages. The document will be available as a PDF therefore cannot be modified by persons other than the researchers. Future work to maintain and update the decision aid may be carried out by the author or supervisors of this thesis. Collaboration with organisations such as, but not limited to, ISPO and BAPO may help to disseminate and promote the decision aid so it can be used in the field. Knowledge mobilisation should be carried out to ensure the work is used in the field of partial hand prosthetics and is accessible to stakeholders including clinicians and people with partial hand limb difference.

### 8.2.2 Iterative improvement and additional tools

Given that education was a theme from the focus group study, a discussion guide to support clinicians in prescription could be developed to compliment the decision aid. This discussion guide could help bridge a knowledge gap and serve as an educational tool for clinicians who use it in their prescription process. Clinicians who do not often

see partial hand cases, as found in the survey study, could benefit from a discussion guide which in turn would benefit the end user.

The decision aid has been designed for adults, and has not considered paediatric cases of partial hand limb difference. Instead of adapting the aid for use in paediatric cases, a similar set of studies could be conducted to draw conclusions about requirements for a decision aid for children. Additionally, the decision aid is designed for use as an online tool or printed. An interactive element could be added if it was to be used as an online tool. For example, readers could click on links within the document to fill in boxes or view manufacturer webpages which may be more engaging. In addition, participants noted the tactility of prostheses and further research could include developing physical tools which can aid the decision-making process. For example, being able to feel the weight and material of a device and see how the device functions could help an individual to select a device for them and set expectations.

No outcome measure, or recommended selection of outcome measures, were found to be recommended specifically for partial hand assessment. Therefore, future work is recommended to investigate outcome measures for partial hand and provide clinicians with a set of outcome measures to assess this population.

### 8.2.3 Testing and validation

Testing the decision aid with stakeholders in the field is recommended to further validate the tool for use in clinical applications. Further iterations and validation of the decision aid could be performed to further improve and maintain the tool. The decision aid could be validated with a large pool of participants to determine

confidence in its efficacy. The participants who took part in the studies in this thesis were familiar with partial hand prescription, either from a prescriber or user perspective. It would be advantageous to include stakeholders who have little to no experience, and gauge their opinions and feedback on what may be useful for them.

The decision aid could be used as a means of justification for more funding in partial hand prosthetic prescription. For example, if an individual uses the aid and finds that they may be a candidate for myoelectric, this information could be gathered to influence policies.

#### 8.2.4 Addressing limitations

Future studies may include approaching wider audiences to obtain a larger dataset.

Participants from the studies in this thesis were predominantly based in the United States. Therefore, studies specifically targeting specific regions, including low- and middle- income countries, could allow geographical comparisons to be made. As healthcare systems vary globally, seeking information specific to regions may allow the aid to be tailored to better suit the person with limb difference.

The decision aid was evaluated using the NICE patient decision aid self-assessment framework. Areas identified for improvement or further development may be targeted to improve the decision aid. Further evaluation could be carried out using the IPDAS checklist, however, further work to justify and eliminate which sections should be used for evaluation is required as not all aspects are relevant for partial hand prosthetic prescription due to the clinical nature of the checklist.

### 8.3 Contributions to knowledge in the field of partial hand prosthetics

This thesis advances knowledge in the field of partial hand prosthetics by deepening the understanding of prosthetic prescription from both clinical and user perspectives. The contributions of this work are both conceptual and practical, addressing a notable gap in the literature and offering an aid which has potential to improve clinical decision-making and patient outcomes.

The primary output and contribution to the field is the development of a novel decision aid for the prescription of partial hand prostheses. At the time of this research, no such tool existed. The aid is grounded in empirical evidence and is designed for use in clinical practice, supporting more consistent, informed, and user-centred decision-making processes. This tool represents a significant step towards improving the prescription journey for individuals with partial hand limb difference.

The research also provides original quantitative and qualitative analyses of data gathered from the literature, clinicians, and partial hand prosthesis users. These analyses explore current practices, lived experiences, and professional opinions, contributing new insights into the factors that influence prosthetic prescription and use. Beyond informing the development of the decision aid, these findings have the potential to deepen understanding of the broader challenges faced by individuals with partial hand loss.

Dissemination of this work has already contributed to academic literature and within the field of prosthetics. Findings from Study 1 and Study 2 have been published in the

Canadian Journal of Prosthetics and Orthotics and Prosthetics and Orthotics International, respectively. Work from Studies 2, 3, 4A, and 4B has been presented at several international conferences, including the ISPO World Congress (Guadalajara, 2023), the BAPO Conference (Glasgow, 2023), the Bionic Reconstruction Conference (New York City, 2023), and TIPS (Rotterdam, 2025). It is anticipated that further publications from Studies 3, 4A, and 4B will add to the academic literature in this field through publication.

In summary, this thesis contributes to knowledge by delivering a novel decision-making aid, generating new insights, and facilitating professional engagement with issues central to partial hand prosthetics.

## 8.4 Conclusion

This research follows a journey beginning with an exploration of how hand function and quality of life are assessed through outcome measures and culminates in the development of a decision aid to support prescription of partial hand prostheses. Studies in this thesis explored both clinician and user perspectives and experiences to build a deeper understanding of challenges, current landscape and realities involved in prosthetic prescription for people with partial hand limb difference.

A scoping review identified gaps in outcome measures for hand activity which shaped the research trajectory to focus on clinical decision-making and factors which influence prescription. Further investigation into clinician's experiences found that real world constraints such as funding can influence device prescription in partial hand more so than what is considered most important. Focus groups explored the perspectives of clinicians' further and highlighted the need for shared decision-making and education, among other key themes, in terms of partial hand prescription. These findings drove the research towards development of a decision aid aimed at supporting shared decision-making in prosthetic prescription. User feedback was sought as well as insights gained through survey and interview studies. Iterative development was carried out and the final decision aid evaluated using the NICE self-assessment framework.

This work contributes to the understanding and practice of partial hand prosthetic prescription. Studies highlighted issues in current assessment and prescription methods, as well as challenges faced by users who shared their individual

experiences. Thereafter, this research provides a practical, evidence-based tool to address these challenges which has the potential to enhance outcomes for people with partial hand limb difference.

Recommended future work includes development of a discussion guide to support clinicians in facilitating discussions with users who are embarking on their prescription journey.

## 9 Reflections

Prior to this PhD research, I was a Biomedical Engineering (BME) student with an interest in prosthetics. I was initially interested in the technology, and was captivated by media articles which showcased the latest products and the achievements of prosthesis users which focused on the technological 'innovations'. Throughout this PhD, my view on prosthetic technology for upper limb has evolved into a more holistic view which encompasses psychosocial and clinical considerations. I have gained knowledge around the shortfalls of devices, barriers to successful outcomes, and the complexity of partial hand prosthetic prescription.

A vast amount of my learning about partial hand prostheses has come from opportunities to learn from stakeholders. These opportunities allowed me to learn more about the real world of prosthetics and users, on top of what I had been learning through academic research and my background in BME. I had the opportunity to shadow an OT at WestMARC who performed outcome measurement assessments on upper limb prosthesis users and allowed me to witness this in real-life practice. A visit to The London Prosthetics Centre also provided me with experience in how private clinics are run and the art of passive silicone devices, which I had not yet been exposed to. I met with an I-Digits user who was visiting Ossur in Livingston, and observed fitting and assessment. This user was experienced, and travelled overseas to the site for their device to be serviced so they did not have to wait for it to be posted to them. This memory sticks with me, as it really drove home the importance of prosthetic devices to individuals who use them and was my first interaction with a partial hand prosthesis user in Scotland.

With upper limb research being relatively small in comparison to other fields, and partial hand even smaller, I have developed a sense of feeling like part of a research community with a shared desire to improve knowledge and outcomes in this area. There are many people who have been advocates for this research, particularly some people with partial hand limb difference who took part in the user engagement study and have connected with me on social media. Likewise, I feel I have become an advocate for the partial hand community and have become increasingly passionate about producing, sharing and contributing to research to improve partial hand prescription and the general knowledgebase to improve outcomes for people in this community. Individuals have welcomed me into their story and journey, which I feel privileged to be part of, and has contributed to my passion for the work presented in this thesis. I believe my understanding of partial hand limb difference, so far, has been encouraged and supported, and is deeper than solely academic research.

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## 11 Appendix

## Appendix A

Study Number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Did the study address a clearly focused research question?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the recruitment strategy appropriate to the aims?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Are there any conflicts of interest?	N	N	N	N	Y	N	N	N	Y	N	N	N	N	N	N	N	Y
Was there a clearly defined study protocol?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Do the benefits of the experimental intervention outweigh the harms and costs?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Have ethical issues been taken into consideration?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Can the results be applied to the context of hand and upper limb activity?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Does the study find anything new or useful?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

## Participant Information Sheet

**Name of department: Biomedical Engineering**

**Title of the study: Experiences Working With Partial Hand Prosthetics**

### **Introduction**

My name is Kirsty Carlyle and I am a PhD student within the department of Biomedical Engineering at the University of Strathclyde, Glasgow, United Kingdom. I am undertaking this study as part of my research in partial hand prostheses. I am conducting this research under the supervision of the Chief Investigator - Sarah Day, Teaching Fellow, department of Biomedical Engineering.

### **What is the purpose of this research?**

The human hand is a complex structure responsible for powerful grips and precise control. In terms of the hand, amputation of the wrist, palm or fingers of the upper limb is defined as partial hand amputation. Additionally, people may have been missing part of their hand since birth.

People who are missing part of their hand may have difficulty carrying out tasks and activities which require power or precision. This is significant as this impairs ability to carry out essential and routine tasks to manage needs. Prosthetic devices are a solution to assist people with partial hands. As well as difficulty carrying out tasks, limb absence can cause significant psychological impacts. Some prosthetic devices are a cosmetic solution – designed to look like an anatomic hand. While prosthetic technology is advancing, there are many people who choose not to use a device, abandon their device, or do not have device options available to them.

The purpose of this study is to investigate partial hand prostheses from the perspective of the workforce who develop, assess or prescribe them. The investigation has an overarching aim of providing a basis for further research in assessing real world use of partial hand prosthetics. The objectives of the investigation are to gain understanding of who is prescribing partial hand prostheses, decision making processes involved, and how devices are chosen.

### **Do you have to take part?**

No. You do not have to take part as participation is voluntary. If you do not wish to take part in the study, there will be no consequences of doing so.

### **What will you do in the project?**

You will begin by following a link to the survey. The consent form is on the first page of the survey. Please answer the questions on the consent form to confirm that you understand. If you give consent to take part in the study you will click the button to continue, and you will be directed on to the survey questions.

The survey includes questions about your background, your experiences with partial hands and outcome measures (if applicable), your opinions, and you will also be invited to share your general thoughts on partial hand prostheses. The survey should take no longer than 15 minutes to complete. After the main survey, you will be asked if you wish to provide the researchers with your contact details in order to be contacted about the research findings or related projects. If you do not wish to provide your contact details, you will exit the survey. If you wish to do provide your contact details, you will be directed to a second survey to provide your contact details, then exit the survey. The screen will state “Thank you for completing the survey” to mark the end of the survey and confirm that your responses have been saved.

The survey will be live **until July 24<sup>th</sup> 2022** and you will be able to take the survey at any point within this period.

No monetary incentive will be provided for taking part in the survey. As the survey online, there are no expenses associated with travel costs.

#### **Who should take part?**

We are looking for participants who work with, or have worked with, partial hand prostheses **or users of partial hand prostheses** within the past 5 years. This may include, but is not limited to, prosthetists, orthotists, occupational therapists, physiotherapists, hand therapists, hand surgeons or engineers. Participants must be able to read and comprehend English.

#### **What information is being collected in the project?**

Information collected includes your experience with partial hand prostheses, your experience with outcome measures, and information about practices involving partial hands i.e. decision making and funding. None of the information collected will be identifiable.

#### **Who will have access to the information?**

The study is conducted in lines with the University General Data Protection Regulation (GDPR) Policy. The University Privacy Notice can be found on the following website: <https://www.strath.ac.uk/ethics/information-sheet-and-consent-form/information>.

Information that you provide will remain confidential. All data will be stored on a secure platform accessed only by the investigators. Only non-identifiable information will be used when findings from the study are shared.

**Where will the information be stored and how long will it be kept for?**

Data obtained from this study will be stored on the University's secure platform and accessed only by researchers. As data is anonymous, it may be stored indefinitely. If you choose to provide your contact details, these may be stored on a secure OneDrive folder for up to 3 years.

**What happens next?**

Thank you for your attention and time in reading the Participant Information.

If you would like to find out more about the project or wish to ask questions before participating, please contact the researchers.

You will be invited to supply your contact details if you wish to be contacted after the study. This is entirely voluntary. Your responses to the survey will remain anonymous regardless of whether you supply your contact details.

The results of this study will be reported in the researcher's (Kirsty Carlyle) PhD thesis and may be published in other academic papers, presentations or conferences. As the survey is anonymous, the identities of participants are unknown to investigators and will therefore not be published.

**Researcher contact details:**

Kirsty Carlyle

PhD Student

Department of Biomedical Engineering

University of Strathclyde

Email: [kirsty.carlyle@strath.ac.uk](mailto:kirsty.carlyle@strath.ac.uk)

**Chief Investigator details:**

Sarah Day

Teaching Fellow

Department of Biomedical Engineering

University of Strathclyde

Email: [sarah.day@strath.ac.uk](mailto:sarah.day@strath.ac.uk)

This research was granted ethical approval by the Department of Biomedical Engineering Ethics Committee, University of Strathclyde.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Linda Gilmour

Secretary to the Departmental Ethics Committee

Department of Biomedical Engineering

University of Strathclyde

Tel: 0141 548 3298

Email: [linda.gilmour@strath.ac.uk](mailto:linda.gilmour@strath.ac.uk)

**Consent Form (consent form is contained within Qualtrics survey – this list is a copy of the actual form)**

**Name of department: Biomedical Engineering**

**Title of the study: Experiences Working With Partial Hand Prosthetics**

**Please read each of the following statements and check the box to confirm:**

- I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction.
- I confirm that I understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long).
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences.
- I understand that anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study.
- I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.
- I have read and understand the University Privacy Notice (<https://www.strath.ac.uk/ethics/information-sheet-and-consent-form/information>)
- I consent to being a participant in the project.

# Partial Hand Prosthetics Survey

## Survey Flow

Block: Default Question Block (1 Question)  
Standard: Consent Form (7 Questions)  
Standard: Demographics (6 Questions)  
Standard: Partial Hand Prosthetic Devices (6 Questions)  
Standard: Outcome Measures (7 Questions)  
Standard: Decision Making (6 Questions)  
Standard: Funding (3 Questions)  
Standard: Additional Comments (1 Question)  
Standard: Contact Details (1 Question)

Branch: New Branch

If

If Would you like to provide your contact details to allow researchers to contact you about this res... Yes Is Selected

**EndSurvey: Advanced**

Branch: New Branch

If

If Would you like to provide your contact details to allow researchers to contact you about this res... Yes Is Not Selected

**EndSurvey:**

---

## Start of Block: Default Question Block

Participant Info Title of the study: Experiences Working With Partial Hand Prosthetics

### Introduction

My name is Kirsty Carlyle and I am a PhD student within the department of Biomedical Engineering at the University of Strathclyde, Glasgow, United Kingdom. I am undertaking this study as part of my research in partial hand prostheses. I am conducting this research under the supervision of the Chief Investigator - Sarah Day, Teaching Fellow, department of Biomedical Engineering.

### What is the purpose of this research?

The human hand is a complex structure responsible for powerful grips and precise control. In terms of the hand, amputation of the wrist, palm or fingers of the upper limb is defined as partial hand amputation. Additionally, people may have been missing part of their hand since birth. People who are missing part of their hand may have difficulty carrying out tasks and activities which require power or precision. This is significant as this impairs ability to carry out essential and routine tasks to manage needs. Prosthetic devices are a solution to assist people with partial hands. As well as difficulty carrying out tasks, limb absence can cause significant psychological impacts. Some prosthetic devices are a cosmetic solution – designed to look like an anatomic hand. While prosthetic technology is advancing, there are many people who choose not to use a device, abandon their device, or do not have device options available to them.

The purpose of this study is to investigate partial hand prostheses from the perspective of the workforce who develop, assess or prescribe them. The investigation has an overarching aim of providing a basis for further research in assessing real world use of partial hand prosthetics. The objectives of the investigation are to gain understanding of who is prescribing partial hand prostheses, decision making processes involved, and how devices are chosen.

### Do you have to take part?

No. You do not have to take part as participation is voluntary. If you do not wish to take part in the study, there will be no consequences of doing so.

### What will you do in the survey?

The consent form is located within the survey. Please answer the questions on the consent form to confirm that you understand. If you give consent to take part in the study you will click the button to continue, and you will be directed on to the survey questions. The survey includes questions about your background, your experiences with partial hands and outcome measures (if applicable), your opinions, and you will also be invited to share your general thoughts on partial hand prostheses. The survey should take no longer than 15 minutes to complete. After the main survey, you will be asked if you wish to provide the researchers with your contact details in order to be contacted about the research findings or related projects. If you do not wish to provide your contact details, you will exit

the survey. If you wish to do provide your contact details, you will be directed to a second survey to provide your contact details, then exit the survey. The screen will state "Thank you for completing the survey" to mark the end of the survey and confirm that your responses have been saved. The survey will be live until July 24th 2022 and you will be able to take the survey at any point within this period. No monetary incentive will be provided for taking part in the survey. As the survey online, there are no expenses associated with travel costs.

Who should take part?

We are looking for participants who work with, or have worked with, partial hand prostheses or users of partial hand prostheses within the past 5 years. This may include, but is not limited to, prosthetists, orthotists, occupational therapists, physiotherapists, hand therapists, hand surgeons or engineers. Participants must be able to read and comprehend English.

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Information collected includes your experience with partial hand prostheses, your experience with outcome measures, and information about practices involving partial hands i.e. decision making and funding. None of the information collected will be identifiable.

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Where will the information be stored and how long will it be kept for?

Data obtained from this study will be stored on the University's secure platform and accessed only by researchers. As data is anonymous, it may be stored indefinitely. If you choose to provide your contact details, these may be stored on a secure OneDrive folder for up to 3 years.

What happens next?

Thank you for your attention and time in reading the Participant Information. If you would like to find out more about the project or wish to ask questions before participating, please contact the researchers. You will be invited to supply your contact details if you wish to be contacted after the study. This is entirely voluntary. Your responses to the survey will remain anonymous regardless of whether you supply your contact details.

The results of this study will be reported in the researcher's (Kirsty Carlyle) PhD thesis and may be published in other academic papers, presentations or conferences. As the survey is anonymous, the identities of participants are unknown to investigators and will therefore not be published.

Researcher contact details:

Kirsty Carlyle, PhD Student, Department of Biomedical Engineering, University of Strathclyde

Email: [kirsty.carlyle@strath.ac.uk](mailto:kirsty.carlyle@strath.ac.uk)

Chief Investigator details:

Sarah Day, Teaching Fellow, Department of Biomedical Engineering, University of Strathclyde

Email: [sarah.day@strath.ac.uk](mailto:sarah.day@strath.ac.uk)

This research was granted ethical approval by the Department of Biomedical Engineering Ethics Committee, University of Strathclyde. If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Linda Gilmour, Secretary to the Departmental Ethics Committee, Department of Biomedical Engineering, University of Strathclyde

Tel: 0141 548 3298

Email: [linda.gilmour@strath.ac.uk](mailto:linda.gilmour@strath.ac.uk)

End of Block: Default Question Block

---

Start of Block: Consent Form

Q1 I confirm I have read and understood the Participant Information for this project and the researcher has answered any queries to my satisfaction.

I confirm (1)

I do not confirm (2)

Skip To: End of Survey If Q1 = 2

---

Q2 I understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long).

- I confirm (1)
- I do not confirm (2)

*Skip To: End of Survey If Q2 = 2*

---

Q3 I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences.

- I confirm (1)
- I do not confirm (2)

*Skip To: End of Survey If Q3 = 2*

---

Q4 I understand that anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study.

- I confirm (1)
- I do not confirm (2)

*Skip To: End of Survey If Q4 = 2*

---

Q5 I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.

- I confirm (1)
- I do not confirm (2)

*Skip To: End of Survey If Q5 = 2*

---

Q6 I have read and understand the University Privacy Notice  
(<https://www.strath.ac.uk/ethics/information-sheet-and-consent-form/information>)

- I confirm (1)
- I do not confirm (2)

*Skip To: End of Survey If Q6 = 2*

---

Q7 Do you consent to being a participant in the project?

- Yes, I consent (1)
- No, I do not consent (2)

*Skip To: End of Survey If Q7 = 2*

**End of Block: Consent Form**

---

**Start of Block: Demographics**

Q8 What is your occupation?

- prosthetist (1)
  - orthotist (2)
  - occupational therapist (3)
  - physiotherapist (4)
  - hand therapist (5)
  - medical doctor (7)
  - other (please specify) (6)
- 



Q9 Have you worked in this field within the last 5 years?

- Yes (1)
  - No (2)
- 

Q10 How long have you worked in this occupation? Please provide answer in years.

- Years worked in occupation: (1) \_\_\_\_\_
-



Q11 In which country do you currently work?

▼ Afghanistan (1) ... Zimbabwe (1357)

---

Q12 Do you prescribe partial hand prosthetics?

Yes (1)

No (2)

---

Q13 Do you assess user interaction with partial hand prosthetic devices?

Yes (1)

No (2)

**End of Block: Demographics**

---

**Start of Block: Partial Hand Prosthetic Devices**

Q14 Which partial hand prosthetic device(s) have you heard of?

- i-Digits (Ossur) (1)
- PIPDriver (Naked Prosthetics) (2)
- MCPDriver (Naked Prosthetics) (3)
- ThumbDriver (Naked Prosthetics) (4)
- GripLock Finger (Naked Prosthetics) (5)
- Passive/cosmetic silicone prosthetics (6)
- M-Finger (7)
- M-Thumb (Partial Hand Solutions) (8)
- Titan Thumb (Partial Hand Solutions) (9)
- Titan Flex (Partial Hand Solutions) (10)
- Titan Partial (Partial Hand Solutions) (11)
- Partial M-Fingers (Partial Hand Solutions) (12)
- Hold-It (Partial Hand Solutions) (13)
- Point Thumb (Point Designs) (14)
- Point Partial (Point Designs) (15)

Point Digit (Point Designs) (16)

Opposition plate (17)

---

*Carry Forward Selected Choices from "Q14"*



Q15 Which partial hand prosthetic device(s) have you worked with?

- i-Digits (Ossur) (1)
- PIPDriver (Naked Prosthetics) (2)
- MCPDriver (Naked Prosthetics) (3)
- ThumbDriver (Naked Prosthetics) (4)
- GripLock Finger (Naked Prosthetics) (5)
- Passive/cosmetic silicone prosthetics (6)
- M-Finger (7)
- M-Thumb (Partial Hand Solutions) (8)
- Titan Thumb (Partial Hand Solutions) (9)
- Titan Flex (Partial Hand Solutions) (10)
- Titan Partial (Partial Hand Solutions) (11)
- Partial M-Fingers (Partial Hand Solutions) (12)
- Hold-It (Partial Hand Solutions) (13)
- Point Thumb (Point Designs) (14)
- Point Partial (Point Designs) (15)

Point Digit (Point Designs) (16)

Opposition plate (17)

---

*Carry Forward Selected Choices from "Q14"*



Q16 Which, if any, partial hand prosthetic devices would you recommend to users (assuming the device is appropriate for their condition)?

- Other (please specify) (1) \_\_\_\_\_
- i-Digits (Ossur) (2)
- PIPDriver (Naked Prosthetics) (3)
- MCPDriver (Naked Prosthetics) (4)
- ThumbDriver (Naked Prosthetics) (5)
- GripLock Finger (Naked Prosthetics) (6)
- Passive/cosmetic silicone prosthetics (7)
- M-Finger (8)
- M-Thumb (Partial Hand Solutions) (9)
- Titan Thumb (Partial Hand Solutions) (10)
- Titan Flex (Partial Hand Solutions) (11)
- Titan Partial (Partial Hand Solutions) (12)
- Partial M-Fingers (Partial Hand Solutions) (13)
- Hold-It (Partial Hand Solutions) (14)
- Point Thumb (Point Designs) (15)
- Point Partial (Point Designs) (16)
- Point Digit (Point Designs) (17)

Opposition plate (18)

---

*Carry Forward Selected Choices from "Q14"*

X→

Q17 Which, if any, partial hand prosthetic devices would you recommend to other practitioners?

- Other (please specify) (1) \_\_\_\_\_
- i-Digits (Ossur) (2)
- PIPDriver (Naked Prosthetics) (3)
- MCPDriver (Naked Prosthetics) (4)
- ThumbDriver (Naked Prosthetics) (5)
- GripLock Finger (Naked Prosthetics) (6)
- Passive/cosmetic silicone prosthetics (7)
- M-Finger (8)
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- Titan Partial (Partial Hand Solutions) (12)
- Partial M-Fingers (Partial Hand Solutions) (13)
- Hold-It (Partial Hand Solutions) (14)
- Point Thumb (Point Designs) (15)
- Point Partial (Point Designs) (16)
- Point Digit (Point Designs) (17)

Opposition plate (18)

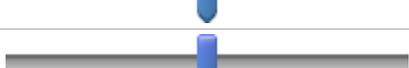
---

Q18 In the last 12 months, how many patients/clients have you fitted with partial hand prosthetics?

- 0 (1)
- 1-5 (2)
- 6-10 (3)
- 11-15 (4)
- 16-20 (5)
- 21-25 (6)
- 26+ (7)
- 

Q19 In the last 12 months, roughly how many of the following types of partial hand prosthetic devices have you worked with?

0 4 8 12 15 19 23 27 31 35 38 42 46 50

Cosmetic ()	
Myoelectric ()	
Body Powered ()	
Body Driven ()	
Mechanical ()	
Activity-specific ()	
Hybrid ()	

End of Block: Partial Hand Prosthetic Devices

---

Start of Block: Outcome Measures

Q20 Do you have experience with using outcome measures with the upper limb population?

Yes (1)

No (2)

---

Page Break

*Display This Question:*

*If Q20 = 1*

Q21 Which outcome measures do you have experience with?

- Southampton Hand Assessment Procedure (SHAP) (1)
- Box and Blocks Test (BBT) (2)
- Nine Hole Peg Test (9HPT) (3)
- Swedish Disabilities of the Arm Shoulder and Hand Questionnaire (DASH) (4)
- Orthotics and Prosthetics User's Survey (OPUS) (5)
- 36-Item Short Form Survey (SF-36) (6)
- Edinburgh Handedness Inventory (EHI) (7)
- Action Research Arm Test (ARAT) (8)
- Trinity Amputation and Prosthetic Experience Scale (TAPES) (9)
- Veterans SF-12 Health Survey (VR-12) (10)
- Jebsen-Taylor Hand Function tests (JTHFT) (11)
- Activity Measure for Upper Limb Amputation (AM-ULA) (12)
- Michigan Hand Outcomes Questionnaire (MHQ) (13)
- University of New Brunswick Skill and Spontaneity Tests (14)
- Upper Extremity Work Demands score (UEWD) (15)

- Carroll Upper Extremity Function test (UEFT) (16)
  - Purdue Pegboard test (PPT) (17)
  - Range of Motion tests (18)
  - Force Control tests (19)
  - Pain (self-reported) (20)
  - Other (please specify) (21)
- 

-----

*Carry Forward Selected Choices from "Q21"*



Q22 Which of these outcome measures do you have experience with in assessing partial hand prosthesis users?

- Southampton Hand Assessment Procedure (SHAP) (1)
- Box and Blocks Test (BBT) (2)
- Nine Hole Peg Test (9HPT) (3)
- Swedish Disabilities of the Arm Shoulder and Hand Questionnaire (DASH) (4)
- Orthotics and Prosthetics User's Survey (OPUS) (5)
- 36-Item Short Form Survey (SF-36) (6)
- Edinburgh Handedness Inventory (EHI) (7)
- Action Research Arm Test (ARAT) (8)
- Trinity Amputation and Prosthetic Experience Scale (TAPES) (9)
- Veterans SF-12 Health Survey (VR-12) (10)
- Jebsen-Taylor Hand Function tests (JTHFT) (11)
- Activity Measure for Upper Limb Amputation (AM-ULA) (12)
- Michigan Hand Outcomes Questionnaire (MHQ) (13)
- University of New Brunswick Skill and Spontaneity Tests (14)
- Upper Extremity Work Demands score (UEWD) (15)
- Carroll Upper Extremity Function test (UEFT) (16)
- Purdue Pegboard test (PPT) (17)

- Range of Motion tests (18)
- Force Control tests (19)
- Pain (self-reported) (20)
- Other (please specify) (21) \_\_\_\_\_

Q23 Please use the scale to show your level of agreement with the following statement:

Strongly disagree   Somewhat disagree   Neither agree nor disagree   Somewhat agree   Strongly agree   Not applicable

0   1   2   3   3   4   5

Outcome measurement tools are useful in assessing partial hand prosthetics ( )	
--	--

Q24 In your opinion, which factors are important when assessing outcomes for partial hand prosthesis users?

Not at all important   Slightly important   Moderately important   Very important   Extremely important

0   1   2   3   4   5

Function ()	
User satisfaction ()	
Comfort ()	
Easy donning/doffing of device ()	

Q25 In your opinion, could outcome measurement tools be improved for assessment of partial hand prosthesis users?

- Yes (3)
- Unsure (4)
- No (5)

*Display This Question:*

*If Q25 = 3*

Q26 Please give a short explanation as to why/how outcome measurement tools could be improved for assessing partial hand prosthesis users

---



---



---



---



---

End of Block: Outcome Measures

---

Start of Block: Decision Making

Q27 Which other professions do you work with in your role?

- prosthetist (1)
  - orthotist (2)
  - occupational therapist (3)
  - physiotherapist (4)
  - engineer (5)
  - other (please specify) (6)
- 
- none (7)

Q28 Are decisions on partial hand device prescription made solely by you, with colleagues, or by someone else?

- I am the sole decision maker for prescription (1)
  - I work with colleagues on decision making for prescription (2)
  - I am not involved in device prescription (3)
-

Display This Question:

If Q28 = 2

And Q28 = 3

Q29 If you are not the sole decision maker in terms of device prescription, who is?

- prosthetist (1)
  - orthotist (2)
  - occupational therapist (3)
  - physiotherapist (4)
  - engineer (5)
  - device user (6)
  - other (please specify) (7)
- 

Q30 In your own opinion, rate the importance of the following factors when deciding which device to prescribe.

Not at all   Slightly   Neither   Slightly   Very  
important   important   important   important   important  
or  
unimportant

0   1   2   3   4   5

Device aesthetics ()	
User's existing function ()	
Presentation of hand (e.g. number of digits) ()	
User's occupation ()	
User's hobbies ()	
Cost of device to user ()	
Cost of device to insurer ()	
Your experience/knowledge of devices ()	

Q31 Do you use tester/loan units to users so the user can trial the device(s) before a final decision is made?

Yes (1)

No (2)

*Display This Question:*

*If Q31 = 1*

Q32 From your experience, please give a short explanation of the influence that providing tester/loan units has on the user?

---



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---

End of Block: Decision Making

---

Start of Block: Funding

Q33 Which funding source(s) pay(s) for partial hand prostheses that you work with?

Private/self funded (1)

State funded (2)

Insurance (3)

Other (please specify) (4)

---

Combination of the above (5)

N/A (6)

---

*Display This Question:*

*If Q12 = 1*

*And Q28 != 3*

Q34 In your experience, has funding influenced your choice of partial hand device prescription?

- Yes (1)
  - No (2)
  - Unsure (3)
- 

Q35 In your experience, does funding influence the range of partial hand devices available for you to work with?

- Yes (1)
- No (2)
- Unsure (3)

**End of Block: Funding**

---

**Start of Block: Additional Comments**

Q36 Please add any additional comments about your experiences of working with partial hand prosthetics

---

**End of Block: Additional Comments**

---

**Start of Block: Contact Details**

Q37 Would you like to provide your contact details to allow researchers to contact you about this research? Your responses will still remain anonymous.

Yes (1)

No (2)

**End of Block: Contact Details**

---

Online Research Survey

## Experiences Working With Partial Hand Prosthetics



- Do you work with (or have you worked with) partial hand prosthetic devices or users of partial hand prostheses?
- Have you practiced this work within the last 5 years?
- Are you willing to take part in an online survey lasting up to 15 minutes?
- Are you able to take part in a survey written in the English language?

We are looking for people who work with partial hand prosthetic devices or users of partial hand prostheses: such as prosthetists, orthotists, occupational therapists, physiotherapists, hand therapists, hand surgeons and engineers.

The purpose of this study is to investigate partial hand prostheses from the perspective of the workforce who develop, assess or prescribe them.

Participation is voluntary and responses will remain anonymous.

If you have any questions or would like further information, please contact the researcher:

Kirsty Carlyle  
Department of Biomedical Engineering  
University of Strathclyde

[Kirsty.Carlyle@strath.ac.uk](mailto:Kirsty.Carlyle@strath.ac.uk)

### Social Media Advertisements

#### Twitter:

Tweet 1:

“Do you work with, or have you worked with, partial hand prosthetic devices or users of partial hand prostheses? We are looking for people to take part in an online survey titled “Experiences Working With Partial Hand Prosthetics”. Please find participant information by following the link to the survey: \*insert survey link\* #PartialHandProsthetics #ProstheticsResearch #ProstheticTechnology”

Tweet 2:

“Do you know someone who works/worked with partial hand prosthetics? Please tag and share.”

Tweet 3:

“Do you work with users of partial hand prostheses? Does someone you know work in this area? We would be grateful if you could spread the word about our survey!” \*insert survey link\*

#### LinkedIn:

“Do you work with, or have you worked with, partial hand prosthetic devices or users of partial hand prostheses? We are looking for people who fit this criteria to take part in an online research study titled “Experiences Working With Partial Hand Prosthetics”.

This study contributes to healthcare research by investigating partial hand prostheses from the perspective of the workforce who develop, assess or prescribe them. The objectives of the investigation are to gain understanding of who is prescribing partial hand prostheses, decision making processes, and factors which influence how devices are chosen.

More information about the study, eligibility, and how to take part can be found by following the link to the survey: \*insert survey link\*

#PartialHandProsthetics #ProstheticsResearch #ProstheticTechnology”

## Appendix F

Q26		
specific to partial hand		9
aesthetics		5
patient satisfaction		5
comfort		4
function		4
self reported		4
adoption time		3
ease of use		3
psychosocial		2
task specific		2
ADL		1
classification		1
customisable		1
different to lower extremity		1
experience		1
soft tissue		1

Q32		
experience	10	
success	8	
acceptance	6	
choice	6	
feedback	5	

### Focus Group Discussion Guide

**Title:** Exploring clinical decision-making in partial hand prosthetics from the clinician's perspective: a focus group study

#### Introduction (5 min)

- Thank participants for joining the focus group
- Introduce the research team
- Review the purpose of the study and plan for using results
- Note that the focus group is being recorded and identities of the participants will not be published in any dissemination
- Remind participants that they provided consent to be video recorded as part of the study, and remind them to keep their video camera switched on for the duration of the session – politely inform participants that video recordings form part of the data analysis and if they cannot use video then researchers will use their discretion
- State that participants should re-join the call should they lose connection

#### Ground Rules

- You are all encouraged to convey your own opinions and experiences, I am interested in hearing your views
- Participants must keep the identities of other participants confidential
- The moderator will guide the discussion to ensure it remains on track and relevant to the topic

#### Opening questions (allow all participants to contribute) (5 min)

1. How long have you worked in the field of partial hand prosthetics?

#### Introductory questions (5 min)

2. What drives you towards prescribing a partial hand device?

#### Transition question (5 min)

3. Can you talk through the process of decision-making when it comes to people with partial hand absence?

#### Key questions (30 mins)

4. Do you use any tools?
5. As you know from the PIS, this focus group is about designing a decision-making tool, what do you think about this idea?
  - a. What would this tool look like?

- b. Would the tool be for clinician use only? Or a shared-decision making tool?
6. Where would you want to find the decision-making tool? / Where should it be hosted?
7. What would you want the outputs to be?
  - a. i.e. myo v BP, or specific devices
8. Who should own it?
  - a. How often should it be reviewed and who by?

**Concluding question and thank you (10 min)**

9. Introduce draft. This is what we worked on from literature searching and the previous survey study. Is there anything else you would like to add?
  - Thank you for your participation and time today
  - Please direct any follow up questions or comments to the researcher at [kirsty.carlyle@strath.ac.uk](mailto:kirsty.carlyle@strath.ac.uk)

## Email Advertisement Template

**The following email will be sent with the Participant Information Sheet and advertisement poster as attachments.**

Dear *[insert name of survey study participant as appropriate]*,

Thank you for your valued participation in the online survey titled “Experiences Working With Partial Hand Prosthetics” in 2022. The findings from the study were presented at the ISPO 19<sup>th</sup> World Congress in April 2023.

We would like to invite you to take part in an online focus group titled “**Exploring clinical decision-making in partial hand prosthetics from the clinician’s perspective**”. This research was granted ethical approval by the Department of Biomedical Engineering Ethics Committee, University of Strathclyde.

This investigation is being carried out as a follow up to the online survey and aims to explore findings from the study in further detail. The findings formed from the focus group investigation will be implemented in the development of a decision-making aid for partial hand prescription.

If interested, the study involves you taking part in a small focus group discussion (6-10 participants) on Zoom which will last approximately 1 hour. The sessions will be held in August and September (dates and times to be confirmed). Participation is entirely voluntary.

Further information can be found on the Participant Information Sheet (attached). If you would like to take part or wish to find out more before participating, I would be happy to hear from you via email.

*[insert link to advert on social media]*

Thank you for your time and support.

Kind Regards,

Kirsty Carlyle  
PhD Student  
Department of Biomedical Engineering  
University of Strathclyde  
Email: [kirsty.carlyle@strath.ac.uk](mailto:kirsty.carlyle@strath.ac.uk)



**Have you prescribed partial hand prosthetics within the last 5 years?**

**Are you willing to take part in an online focus group for 1 hour?**

**Are you an English language speaker?**

You may be eligible for participation in our research study.

### Online Focus Group

## Exploring clinical decision-making in partial hand prosthetics from the clinician's perspective

We are looking for people who prescribe, or have prescribed, partial hand prosthetics to take part in an small group discussion with other clinicians. You may work in prescription alone or with colleagues.

We aim to gain an understanding of the decision-making processes involved in prescription of partial hand prosthetics. This study will provide an opportunity for feedback from clinicians on the appropriate methods and requirements for developing a decision-making tool to aid in the device prescription.

Participation is voluntary and your identity will not be published.

If you are interested in taking part or would like further information, please contact the researcher:

Kirsty Carlyle  
PhD Student  
[Kirsty.Carlyle@strath.ac.uk](mailto:Kirsty.Carlyle@strath.ac.uk)

**Location:** online using Zoom software

**Date:** various dates in August & September 2023

**Time:** to be confirmed

# Participant Information Sheet

**Name of department:** Biomedical Engineering

**Title of the study:** Exploring clinical decision-making in partial hand prosthetics from the clinician's perspective: a focus group study

## Introduction

My name is Kirsty Carlyle and I am a PhD student within the department of Biomedical Engineering at the University of Strathclyde, Glasgow, United Kingdom. I am undertaking this study as part of my research in partial hand prosthetics. I am conducting this research under the supervision of the Chief Investigator - Sarah Day, Senior Teaching Fellow, department of Biomedical Engineering and external investigator Maggie Donovan-Hall, Associate Professor, University of Southampton.

## What is the purpose of this research?

In terms of the hand, amputation of the wrist, palm or fingers of the upper limb is defined as partial hand amputation. Additionally, people may have been missing part of their hand since birth. People who are missing part of their hand may have difficulty carrying out tasks and activities which require power or precision. This is significant as this impairs ability to carry out essential and routine tasks to manage needs. Prosthetic devices to assist people with partial hand limb difference can be categorised into the following areas: cosmetic, positional, body powered, mechanical, externally powered and assistive. Therefore, there are a range of devices available to people with limb difference and their clinician. However, little is known about the decision-making processes involved in selecting which of these devices to provide the end user with. Further, while prosthetic technology is advancing, there are many people who choose not to use a device, abandon their device, or do not have device options available to them.

This investigation is being carried out as a follow up to a previously conducted online survey of clinician's experiences working with partial hand prosthetics. The investigation aims to explore findings from the survey study in further detail. The findings formed from this focus group study will be implemented in the researcher's development of a decision-making aid.

## Do you have to take part?

No. You do not have to take part as participation is voluntary.

You are free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences. However, pseudo-anonymous data (raw data which has been anonymised through applying codes to participants) cannot be withdrawn once you have attended the focus group session.

## What will you do in the project?

You will be asked to provide consent should you wish to take part in the study. Following confirmation of participation via email, you will be invited to join the focus group session on a specified time and date. You do not need to prepare anything prior to taking part in the focus group. You will be welcomed in to the focus group session on Zoom through the link provided to you via email. You must conduct the session in a private room to prevent a breach of confidentiality. You will

be asked to keep your video camera switched on for the duration of the session. Video and audio recordings from the focus group session will be collected for data analysis purposes and accessed only by the investigators.

No monetary incentive will be provided for taking part. As the focus group is online, there are no expenses associated with travel costs.

The researcher will ask questions about your experiences and opinions on prescription of partial hand prosthetics. You will be provided with an opportunity at the end of the session to add any other comments on the topic that you feel weren't discussed and should be noted.

We are inviting you to take part in a small focus group discussion (6-10 participants) on Zoom which will last approximately 1 hour. The sessions will be held in August and September at dates and times TBC.

#### **Who should take part?**

We are looking for participants who prescribe, or have prescribed, partial hand prosthetics within the past 5 years. Participants may have worked on prescription alone or alongside colleagues. Participants must be English language speakers. Participants must also have access to a device which enables taking part in an online Zoom meeting. Participants must be at least 21 years of age.

If you have questions about your eligibility, please contact the researchers.

#### **What information is being collected in the project?**

Information collected includes your experiences with prescribing partial hand prosthetics, your opinions on decision-making processes involved in prescription and feedback on a tool to assist with prescription. All information collected will be pseudo-anonymised and all data published will be non-identifiable.

#### **Who will have access to the information?**

The study is conducted in line with the University General Data Protection Regulation (GDPR) Policy. The University Privacy Notice can be found on the following website: [https://www.strath.ac.uk/media/ps/strategyandpolicy/University\\_Privacy\\_Notice\\_Conferences\\_and\\_Events\\_v1.1.pdf#:~:text=This%20privacy%20notice%20explains%20how%20the%20University%20of,read%20this%20notice%20prior%20to%20providing%20your%20information.](https://www.strath.ac.uk/media/ps/strategyandpolicy/University_Privacy_Notice_Conferences_and_Events_v1.1.pdf#:~:text=This%20privacy%20notice%20explains%20how%20the%20University%20of,read%20this%20notice%20prior%20to%20providing%20your%20information.)

Information that you provide during the focus group will remain confidential. All data will be stored on a secure platform accessed only by the investigators. Only non-identifiable information will be used when findings from the study are shared.

#### **Where will the information be stored and how long will it be kept for?**

Data obtained from this study will be stored on the University's secure platform and accessed only by researchers. Data collected will be made pseudo-anonymous. Pseudo-anonymised data (i.e. data that do not identify you personally) cannot be withdrawn once they have been included in the study and may be stored indefinitely. Identifiable data will be destroyed once it has been made pseudo-anonymous.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

All personal data will be processed in accordance with data protection legislation.

**What happens next?**

Thank you for your attention and time in reading the Participant Information.

If you would like to find out more about the study or wish to ask questions before participating, please contact the researchers.

The results of this study will be reported in the researcher's (Kirsty Carlyle) PhD thesis and may be published in other academic papers, presentations or conferences. All data published will be anonymous.

**Researcher contact details:**

Kirsty Carlyle  
PhD Student  
Department of Biomedical Engineering  
University of Strathclyde  
Email: [kirsty.carlyle@strath.ac.uk](mailto:kirsty.carlyle@strath.ac.uk)

**Chief Investigator contact details:**

Sarah Day  
Teaching Fellow  
Department of Biomedical Engineering  
University of Strathclyde  
Email: [sarah.day@strath.ac.uk](mailto:sarah.day@strath.ac.uk)

This research was granted ethical approval by the Department of Biomedical Engineering Ethics Committee, University of Strathclyde.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Linda Gilmour  
Secretary to the Departmental Ethics Committee  
Department of Biomedical Engineering  
University of Strathclyde  
Tel: 0141 548 3298  
Email: [linda.gilmour@strath.ac.uk](mailto:linda.gilmour@strath.ac.uk)

# Consent Form

**Name of department: Biomedical Engineering**

**Title of the study: Exploring clinical decision-making in partial hand prosthetics from the clinician's perspective: a focus group study**

**Please read each of the following statements and check the box to confirm:**

- I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction.
- I confirm that I have read and understood the Privacy Notice for Participants in Research Projects and understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long).
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences.
- I understand that pseudo-anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study.
- I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project.
- I consent to being audio recorded as part of the project
- I have access to a device which allows me to join a Zoom call with audio and video and consent to having both turned on

(PRINT NAME)	
Signature of Participant:	Date:

- I consent to being video recorded as part of the project

(PRINT NAME)	
Signature of Participant:	Date:



# Prosthesis User Screening Survey

## Survey Flow

**Block: Participant Information Sheet (1 Question)**

**Standard: Consent Form (1 Question)**

**Standard: Demographics (12 Questions)**

**Standard: Device Prescription (13 Questions)**

**Standard: Contact Details (2 Questions)**

Page Break

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## Start of Block: Participant Information Sheet

**Name of department: Biomedical Engineering**

**Title of the study: Developing a patient decision aid for partial hand prosthetic prescription**

My name is Kirsty Carlyle and I am a PhD student within the Department of Biomedical Engineering at the University of Strathclyde, Glasgow, United Kingdom. I am undertaking this study as part of my research in partial hand prosthetics. I am conducting this research under the supervision of the Chief Investigator - Sarah Day, Senior Teaching Fellow, Department of Biomedical Engineering and external investigator Maggie Donovan-Hall, Associate Professor, University of Southampton.

This investigation involves two studies:

- Study 1: Screening survey
- Study 2: One-to-one interviews

This Participant Information Sheet is specific to Study 1. Please note that it may not be possible for all survey participants to be invited to take part in Study 2.

### **What is the purpose of this research?**

In terms of the hand, amputation of the wrist, palm or fingers of the upper limb is defined as partial hand amputation. Additionally, people may have been missing part of their hand since birth (referred to as congenital). People who have partial hand limb absence may have difficulty carrying out tasks and activities which require power or precision. This is significant as this impairs ability to carry out essential and routine tasks to manage needs. Prosthetic devices to assist people with partial hand limb absence may be categorised into the following areas: cosmetic/silicone, body powered, myoelectric, mechanical and activity specific. Therefore, there are a range of devices available to people with limb absence and their clinician. However, little is known about the decision-making processes involved in selecting which of these devices to provide the end user with. Further, while prosthetic technology is advancing, there are many people who choose not to use a device, abandon their device, or do not have device options available to them. The overall investigation (Studies 1 & 2) aims to guide the development of a patient decision aid for partial hand prosthetic prescription through means of patient feedback and involvement studies. The investigation also aims to find out what patients require in general in terms of decision aids throughout the prescription process. Study 1 aims to obtain information directly from people who have been provided with a partial hand prosthesis to learn more about their condition and their prescription experience.

### **Do you have to take part?**

No. You do not have to take part as participation is voluntary. You are free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any

consequences. Please note that anonymous data collected from the screening survey cannot be withdrawn once the survey has been completed. If you are invited to interview, please note that pseudo-anonymous data (raw data which has been anonymised through applying code names to participants) cannot be withdrawn once you have attended the interview session.

### **What will you do in the project?**

You will begin by following a link to the survey. The consent form is on the first page of the survey. Please answer the questions on the consent form to confirm that you understand. If you give consent to take part in the study you will click the button to continue, and you will be directed on to the survey questions. The survey includes questions about your partial hand limb absence, amputation (if applicable), types of prosthesis you have been prescribed and your experience with the prescription process. The survey should take no longer than 15 minutes to complete. At the end of the main survey, you will be asked if you wish to provide the researchers with your contact details in order to be considered for Study 2 - Interviews. Providing contact details is voluntary. You will then exit the survey and the screen will state "Thank you for completing the survey" to confirm that your responses have been saved. The survey will be live until 31st May 2024. You will be able to take the survey at any point within this period. Please note that interviews for Study 2 – Interviews will take place before the survey closing date. No monetary incentive will be provided for taking part in the survey. As the survey is online, there are no expenses associated with travel costs.

### **Who should take part?**

We are looking for people who have been prescribed a partial hand prosthesis. You may or may not currently use a prosthesis. If you do not currently use a prosthesis, you must have used one within the past 5 years. We are looking for adults aged 18 or over. Additionally, you may live anywhere across the globe but must be an English language speaker to take part. Participation is open to people who have access to a device which enables you to take part in an online survey. Please note that for Study 2 – Interviews, you must also be able to take part in an online meeting held on Zoom with audio and video. What information is being collected in the project? Information collected includes your demographic data (age, sex, occupation), level of partial hand limb absence, amputation information (if applicable), your experience with prosthetic devices, your experience with the prescription process. You will be able to enter any additional comments related to the survey questions. Contact details will only be collected if you wish to be invited to Study 2 – Interviews. This is not compulsory. These are the only identifiable data which will be collected in the study and will be destroyed once no longer required. No identifiable data will be used for data analysis or in publications.

### **Who will have access to the information?**

The study is conducted in lines with the University General Data Protection Regulation (GDPR) Policy. The University Privacy Notice can be found on the following website: <https://www.strath.ac.uk/ethics/>. Information that you provide will remain confidential. All data will be stored on a secure platform accessed only by the investigators. Only non-identifiable information will be used when findings from the study are shared.

**Where will the information be stored and how long will it be kept for?**

Data obtained from this study will be stored on the University's secure platform and accessed only by researchers. Anonymous data may be stored indefinitely. If you choose to provide your contact details, these may be stored on a secure OneDrive folder for up to 3 years. Thank you for reading this information – please ask any questions if you are unsure about what is written here. All personal data will be processed in accordance with data protection legislation. Please read our <https://www.strath.ac.uk/ethics/> for more information about your rights under the legislation.

**What happens next?**

Thank you for your attention and time in reading the Participant Information. If you would like to find out more about the study or wish to ask questions before participating, please contact the researchers. If you decide to take part in the survey (study 1) and opt-in to providing your contact details, you may be contacted via email to invite you to take part in an interview (Study 2). Please note that the researchers wish to capture a diverse range of experiences of partial hand limb absence and it may not be feasible to interview every participant who takes part in the survey. If selected, you will receive a Participant Information Sheet specific to Study 2. The results of this study will be reported in the researcher's (Kirsty Carlyle) PhD thesis and may be published in other academic papers, presentations or conferences. All data published will be anonymous.

**Researcher contact details:**

Kirsty Carlyle, PhD Student, Department of Biomedical Engineering, University of Strathclyde.  
Email: [kirsty.carlyle@strath.ac.uk](mailto:kirsty.carlyle@strath.ac.uk)

**Chief Investigator details:**

Sarah Day, Senior Teaching Fellow, Department of Biomedical Engineering, University of Strathclyde  
Email: [sarah.day@strath.ac.uk](mailto:sarah.day@strath.ac.uk)

This research was granted ethical approval by the University of Strathclyde Ethics Committee. If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee

Research & Knowledge Exchange Services, University of Strathclyde, Graham Hills Building, 50  
George Street, Glasgow, G1 1QE

Telephone: 0141 548 3707

Email: [ethics@strath.ac.uk](mailto:ethics@strath.ac.uk)

**End of Block: Participant Information Sheet**

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**Start of Block: Consent Form**

**Consent Form for Screening Survey (Study 1)** I confirm that I have read and understood the Participant Information Sheet for the project and the researcher has answered any queries to my satisfaction. I confirm that I have read and understood the Privacy Notice for Participants in Research Projects and understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long). I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences. I understand that anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study. I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.

- I have read and understood the Participant Information Sheet, and consent to being a participant in the study (1)
- I do not consent to being a participant in the study (2)

*Skip To: End of Survey If QID2 = I do not consent to being a participant in the study*

**End of Block: Consent Form**

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**Start of Block: Demographics**

Q1 What is your age?

- Under 18 (1)
  - 18 - 24 (2)
  - 25 - 34 (3)
  - 35 - 44 (4)
  - 45 - 54 (5)
  - 55 - 64 (6)
  - 65 - 74 (7)
  - 75 - 84 (8)
  - 85 or older (9)
- 

Q2 Which gender do you identify as?

- Male (1)
  - Female (2)
  - Non-binary / third gender (3)
  - Prefer not to say (4)
  - Other (please type your answer) (5)
-

---

Q3 Please select which statement relates to you

- I was born with partial hand limb difference (congenital) (1)
- I have had partial hand amputation (2)

---

*Display This Question:*

*If Q3 = I have had partial hand amputation*

Q4 In which year did your amputation take place?

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*Display This Question:*

*If Q3 = I have had partial hand amputation*

Q5 What was the reason for your amputation?

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Page Break

Q6a In your own words, please describe your level of partial hand limb absence.

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Q6b You may choose to upload a picture of your partial hand limb difference here. This can be a photograph or a line drawing which shows your level of limb absence.

Please note that if you choose to upload a picture, this will be destroyed after data analysis. Your picture will not be shared or used in any publications.

*Display This Question:*

*If You may choose to upload a picture of your partial hand limb difference here. This can be a photograph or a line drawing which shows your level of limb absence. Please note that if you choose to upl... File Is Not Uploaded*

Q6c Does your partial hand limb absence include your thumb?

- I have a full thumb (1)
- I have a partial thumb (2)
- I do not have a thumb (3)

Display This Question:

*If You may choose to upload a picture of your partial hand limb difference here. This can be a photograph or a line drawing which shows your level of limb absence. Please note that if you choose to upl... File Is Not Uploaded*

Q6d Does your partial hand limb absence include your fingers?

- I have fingers (1)
  - I have partial fingers (2)
  - I do not have fingers (3)
  - Other (please specify in text box) (4)
- 

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Page Break

Q7 What is your current employment status?

- I am employed (1)
- I am not employed (2)

---

*Display This Question:*

*If Q7 = I am employed*

Q8 What is your current occupation?

---

---

*Display This Question:*

*If Q3 = I have had partial hand amputation*

Q9 What was your occupation at the time of your amputation?

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End of Block: Demographics

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Start of Block: Device Prescription

Q10 Has someone prescribed a partial hand prosthesis to you?

Yes (1)

No (2)

*Skip To: End of Survey If Q10 = No*

Q11 How many prostheses have been prescribed to you?

▼ 1 (1) ... 12+ (12)

Q12 In which country (or countries) have you received a prosthesis prescription?

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*Display This Question:*

*If Q11 != 1*

Q13 In which year did you receive your **first** partial hand prosthesis?

---

Q14 In which year did you receive your **most recently prescribed** partial hand prosthesis?

---

Q15 What type of prosthesis/prostheses have you been prescribed? You may select multiple.

- Myoelectric (1)
- Body-powered (2)
- Mechanical (3)
- Silicone/cosmetic (4)
- Activity specific (5)
- Other (please specify in text) (6)

---

*Carry Forward Selected Choices from "Q15"*

X→

Q16 Which type of prosthesis/prostheses do you **currently use**? You may select multiple.

- No device (1)
- Myoelectric (2)
- Body-powered (3)
- Mechanical (4)
- Silicone/cosmetic (5)
- Activity specific (6)
- Other (please specify in text) (7)

---

Q18 Were you given any physical information packs (e.g. leaflets) by the person/centre who supplied your prosthesis?

- Yes (1)
- No (2)

---

*Display This Question:*

*If Q18 = Yes*

Q19 Please describe the information contained in physical packs (e.g. leaflets)

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Q20 Thinking about when you were prescribed your prosthesis, would you have liked to know about all the different prosthetic options available for partial hand limb difference, or just the options which are available specifically for you?

- It is better to know all of the options (1)
- It is better to know about the options available specifically for me (2)
- I am unsure (3)

---

Q21 Thinking about when you were prescribed your prosthesis, have you ever been shown a physical example of the prosthesis before measurements were taken?

- Yes (1)
  - No (2)
  - I do not remember (3)
-

Q22 Do you think it would be useful to see a physical example of each type of prosthesis before deciding on the prescription?

- Definitely not (1)
- Probably not (2)
- Might or might not (3)
- Probably yes (4)
- Definitely yes (5)

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Page Break

Q23 Do you have any comments or suggestions related to the prescription process for partial hand?

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End of Block: Device Prescription

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Start of Block: Contact Details

Q24 Do you wish to be contacted by the researchers to take part in an interview?

Yes (1)

No (2)

*Skip To: End of Survey If Q24 = No*

---

Q25 Please provide your name and email address. (Please note that it may not be possible to interview all participants)

Name (1) \_\_\_\_\_

Email Address (2) \_\_\_\_\_

End of Block: Contact Details

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# Appendix M

## Interview questions

### Introduction

- Inform the participant of what the interview involves - 'housekeeping'
- Remind participant of objectives
- Let participant know that we can pause at any time and they are not obliged to answer anything they are not comfortable with
- Remind participant that the session is being recorded

### Section 1: Prescription

1. When you were in the process of being prescribed your prosthesis, what mattered most to you at that time?
2. What information were you provided with by the prescriber?
  - a. Did they provide you with information to research online by yourself?
    - i. If so – what information?
3. Have you asked questions about your limb difference or prosthesis to a professional?
  - a. Which professional?
  - b. What did you ask?
4. Why do you think you were given X prosthesis?
  - a. Did the prescriber explain why X over Y?

### Section 2: Patient decision aid development

1. What information do you think people with PH limb difference should be given during the prescription process
2. How do you think the prosthesis options should be communicated to people in prescription?
  - a. Visuals, statistics, written information...
3. How do you feel about a patient decision aid for partial hand limb difference?
4. If a patient decision aid was to be made available, where do you think it should be located?
  - a. Online, printed...
  - b. Available to use at home or in clinic with prescriber
5. What resources do you think would be beneficial (i.e. links to websites, support groups) to be given at the prescription point of the process?

### Section 3: Patient decision aid draft

1. What do you think about the template?
2. What do you think about the order of the content?
3. Looking back at your own experience with the prescription process, do you feel a patient decision aid like this would have impacted your experience?
  - a. What about the outcome?

General follow up

1. Any additional thoughts you would like to share?

Thank you and exit

# Appendix N

## Decision Aid Purpose:

The purpose of a patient decision aid is to prepare the patient by providing information to make an informed decision with their personal values at the forefront and to prompt discussions with their healthcare provider.



The purpose of a patient decision aid is not to persuade people to choose one option over another or replace interactions with health professionals.



## Examples of PDA's

Inhaler type	How are they used?	Do they contain propellant (gas)?
<p>Metered dose inhalers (MDIs)</p>	You press on a canister in the inhaler to release a puff of medicine and propellant (gas), which you breathe in. Some MDIs have a counter to tell you how many doses you have left, some do not. You can also use an MDI with a spacer to help make it more effective.	Yes
<p>Breath-actuated inhalers (BAIs)</p>	First, you set the inhaler (how to do this depends on the make of inhaler). When you breathe in, a puff of medicine and propellant (gas) is released automatically. BAIs do not have a counter to tell you how many doses you have left.	Yes
<p>Dry powder inhalers (DPIs)</p>	You press a button or lever, load a capsule or twist a dial to get the inhaler ready. The medicine is released when you breathe in. You can see how many doses you have left.	No
<p>Soft mist inhalers (SMIs)</p>	You press a button and the medicine is released into a mist, which you breathe in. You can see how many doses you have left.	No

At the moment only a medicine for severe asthma is available in an SMi.

### How you feel about the options

You can use the table to help you make a note about how important the issues are to you.

Issue	How important is this to me?			
	Very important	Important	Not important	Not at all important
Whether the treatment is a tablet, injection, IUS or implant				
Likely effect on my endometriosis pain				
Likely effect on my periods				
Issues if I want to stop using it				
Effectiveness as a contraceptive				
Issues if I want to try for a baby				
The risk of common side effects				
The risk of blood clots such as DVT				
The risk of other serious side effects				

Other concerns or questions I would like to discuss:

#### What is this leaflet?

This leaflet is about an enlarged prostate. It is also called benign prostate enlargement (BPE). It is not cancer. This leaflet will help you decide which treatment to choose. You should go through the relevant part for you and then talk to your healthcare professional. There are pages you can fill in.

**Read Part 1** if you have symptoms or your GP says you have an enlarged prostate. **Pages 2 – 7**

**Read Part 2** if you are referred to hospital to see a specialist and are thinking about surgery. **Pages 8 – 15**

#### What is a prostate?

The prostate is about the size of a plum. It sits around the tube (urethra) that takes urine from the bladder, through the penis, and out of the body. It makes semen and controls the flow of urine (pee) from the bladder.

All prostates grow bigger as you get older. How quickly and how big varies from person to person. In some people, enlarged prostate can cause symptoms because it squeezes the urethra or puts pressure on your bladder. Sometimes it gets bigger but does not press on the urethra or bladder.

#### What are the symptoms?

- Peeing more often, needing to pee urgently or leaking, waking up at night to pee.
- Feeling like your bladder doesn't completely empty.
- Problems with flow.
- You may have problems with erections.

BPE is not cancer. If you an have enlarged prostate it does not mean you are more likely to get prostate cancer.

#### What can I do about an enlarged prostate?

**Do nothing** – you can always choose not to have treatment

**At the GP (Part 1)**

- Things I can do myself Page 5
- Medicines Pages 6 & 7

**At the hospital (Part 2)**

- Medicines Pages 6 & 7
- Surgery Pages 10 – 14
- Catheter Page 15

#### I am having problems with

(tick which apply to you)

- leaking pee (urine)
- urgency
- being able to ejaculate
- getting and maintaining erections
- getting up at night to pee
- needing to pee more often
- stream that stops and starts
- feeling like bladder does not fully empty
- needing to strain or push to pee
- needing to pee without warning
- slow or less flow of pee
- waiting for flow to start
- splitting or spraying of stream

#### What would you like most help with?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

#### My symptoms are

(mark your answers on each scale)

No / not at all | Yes / A lot

- making me anxious or affecting my wellbeing or self-worth
- limiting my daily activities such as going shopping or socialising
- causing relationship issues because I have problems with erections or ejaculation
- affecting my sleep

#### What have you already tried?

\_\_\_\_\_

\_\_\_\_\_

The last two pages of the leaflet can help you prepare for your next appointment and include links for more information.

Select the options you wish to compare

No Treatment
  Topical Treatments
  Oral Treatments
  Light and Laser Treatments
  Miscellaneous/ Adjunctive Treatments

	No Treatment	Topical Treatments	Oral Treatments	Miscellaneous/ Adjunctive Treatments
What is it?	You can choose to wait and see if your acne clears up on its own.	<p>These are treatments applied onto the skin as lotions, gels, creams and foams. They can be used alone, or with other topical or oral (pill) drugs.</p> <p>These are the different topical treatments:</p> <ul style="list-style-type: none"> <li>• Azelaic Acid</li> <li>• Benzoyl Peroxide</li> <li>• Combination treatments</li> <li>• Dapsone (Aczone)</li> <li>• Salicylic Acid</li> <li>• Topical Antibiotics</li> <li>• Topical Retinoids</li> </ul>	<p>These are treatments taken by mouth. They are sometimes used alone or with other treatments to combine their effects.</p> <p>These are the different oral treatments:</p> <ul style="list-style-type: none"> <li>• Hormonal treatments</li> <li>• Oral antibiotics</li> <li>• Oral isotretinoin treatment</li> </ul>	<p>These are treatments that do not fit in the traditional categories. Some of these treatments have been practiced for a long time or in different parts of the world.</p> <p>These are some types of treatments:</p> <ul style="list-style-type: none"> <li>• Chemical peels</li> <li>• Corticosteroid shots (These are shots into individual acne spots).</li> <li>• Diet changes (These are changes in what you eat and drink).</li> <li>• Herbal treatments</li> </ul>

## Content

1. Introduction
2. What does the research show?
3. What matters most to me?
4. Funding
5. Check your understanding
6. How comfortable are you about making this decision?
7. What are the next steps?

## Section 1 - Introduction

- This decision aid is for you if...
- What is partial hand limb difference?
- What are prostheses?
- Why am I being asked about prostheses?
- How to proceed with the decision aid

## Section 2 – What does the research show?

- Benefits
- Harms

## Section 3 – What matters most to me?

- Design requirements
- Goal setting

## Section 4 – Funding

- Discuss with provider
- Links

## Section 5 – Check your understanding

## Section 6 – How comfortable are you about making this decision?

## Section 7 – What are your next steps?

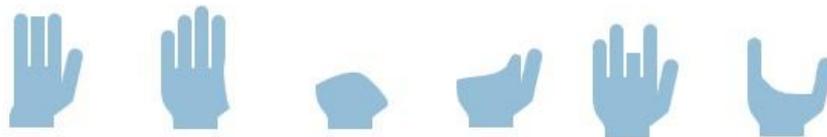
- Discuss with provider
- Links to support groups



## Do you have partial hand limb absence?

Opportunity to take part in online research in our study:

**“Developing a patient decision aid for partial hand prosthetic prescription”**



- ✓ *Do you have partial hand limb absence?*
- ✓ *Are you aged 18 or over?*
- ✓ *Have you used a partial hand prosthesis within the last 5 years?*
- ✓ *Are you an English language speaker?*

**Study 1:** Screening survey  
**Study 2:** One-to-one interview

Follow the **link to the survey** to read the full Participant Information Sheet and take part:  
\*link to survey\*

If you have any questions about this investigation, or would like further information, please contact the researcher:

Kirsty Carlyle  
PhD Student  
Department of Biomedical Engineering  
kirsty.carlyle@strath.ac.uk

Scan QR  
code to  
access  
survey

QR CODE  
HERE

# Participant Information Sheet for Study 1 - Survey

Please note: this participant information sheet will be contained on the first page of the Qualtrics survey.

**Name of department: Biomedical Engineering**

**Title of the study: Developing a patient decision aid for partial hand prosthetic prescription**

## Introduction

My name is Kirsty Carlyle and I am a PhD student within the Department of Biomedical Engineering at the University of Strathclyde, Glasgow, United Kingdom. I am undertaking this study as part of my research in partial hand prosthetics. I am conducting this research under the supervision of the Chief Investigator - Sarah Day, Senior Teaching Fellow, Department of Biomedical Engineering and external investigator Maggie Donovan-Hall, Associate Professor, University of Southampton.

This investigation involves two studies:

- Study 1: Screening survey
- Study 2: One-to-one interviews

Please note that study 2 has now closed and interviews have been carried out, however, the researchers welcome you to contact us if you would like to discuss the topic or survey questions further. This Participant Information Sheet is specific to Study 1.

## What is the purpose of this research?

In terms of the hand, amputation of the wrist, palm or fingers of the upper limb is defined as partial hand amputation. Additionally, people may have been missing part of their hand since birth (referred to as congenital). People who have partial hand limb absence may have difficulty carrying out tasks and activities which require power or precision. This is significant as this impairs ability to carry out essential and routine tasks to manage needs. Prosthetic devices to assist people with partial hand limb absence may be categorised into the following areas: cosmetic/silicone, body powered, myoelectric, mechanical and activity specific. Therefore, there are a range of devices available to people with limb absence and their clinician. However, little is known about the decision-making processes involved in selecting which of these devices to provide the end user with. Further, while prosthetic technology is advancing, there are many people who choose not to use a device, abandon their device, or do not have device options available to them.

The overall investigation (Studies 1 & 2) aims to guide the development of a patient decision aid for partial hand prosthetic prescription through means of patient feedback and involvement studies. The investigation also aims to find out what patients require in general

in terms of decision aids throughout the prescription process. Study 1 aims to obtain information directly from people who have been provided with a partial hand prosthesis to learn more about their condition and their prescription experience. Study 2 aims to explore the topic in more depth and provide participants with the opportunity to discuss their thoughts and opinions about their lived experience and decision-making in partial hand prosthetics.

### **Do you have to take part?**

No. You do not have to take part as participation is voluntary.

You are free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences. Data analysed in this study will be pseudonymised (i.e. a code name will be applied to each participant, making you unidentifiable).

### **What will you do in the project?**

You will begin by following a link to the survey. The consent form is on the first page of the survey. Please answer the questions on the consent form to confirm that you understand. If you give consent to take part in the study you will click the button to continue, and you will be directed on to the survey questions.

The survey includes questions about your partial hand limb absence, amputation (if applicable), types of prosthesis you have been prescribed and your experience with the prescription process. Some questions may be skipped if you do not wish to answer. The survey should take no longer than 15 minutes to complete. At the end of the main survey, you will be asked if you wish to provide the researchers with your contact details in order to be considered for Study 2 - Interviews. Providing contact details is voluntary. You will then exit the survey and the screen will state "Thank you for completing the survey" to confirm that your responses have been saved.

The survey will be live until 30<sup>th</sup> September 2024. You will be able to take the survey at any point within this period. Please note that interviews for Study 2 – Interviews will take place before the survey closing date.

No monetary incentive will be provided for taking part in the survey. As the survey is online, there are no expenses associated with travel costs.

### **Who should take part?**

We are looking for people who have been prescribed a partial hand prosthesis. You may or may not currently use a prosthesis. If you do not currently use a prosthesis, you must have used one within the past 5 years. We are looking for adults aged 18 or over. Additionally, you may live anywhere across the globe but must be an English language speaker to take part. Participation is open to people who have access to a device which enables you to take part in an online survey.

### **What information is being collected in the project?**

Information collected includes information about you (age, gender, occupation), level of partial hand limb absence, amputation information (if applicable), your experience with

prosthetic devices, your experience with the prescription process. You will be able to enter any additional comments related to the survey questions.

Contact details will only be collected if you wish to provide them. This is not compulsory. These are the only identifiable data which will be collected in the study and will be destroyed once no longer required. No identifiable data will be used for data analysis or in publications.

#### **Who will have access to the information?**

All personal data will be processed in accordance with data protection legislation. The University Privacy Notice can be found on the following website: <https://www.strath.ac.uk/ethics/>. Information that you provide will remain confidential. All data will be stored on a secure platform accessed only by the investigators. Only non-identifiable information will be used when findings from the study are shared.

#### **Where will the information be stored and how long will it be kept for?**

Data obtained from this study will be stored on the University's secure platform and accessed only by researchers. Anonymous data may be stored indefinitely. If you choose to provide your contact details, these may be stored on a secure OneDrive folder for up to 3 years.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

All personal data will be processed in accordance with data protection legislation. Please read our <https://www.strath.ac.uk/ethics/> for more information about your rights under the legislation.

#### **What happens next?**

Thank you for your attention and time in reading the Participant Information.

If you would like to find out more about the study or wish to ask questions before participating, please contact the researchers.

The results of this study will be reported in the researcher's (Kirsty Carlyle) PhD thesis and may be published in other academic papers, presentations or conferences. All data published will be anonymous.

The following websites can provide further information and support for people with limb difference:

- Limbless Association – support services for people with amputation e.g. amputee resource pack and support group events <https://limbless-association.org/how-we-can-help/>
- Amputation Foundation – charitable organisation providing assistance to people with amputation, e.g. legal information and counselling <https://amputationfoundation.org/>
- Amputee Coalition – information and support for people with amputation and their caregivers <https://www.amputee-coalition.org/>

- Mind – UK based charitable organisation offering mental health information and support <https://www.mind.org.uk/information-support/>

**Researcher contact details:**

Kirsty Carlyle  
PhD Student  
Department of Biomedical Engineering  
University of Strathclyde  
Email: [kirsty.carlyle@strath.ac.uk](mailto:kirsty.carlyle@strath.ac.uk)

**Chief Investigator details:**

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Department of Biomedical Engineering  
University of Strathclyde  
Email: [sarah.day@strath.ac.uk](mailto:sarah.day@strath.ac.uk)

This research was granted ethical approval by the University of Strathclyde Ethics Committee.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee  
Research & Knowledge Exchange Services  
University of Strathclyde  
Graham Hills Building  
50 George Street  
Glasgow  
G1 1QE

Telephone: 0141 548 3707  
Email: [ethics@strath.ac.uk](mailto:ethics@strath.ac.uk)

# Consent Form for Screening Survey (Study 1)

Please note: this is a copy of the consent form contained within the Qualtrics survey.

**Name of department: Biomedical Engineering**

**Title of the study: Developing a patient decision aid for partial hand prosthetic prescription**

- I confirm that I have read and understood the Participant Information Sheet for the project and the researcher has answered any queries to my satisfaction.
- I confirm that I have read and understood the Privacy Notice for Participants in Research Projects and understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long).
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences.
- I understand that anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study.
- I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project.

## Email Invitation Template

**The following email will be sent with the Participant Information Sheet for Study 2**

Dear *[insert name of survey study participant as appropriate]*,

Thank you for your valued participation in the online screening survey for our investigation titled “Developing a patient decision aid for partial hand prosthetic prescription”. We appreciate your interest in Study 2.

We would like to invite you to take part in online one-to-one interview which forms study 2 of this investigation. This research was granted ethical approval by the Department of Biomedical Engineering Ethics Committee, University of Strathclyde.

This investigation is being carried out to gain feedback and input into developing a patient decision aid from people who have been prescribed a partial hand prosthesis.

If interested, the study involves you taking part in an interview on Zoom which will last approximately 1 hour. Interview sessions will be held March and May. I have attached some suggested time slots at the bottom of this email and would appreciate if you could let us know your availability within this period. Participation is entirely voluntary.

Further information can be found on the Participant Information Sheet (attached). If you would like to take part or wish to find out more before participating, I would be happy to hear from you via email.

*[insert link to advert on social media]*

Thank you for your time and support.

Kind Regards,

Kirsty Carlyle  
PhD Student  
Department of Biomedical Engineering  
University of Strathclyde  
Email: [kirsty.carlyle@strath.ac.uk](mailto:kirsty.carlyle@strath.ac.uk)

## **Participant Information Sheet for Study 2 - Interviews**

**Name of department: Biomedical Engineering**

**Title of the study: Developing a patient decision aid for partial hand prosthetic prescription**

### **Introduction**

My name is Kirsty Carlyle and I am a PhD student within the Department of Biomedical Engineering at the University of Strathclyde, Glasgow, United Kingdom. I am undertaking this study as part of my research in partial hand prosthetics. I am conducting this research under the supervision of the Chief Investigator - Sarah Day, Senior Teaching Fellow, Department of Biomedical Engineering and external investigator Maggie Donovan-Hall, Associate Professor, University of Southampton.

This investigation involves two studies:

- Study 1: Screening survey
- Study 2: One-to-one interviews

This Participant Information Sheet is specific to Study 2.

### **What is the purpose of this research?**

In terms of the hand, amputation of the wrist, palm or fingers of the upper limb is defined as partial hand amputation. Additionally, people may have been missing part of their hand since birth (referred to as congenital). People who have partial hand limb absence may have difficulty carrying out tasks and activities which require power or precision. This is significant as this impairs ability to carry out essential and routine tasks to manage needs. Prosthetic devices to assist people with partial hand limb absence may be categorised into the following areas: cosmetic/silicone, body powered, myoelectric, mechanical and activity specific. Therefore, there are a range of devices available to people with limb absence and their clinician. However, little is known about the decision-making processes involved in selecting which of these devices to provide the end user with. Further, while prosthetic technology is advancing, there are many people who choose not to use a device, abandon their device, or do not have device options available to them.

The overall investigation (Studies 1 & 2) aims to guide the development of a patient decision aid for partial hand prosthetic prescription through means of patient feedback and involvement studies. The investigation also aims to find out what patients require in general in terms of decision aids throughout the prescription process.

### **Do you have to take part?**

No. You do not have to take part as participation is voluntary.

You are free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences. However, pseudo-anonymous data (raw data which has been anonymised through applying code names to participants) cannot be withdrawn once you have attended the interview session.

#### **What will you do in the project?**

You will be asked to provide consent should you wish to take part in the study. Following confirmation of participation via email, you will be invited to join an online interview session on a specified time and date. You do not need to prepare anything prior to taking part in the interview.

You will be welcomed in to the interview on Zoom through the link provided to you via email. It is recommended that you conduct the session in a private room to prevent a breach of confidentiality and prevent risk of a third party overhearing the discussion. You will be asked to keep your video camera switched on for the duration of the session. Video and audio recordings from the interview session will be collected for data analysis purposes and accessed only by the investigators.

No monetary incentive will be provided for taking part. As the focus group is online, there are no expenses associated with travel costs.

The researcher will ask questions about your experiences of prosthesis prescription and opinions on a proposed patient decision aid for partial hand prosthetic prescription. You will be provided with an opportunity at the end of the session to add any other comments on the topic that you feel weren't discussed and should be noted.

We are inviting you to take part in a one-to-one interview with the researcher (Kirsty Carlyle) on Zoom which will last approximately 1 hour. The sessions will be held between March and May at a scheduled date and time agreed between you and the researcher.

#### **Who should take part?**

We are looking for people who have been prescribed a partial hand prosthesis. You may or may not currently use a prosthesis. If you do not currently use a prosthesis, you must have used one within the past 5 years. We are looking for adults aged 18 or over. Additionally, you may live anywhere across the globe but must be an English language speaker to take part. You must also be able to take part in an online meeting held on Zoom with audio and video.

#### **What information is being collected in the project?**

Information collected includes your experience with the prescription process, your thoughts about your prescription, your opinions on the information that should be given to people with partial hand absence at time of prescription and your opinions on a patient decision aid in development. You will be shown a version of a patient decision aid for partial hand absence which is currently under development by the researchers. Your feedback and opinions on this aid will be valued by the researchers. You will be given an opportunity to provide any additional thoughts or comments related to the discussion at the end of the interview.

All information collected will be pseudo-anonymised and all data published will be non-identifiable.

**Who will have access to the information?**

The study is conducted in lines with the University General Data Protection Regulation (GDPR) Policy. The University Privacy Notice can be found on the following website: <https://www.strath.ac.uk/ethics/>. Information that you provide will remain confidential. All data will be stored on a secure platform accessed only by the investigators. Only non-identifiable information will be used when findings from the study are shared.

**Where will the information be stored and how long will it be kept for?**

Data obtained from this study will be stored on the University's secure platform and accessed only by researchers. Data collected will be made pseudo-anonymous. Pseudo-anonymised data (i.e. data that do not identify you personally) cannot be withdrawn once they have been included in the study and may be stored indefinitely. Identifiable data will be destroyed once it has been made pseudo-anonymous.

All personal data will be processed in accordance with data protection legislation. Please read our <https://www.strath.ac.uk/ethics/> for more information about your rights under the legislation. Thank you for reading this information – please ask any questions if you are unsure about what is written here.

**What happens next?**

Thank you for your attention and time in reading the Participant Information. If you would like to find out more about the study or wish to ask questions before participating, please contact the researchers.

If you decide to take part in the interview, you will be contacted via email to arrange a suitable date and time with the researcher. You will be also provided with a consent form to confirm your participation. The researcher will send a Zoom meeting invitation, with instructions on how to join the meeting, and up to 2 email reminders prior to the interview session.

The results of this study will be reported in the researcher's (Kirsty Carlyle) PhD thesis and may be published in other academic papers, presentations or conferences. All data published will be anonymous.

**Researcher contact details:**

Kirsty Carlyle  
PhD Student  
Department of Biomedical Engineering  
University of Strathclyde  
Email: [kirsty.carlyle@strath.ac.uk](mailto:kirsty.carlyle@strath.ac.uk)

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This research was granted ethical approval by the University of Strathclyde Ethics Committee.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee  
Research & Knowledge Exchange Services  
University of Strathclyde  
Graham Hills Building  
50 George Street  
Glasgow  
G1 1QE

Telephone: 0141 548 3707  
Email: [ethics@strath.ac.uk](mailto:ethics@strath.ac.uk)

## Consent Form for Interview (Study 2)

**Name of department: Biomedical Engineering**

**Title of the study: Developing a patient decision aid for partial hand prosthetic prescription (Study 2 - Interviews)**

- I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction.
- I confirm that I have read and understood the Privacy Notice for Participants in Research Projects and understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long).
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences.
- I understand that pseudo-anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study.
- I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project.
- I consent to being audio and/or video recorded as part of the project.
- I have access to a device which allows me to join a Zoom meeting with audio and video, and consent to having both turned on.

(PRINT NAME)	
Signature of Participant:	Date:

### **Partial hand limb difference: a guide to making a decision about prostheses**

#### **Introduction to this guide**

This guide is here to help you make decisions about prosthetic options. It gives you useful information and includes pages you can fill out. You can bring it with you to talk with your doctor or other healthcare professionals.

The goal of this guide is not to tell you what to choose, but to help you understand your options. The purpose is not supposed to replace talking with your healthcare team.

#### **This decision aid is for you if...**

This guide focuses on partial hand prosthetics. It explains what a partial hand limb difference is and the different options available. You might be a good fit for some or all of these prosthetic options.

#### **Graphic #1: patient speaking to clinician/prosthetist, making a decision**

#### **Contents**

Section 1 - Information about partial hand limb difference and prostheses – page X

Section 2 - Interactive sheets – page X

Section 3 - Further support – page X

#### **SECTION 1 – Information**

##### **What is partial hand limb difference?**

Partial hand limb difference means someone only has part of their hand or is missing some or part of their fingers. Therefore, this could include having some fingers, a thumb, or part of the palm. You might also hear this called limb absence.

Partial hand limb difference can happen be the result of either of the following:

- **Amputation:** This is when part of a limb is surgically removed because of an injury or illness.
- **Congenital difference:** This means a person is born with it. A congenital limb difference happens when a baby is born with a hand that hasn't fully formed, so part of the hand is missing.

#### **Graphic #2: partial hands**

##### **What are prostheses?**

**Prostheses** are artificial body parts that can help people with limb differences. A prosthesis can be designed to replace the function of the missing body part, improve how it looks, or do both.

**Residual limb** or 'residuum' means the part of the limb that is still there. For example, if you are missing fingers, the rest of your hand is called your residual limb.

A **socket** is part of your prosthesis. It is the part that contacts with your residual hand. Sockets are custom made to the shape of your residual limb. Sockets are usually lightweight, comfortable, and can protect your residual limb.

### Graphic #3: partial hand prostheses

**Who might I work with on my journey to being provided with a prosthesis?**

There are many types of professionals who work in prosthetics for people with partial hand limb differences. The team you meet can vary depending on where you live. Here are some common roles you might work with:

- **Prosthetist (CPO, clinician):** This person may prescribe, fit, and check your prosthesis.
- **Occupational Therapist (OT):** An OT can help you learn how to do daily tasks and activities. They may also teach you how to use your prosthesis.
- **Physiotherapist (physical therapist, PT):** A physiotherapist helps with rehabilitation and can give you exercises to improve your strength and movement.
- **Hand Therapist (CHT):** A hand therapist specialises in the hand. They might assess your hand, give you exercises, and sometimes prescribe a prosthesis.
- **Mental Health Worker (psychologist, counsellor, nurse):** This person supports your mental health and helps you cope with any emotional challenges related to limb difference.
- **Social Worker:** A social worker can help with practical things like organising paperwork, applying for funding, or managing other parts of your care or treatment.
- **Surgeon:** If you need surgery, you may work with a surgeon. Some surgeons specialize in hands, orthopaedics (bones), trauma (accidents), or other areas. They may work closely with prosthetists or other team members.
- **Rehabilitation Physician (rehab doctor):** This doctor may help after surgery by referring you to other specialists, like a prosthetist or occupational therapist.

### Graphic #4: different healthcare workers – prosthetist, surgeon, nurse, hospital

Text box at side/bottom of page:

Icon: light bulk/key point

- Different occupations may be involved in your journey – from prosthesis assessment to post-prescription care

### How much does a prosthesis cost? Icon:funding

The cost of prostheses may be fully, partially or not at all covered by funding depending on your situation, reason for limb difference, geographical location and insurance coverage. The price range for prostheses varies and may require consideration when choosing your device. You may wish to discuss funding with provider.

### When would I get a prosthesis and what happens after?

#### First prosthesis

People get their first prosthesis at different times. If you've had an amputation, you may start working with a team to help you get ready for a prosthesis. After surgery, your residual limb may change shape as it heals, so you may need to wait before getting fitted. Over time, your residual limb could keep changing shape, which means you might need new fittings and sockets. If you have congenital limb difference, you may need to build strength or train your residual limb to get ready for using a prosthesis.

#### Training

All prostheses require a period of practice, training and adaptation. For example, a **myoelectric prosthesis** requires learning how to control it and perform different hand movements. Training usually starts with practice alongside your clinician and continues at home or work. **Passive devices** which do not have moving parts may need less training but may still require time to get used to. Depending on what stage of your journey you receive your prosthesis, you may have adapted to not

having a hand, and it could take time to get comfortable with having the prosthesis attached to your residual limb.

### Learning

Learning is an important part of using a prosthesis. You may learn how to use your prosthesis through training or from other prosthesis users. You'll learn how your prosthesis works, what it can do, and what it can't do. You might also learn from other prosthesis users about their experiences. You may also learn how to perform tasks and achieve goals with your residual limb instead of a prosthesis.

Adjusting emotionally is part of the journey too. You may feel both positive and negative emotions as you get used to being a prosthesis user. Talking to support groups or others with limb differences can help you navigate and express these emotions.

### Maintenance

Your prosthesis will require care, maintenance and sometimes replacement. Frequency of maintenance and replacement may depend on factors such as prosthesis type, amount of use, changes to your residual limb and following after care instructions given to you by your provider. It is important to follow instructions for how to take care of and clean your prosthesis. Instructions may be given by your provider and/or the manufacturer of your prosthesis. Some prostheses may also require servicing.

### **Why am I being asked about prostheses?**

There are different types of prostheses available. Each option has its own benefits and limitations. Whether a device is right for you can depend on factors including - but not limited to - your existing function, the shape of your residual limb, occupational needs, hobbies, goals or preferences for how you want your device to look. The decision to use, or not use, a prosthesis is up to you.

### **What does the prescription process involve?**

**Graphic #8 showing journey:**

### What are the prosthesis options for my condition?

The table below summarises prosthesis types available for partial hand limb difference. This table is intended to introduce prosthesis types and manufacturers. Not all options or manufacturers are included in this table - you may wish to speak to your provider or research online to find out more.

Type	Other terms used to describe	Image	Examples	
Body-powered	Body-driven	*insert graphic #3.3	PIPDriver	Naked Prosthetics
Myoelectric	Muscle controlled, bionic, robotic	*insert graphic #3.2	I-Digits	Ossur
Mechanical	Ratcheting	*insert graphic #3.4	Point Digit	Point Designs
Activity-specific	Sports prosthesis	*insert graphic #3.7	Paww	Koalaa
Passive	Cosmetic, silicone	*insert graphic #3.1	12 Custom silicone partial hand prostheses	13 Ottobock
Assistive device	Opposition plate, tools	*insert graphic #3.6	Custom made	various
No prosthesis	N/A	*insert graphic of partial hands – same as graphic #2 in document	N/A	N/A

**Body-powered** prostheses use the function you may already have in your fingers, hand or wrist to move the prosthesis. This type of prosthesis does not require a socket.

**Myoelectric** prostheses use signals from muscles to control the prosthesis. The prosthesis responds to different muscle signals by creating various grips – such as pointing a finger or closing the device round an object.

**Mechanical** prostheses use mechanical systems, such as a ratcheting system, to move. You may use your other hand, or a surface such as a table, to move the fingers.

**Activity-specific** prostheses are designed for specific tasks like sports, work, hobbies or activities of daily living. Activity specific devices include tools for sports such as swimming or fixtures that allow you to hold objects such as hand tools.

**Passive** prostheses are designed to look like the missing body part can include details like hair and nails. These devices are not designed with a functional purpose. If your partial hand limb difference affects only one hand, this type of device may be modelled based on your other hand.

**Assistive devices** may not look like a hand and may not have fingers. Some attach to your residual limb and use features like plates or hooks. They may require you to use existing function in your residuum to press against an existing thumb or palm for example to create a grip.

**No prosthesis** is an option in which you choose not to use a device. You may perform tasks and feel satisfied without using a device.

Text box at side/bottom of page: **icon: light bulb/key point**

- You may choose not to have a prosthesis
- You may use multiple devices

## What does the research show?

A review published in 2022 looked at and compared different prosthetic options for people with partial hand limb difference (Kim 2023). Another article from 2020 described types of partial hand prostheses available and explained options which might work best depending on the level of amputation [11].

### Advantages

Research shows that using a prosthesis regularly can improve health, increase quality of life and help people to adapt to life after amputation (Kuret 2019). Some benefits of using a prosthesis include:

- **Increased independence:** Prosthesis use can help with carrying out daily activities, such as cooking, dressing and cleaning [3]
- **Returning to work and hobbies:** Being able to carry out such tasks independently can lead to better quality of life a higher level of satisfaction [5-7]
- **Pain and mental health:** Regularly using a prosthesis can also reduce pain and improve emotional wellbeing [8-10].

You don't have to wear a prosthesis all of the time to experience benefits. For example, you can remove it when you sleep or rest. Additionally, if you choose not to use a prosthesis, you may avoid relying on a device and be able to adapt to performing tasks with your residual limb.

### Challenges

#### a. Limitations of prostheses

A prosthesis cannot replace a hand and can be limited in what it can do. A prosthesis is unlikely to achieve the same level of function as a hand. Additionally, you cannot feel objects through your prosthesis so may rely on other senses such as sight in order to use the device. You may find it easier to take off the prosthesis to perform some tasks, particularly tasks such as washing dishes or showering as some prostheses cannot get wet.

Training with a prosthesis may involve learning, practicing and assessing your progress which can take time. You may benefit from seeking support from other users or professionals to help you achieve your goals.

Wearing a prosthesis comes with some challenges. Sockets should be comfortable, but you may feel discomfort if your residual limb gets warm or sweaty inside. Your prosthetist may adjust or remake your socket, which can take time to get right.

#### b. Limitations due to partial hand limb difference

If you have congenital limb difference, or receive your prosthesis after a long period following amputation, you may have become used to not having a hand. You may have adapted to life with limb difference, which could make it challenging to get used to wearing a prosthesis.

If you choose not to use a prosthesis, you might rely more on your other hand, or other body parts, to do tasks. Over time, this could cause overuse injuries or issues with your balance and posture. You can consult with your provider to avoid issues and find solutions.

Text box at side/bottom of page:  icon: light bulb/key point

- Learning and training to use a prosthesis can bring many benefits  
A prosthesis cannot produce the same level of function as a hand, so can be limited

## SECTION 2– Interactive sheets

### What matters most to me?

Thinking about what matters to you could help you choose which prosthesis could prove most beneficial to you. Additionally, what matters most to you could change over time. It may be useful to share this page this with your provider. You may wish to use the 'date' columns to revisit this section after you receive a prosthesis and track your journey.

**Graphic #6: person thinking about what matters most to them**

**Text input box: What matters most to you right now?**

Answer: \_\_\_\_\_ date: \_\_\_\_\_

Answer: \_\_\_\_\_ date: \_\_\_\_\_

Answer: \_\_\_\_\_ date: \_\_\_\_\_

Step 1: Look at the examples provided and see which prosthesis type typically works well, or does not work well, to meet each requirement.

Step 2: Think about what you require support with and write these down in the blank rows. You may wish to think of a specific task or feature based on your answers above.

Step 4: Speak to your provider to find out more about devices types which meet your requirements.

Note: the is provided as an example only.

Y - **icon: tick (green)** Yes – device might match the requirement very well

M - **icon: question mark (orange)** – device might match the requirement

N - **icon: cross (red)** device might not match the requirement

Colours only

Requirement	Body-powered	Myoelectric	Mechanical	Activity-specific	Passive	Assistive device	No prosthesis
Heavy physical activity <i>e.g. weightlifting, farming</i>	Y	?	Y	?	N	?	?
Fine motor skills <i>e.g. handwriting</i>	Y	Y	?	?	N	N	?
Sports	?	?	?	Y	N	?	?
Hobbies	?	?	?	?	?	?	?
Kitchen tasks <i>e.g. chopping food</i>	Y	Y	Y	Y	N	?	?
Looks like a hand <i>e.g. skin texture, nails</i>	N	N	N	N	Y	N	?

Use in water	Y	N	?	?	?	?	?

Task	Not at all difficult (1)    Neither difficult or not difficult (5)					Not important (1)    Neither important or unimportant (3)    Very important (5)				
	1	2	3	4	5	1	2	3	4	5
Cutting food	1	2	3	4	5	1	2	3	4	5
Dressing	1	2	3	4	5	1	2	3	4	5
Washing	1	2	3	4	5	1	2	3	4	5
Tie shoes	1	2	3	4	5	1	2	3	4	5
Driving car	1	2	3	4	5	1	2	3	4	5
Riding a bike	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5

**Goal setting**

**Graphic #5: throwing a dart with a partial hand prosthesis towards a target**

A prosthesis does not need to be worn for all tasks throughout the day. For example, you may use a prosthesis to carry out work, but find some tasks easier without the device.

Step 1: Think about how difficult it is to carry out the tasks listed and rate difficulty using the scale.

Step 2: Think about how important this task is to you and rate using the scale.

Step 3: Use the blank columns to list tasks that are specific to your daily life. Repeat steps 1 & 2.

Step 4: You may wish to revise this list to assess your progress as you adapt to life with/without a prosthesis.



### SECTION 3 – Further support

#### Check your understanding

Place a tick next to each key point to show you understand. Any key point(s) which you are unsure of should be discussed with your provider.

Key points	I understand
Partial hand prostheses can help people who have lost part of their fingers or hand	
Prosthetists can fit and assess prostheses - other occupations may be involved too	
You may benefit from having more than one prosthesis	
You may choose not to use a prosthesis	
Some people wear a prosthesis for a small part of the day, others may use it for long periods	
Setting goals can help you and your provider choose the best prosthesis for you	
You may not be a candidate for all prosthesis options	
Funding varies between individuals – speak to your provider to find out your options	
You can find support by joining online communities	

#### How comfortable are you about making this decision?

I know enough about the advantages and limitations of prostheses Y/N

I am clear about what matters most to me Y/N

I have support and advice to make a decision Y/N

I feel able to make the best decision for me Y/N

I would like more information to help make a decision Y/N

I have questions for my provider:

Q: \_\_\_\_\_

Q: \_\_\_\_\_

Q: \_\_\_\_\_

## Links to resources and communities **webpage, internet**

- Resources
  - Arm Dynamics | “Finger and Partial Hand Prosthetic Options”  
[armdynamics.com/our-care/finger-and-partial-hand-prosthetic-options-1](http://armdynamics.com/our-care/finger-and-partial-hand-prosthetic-options-1)
  - O&P Virtual Library | “7C: Aesthetic Restoration” [oandplibrary.org/alp/chap07-03.asp](http://oandplibrary.org/alp/chap07-03.asp)
  - Advance Medical Care | “Prosthetic Hand: What is it, Types, and Life-Changing Benefits” [advancemedical.ae/prosthetic-hand-what-is-it-types-and-benefits/#What\\_are\\_the\\_Benefits\\_of\\_Prosthetic\\_Hands](http://advancemedical.ae/prosthetic-hand-what-is-it-types-and-benefits/#What_are_the_Benefits_of_Prosthetic_Hands)
- YouTube channels and videos
  - Manufacturers and clinics:
    - @ArmDynamics | [Arm Dynamics - YouTube](#)
    - @OssurAcademy | [Össur Academy - YouTube](#)
    - @HangerNews | [Hanger Clinic - Youtube](#)
  - Prosthesis users:
    - [Jeffgivingahand Soelberg - YouTube](#)
    - <https://www.youtube.com/@stuartchasevideos>
- Charities and support groups
  - Finger and Partial-Hand Amputee Peer + Support Group | Facebook | [facebook.com/groups/fingerandpartialhandamputees/](https://www.facebook.com/groups/fingerandpartialhandamputees/)
  - Finding Your Feet | [findingyourfeet.net/local-amputee-support-groups-directory/](http://findingyourfeet.net/local-amputee-support-groups-directory/) (England and Scotland)
  - Jeff Giving a Hand | Facebook | <https://www.facebook.com/groups/Jeffgivingahand.org/>
  - Community Connections | Amputee Coalition | [amputee-coalition.org/limb-loss-resource-center/community-connections/](http://amputee-coalition.org/limb-loss-resource-center/community-connections/) (USA)

*This decision aid was created to support people with partial hand limb difference in making a decision about prosthesis prescription. Content for the decision aid was developed with input from prosthesis users, healthcare professionals and researchers in the field of partial hand prosthetics.*

## References

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- Grob M, Papadopulos NA, Zimmermann A, Biemer E, Kovacs L. The psychological 679 impact of severe hand injury. *J Hand Surg Eur Vol.* 2008;33(3):358-362.
- Graham EM, Hendrycks R, Baschuk CM, Atkins DJ, Keizer L, Duncan CC, Mendenhall SD. Restoring Form and Function to the Partial Hand Amputee: Prosthetic Options from the Fingertip to the Palm. *Hand Clinics*, 2021, Vol 37(1), p167-187

## Crunch Design inspiration photos and requests for graphics

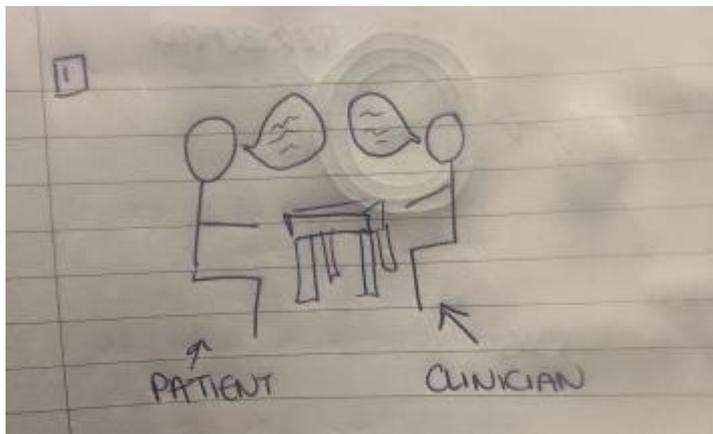
### Patient Decision Aid for Partial Hand – Kirsty Carlyle, Strathclyde Uni

#### Notes:

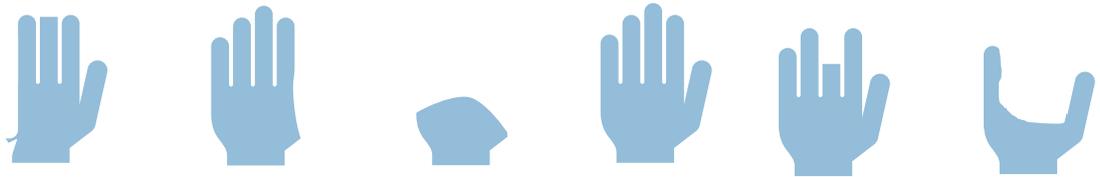
- There are three sections – can sections please be themed using different colours.
- Bold text has been used to identify subheadings, and is also in-text for emphasis
- Prostheses example photos and links are given in this document to aid the line drawings I have done – we do not need these to look exactly the same, but to show the principles i.e. do they attach to the finger, do they have a socket, do they have joints, are they skin coloured
- I am trying to get better images for **examples 3.6 and 3.7**
- Please let me know if you have any questions about the prosthetics!

#### Graphics (# corresponds to # on draft document)

1. Patient speaking to clinician/prosthetist and making a decision



2. Showing different levels of partial hand absence. Hands with missing parts of fingers, missing fingers, missing part of palm. Example below is something I previously created for a poster. Please include various skin tones throughout the images.



### 3. Partial hand prostheses

Not drawn to scale. Aiming to show devices for part of fingers, down to devices which cover part of the hand. Doesn't need to look exactly like the inspiration photos – our aim is to show how some of the different devices can attach i.e. to the finger (1+3), thumb (5) or palm (4) and some of the joints i.e. some have ratcheting systems (4) and some are powered by batteries (2). Inspiration for each drawing:

- (1) silicone partial finger [Custom silicone partial hand prostheses |](#)
- (2) Ossur I-Digits [i-Digits® Quantum Myoelectric Partial Hand. Ossur.com](#)
- (3) Naked Prosthetics PIP driver - [PIPDriver - Naked Prosthetics](#)
- (4) Point Designs Point Digit [Point Digit: Heavy-Duty Titanium Full Prosthetic Finger](#)
- (5) Naked Prosthetics thumb driver [ThumbDriver - Naked Prosthetics](#)
- (6) Assistive device – see below
- (7) Activity specific - [The Paww | Koalaa](#) (various tools which snap on to a sleeve)

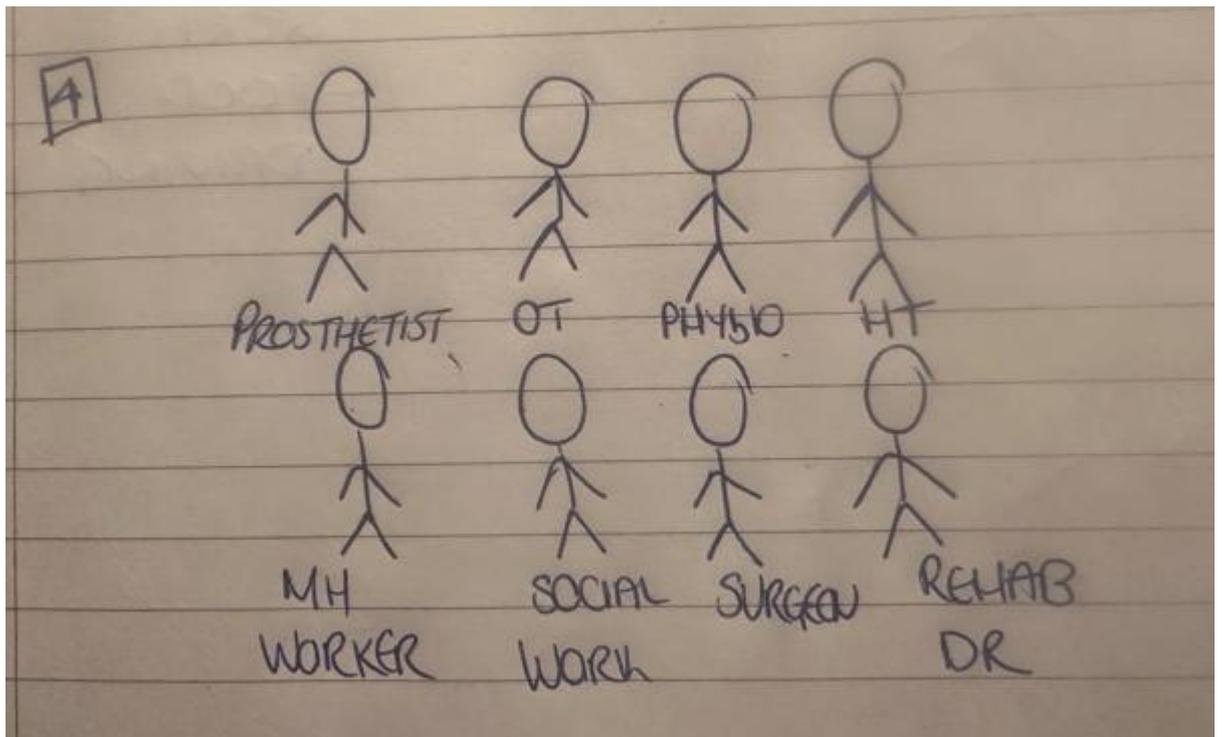
Example for 3.6: A prosthetic opposing thumb as shown in the image below that is solid material, the user presses the rest of their hand against this to hold or grasp objects. I may be able to get a better image for what I am trying to show here.



4. Multidisciplinary healthcare workers. Grouped together or spread out like inspiration photo.

- \*Prosthetist (holding prosthetic hand)
- \*Occupational Therapist
- \*Physiotherapist

- Hand therapist
- Mental health worker (showing hand to ear, listening)
- Social worker (holding clipboard/paperwork)
- \*Surgeon (in scrubs)
- Rehabilitation doctor (short sleeved smart clothes)



Inspiration picture below contains the people marked with \* from list above

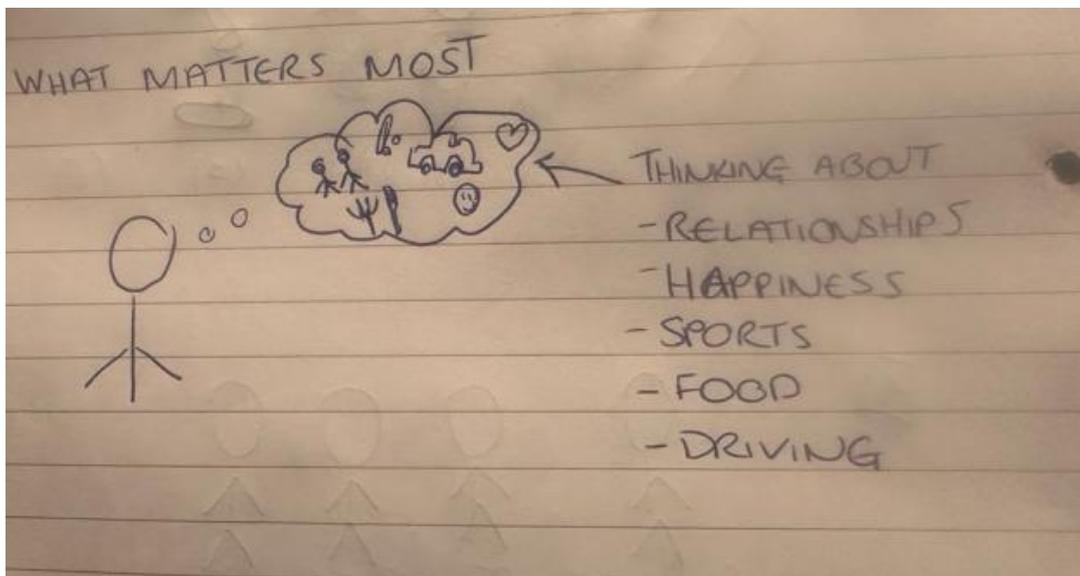


5. Partial hand prosthesis user aiming dart at dartboard

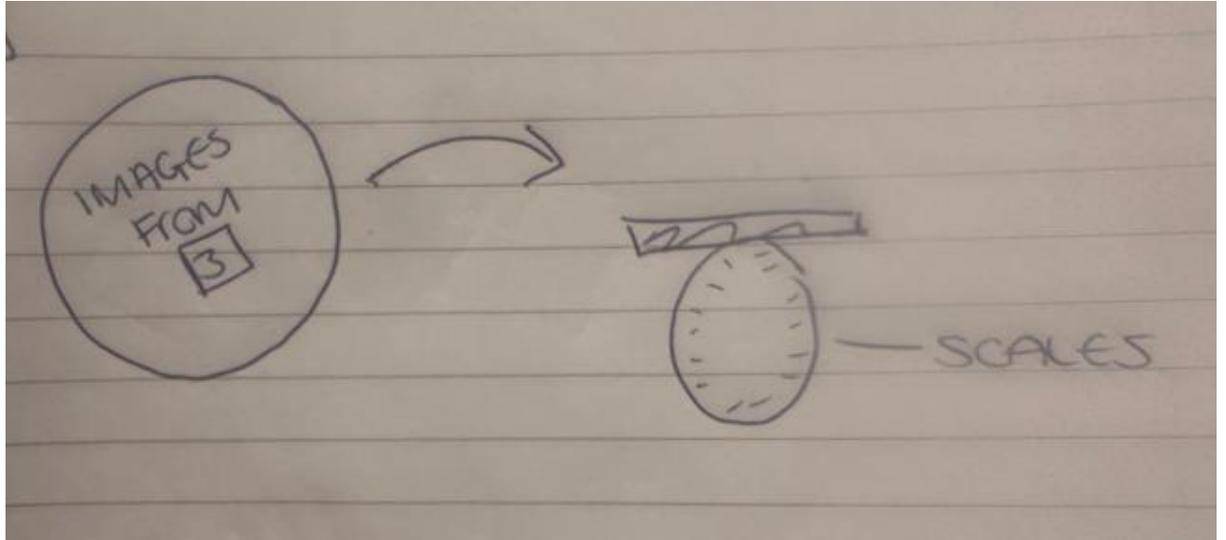


6. Person thinking about what matters most to them

Inspiration: person with thought bubble thinking about relationships, happiness, sports, eating food, driving, handshaking



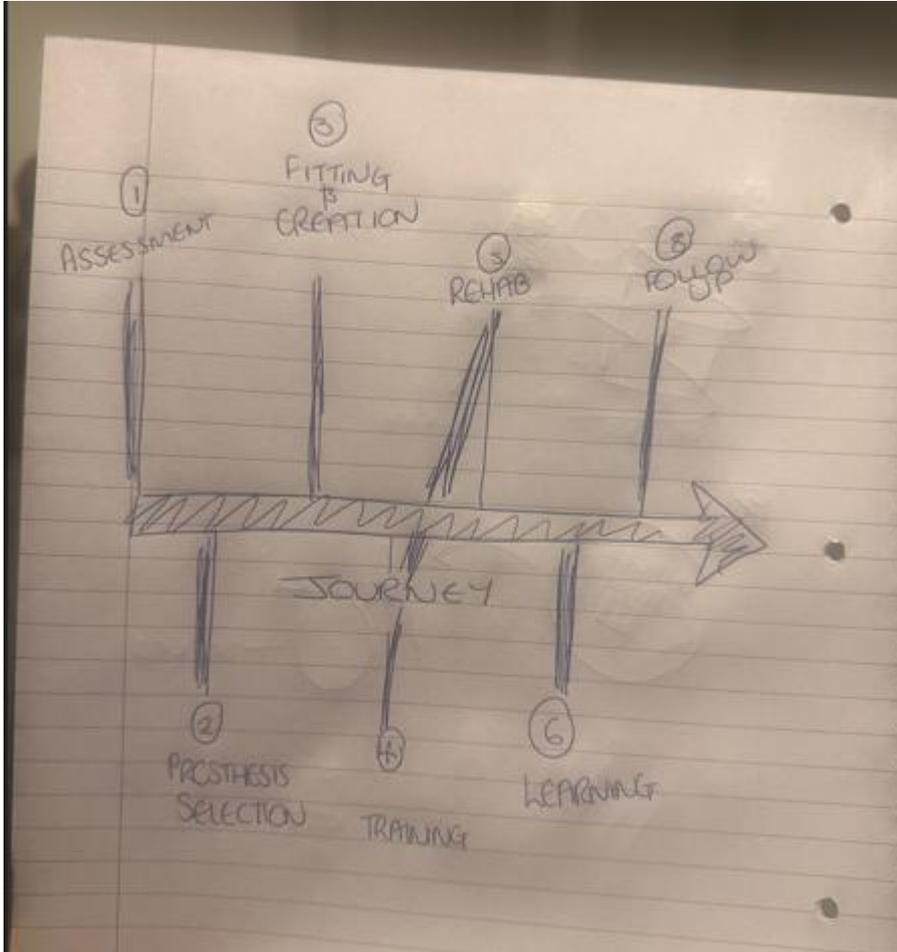
7. Ranking/weighting the prostheses contained in graphic #3. Either placed on a scale or next to a ranking chart



8. Graphic showing the list of stages as a journey

Idea: a path flowing horizontally or vertically. Please include the text. Open to ideas 😊

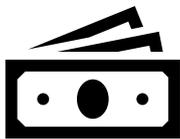
1. Assessment
2. Prosthesis selection
3. Fitting and creation
4. Training & 5. Rehabilitation [joined together at same stage]
5. Learning
6. Maintenance
7. Follow up



Icon inspiration:



Funding



and/or

Check your understanding



What does the research show



Links to resources and communities



Lightbulb/key point

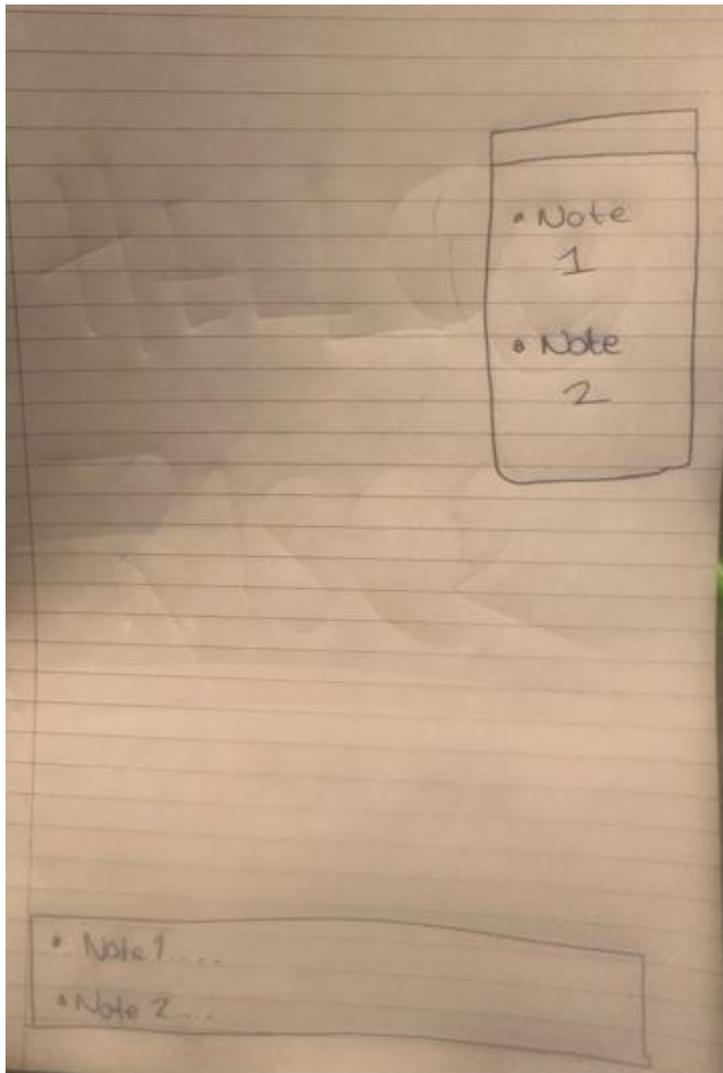


or



Text box at side/bottom of page:

I have added some key notes in red in the document. Can these please be placed in standalone boxes at the bottom or side of the page.



## Partial Hand Limb Difference: A Guide to Making Decision About Prostheses

### ▶ Introduction to this guide

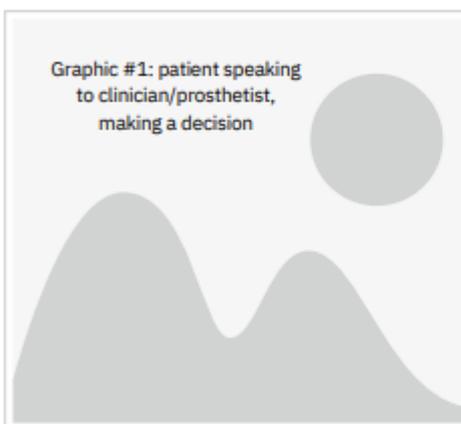
This guide is here to help you **make decisions about prosthetic options**. It gives you useful information and includes pages you can fill out. You can bring it with you to talk with your doctor or other healthcare professionals.

The goal of this guide is not to tell you what to choose, but to help you understand your options. The purpose is not supposed to replace talking with your healthcare team.

### This decision aid is for you if...

This guide focuses on **partial hand prosthetics**. It explains what a partial hand limb difference is and the different options available. You might be a good fit for some or all of these prosthetic options.

Graphic #1: patient speaking  
to clinician/prosthetist,  
making a decision



## Contents

**1**

Information about partial hand  
limb difference and prostheses

Page  
**05**

**2**

Interactive sheets

Page  
**05**

**3**

Further Support

Page  
**05**

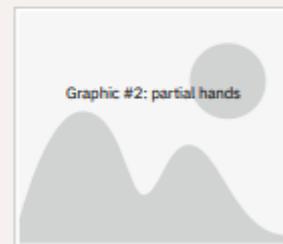
## Section 1 Introduction

### What is partial hand limb difference?

**Partial hand limb difference** means someone only has part of their hand or is missing some or part of their fingers. Therefore, this could include having some fingers, a thumb, or part of the palm. You might also hear this called limb absence.

Partial hand limb difference can result from:

- **Amputation:** This is when part of a limb is surgically removed because of an injury or illness.
- **Congenital difference:** This means a person is born with it. A congenital limb difference happens when a baby is born with a hand that hasn't fully formed, so part of the hand is missing.



### What are Prosthesis?

**Prostheses** are artificial body parts that can help people with limb differences. A prosthesis can be designed to replace the function of the missing body part, improve how it looks, or do both.

**Residual limb** or 'residuum' means the part of the limb that is still there. For example, if you are missing fingers, the rest of your hand is called your residual limb.

**A socket** is part of your prosthesis. It is the part that contacts with your residual hand. Sockets are custom made to the shape of your residual limb. Sockets are usually lightweight, comfortable, and can protect your residual limb.



## Who might I work with on my journey to being provided with a prosthesis?



There are many types of professionals who work in prosthetics for people with partial hand limb differences.

The team you meet can vary depending on where you live. Here are some common roles you might work with:



- **Prosthetist (CPO, clinician):** This person may prescribe, fit, and check your prosthesis.
- **Occupational Therapist (OT):** An OT can help you learn how to do daily tasks and activities. They may also teach you how to use your prosthesis.
- **Physiotherapist (physical therapist, PT):** A physiotherapist helps with rehabilitation and can give you exercises to improve your strength and movement.
- **Hand Therapist (CHT):** A hand therapist specialises in the hand. They might assess your hand, give you exercises, and sometimes prescribe a prosthesis.
- **Mental Health Worker (psychologist, counsellor, nurse):** This person supports your mental health and helps you cope with any emotional challenges related to limb difference.
- **Social Worker:** A social worker can help with practical things like organising paperwork, applying for funding, or managing other parts of your care or treatment.
- **Surgeon:** If you need surgery, you may work with a surgeon. Some surgeons specialize in hands, orthopaedics (bones), trauma (accidents), or other areas. They may work closely with prosthetists or other team members.
- **Rehabilitation Physician (rehab doctor):** This doctor may help after surgery by referring you to other specialists, like a prosthetist or occupational therapist.



- Different occupations may be involved in your journey – from prosthesis assessment to post-prescription care.

## How much does a prosthesis cost?



The cost of prostheses may be fully, partially or not at all covered by funding depending on your situation, reason for limb difference, geographical location and insurance coverage.

The price range for prostheses varies and may require consideration when choosing your device. You may wish to discuss funding with provider.

## When would I get a prosthesis and what happens after?

### First prosthesis

People get their first prosthesis at different times. If you've had an amputation, you may start working with a team to help you get ready for a prosthesis. After surgery, your residual limb may change shape as it heals, so you may need to wait before getting fitted. Over time, your residual limb could keep changing shape, which means you might need new fittings and sockets. If you have congenital limb difference, you may need to build strength or train your residual limb to get ready for using a prosthesis.

### Training

All prostheses require a period of practice, training and adaptation. For example, a myoelectric prosthesis requires learning how to control it and perform different hand movements. Training usually starts with practice alongside your clinician and continues at home or work. Passive devices which do not have moving parts may need less training but may still require time to get used to. Depending on what stage of your journey you receive your prosthesis, you may have adapted to not having a hand, and it could take time to get comfortable with having the prosthesis attached to your residual limb.

### Learning

Learning is an important part of using a prosthesis. You may learn how to use your prosthesis through training or from other prosthesis users. You'll learn how your prosthesis works, what it can do, and what it can't do. You might also learn from other prosthesis users about their experiences. You may also learn how to perform tasks and achieve goals with your residual limb instead of a prosthesis.

Adjusting emotionally is part of the journey too. You may feel both positive and negative emotions as you get used to being a prosthesis user. Talking to support groups or others with limb differences can help you navigate and express these emotions.

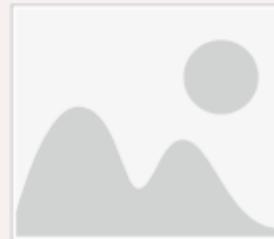
### **Maintenance**

Your prosthesis will require care, maintenance and sometimes replacement. Frequency of maintenance and replacement may depend on factors such as prosthesis type, amount of use, changes to your residual limb and following after care instructions given to you by your provider. It is important to follow instructions for how to take care of and clean your prosthesis. Instructions may be given by your provider and/or the manufacturer of your prosthesis. Some prostheses may also require servicing.

### **Why am I being asked about prostheses?**



There are different types of prostheses available. Each option has its own benefits and limitations. Whether a device is right for you can depend on factors including - but not limited to - your existing function, the shape of your residual limb, occupational needs, hobbies, goals or preferences for how you want your device to look. The decision to use, or not use, a prosthesis is up to you.



## What does the prescription process involve?

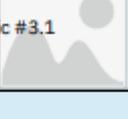
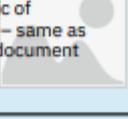


Graphic #8 showing journey:

## What are the prosthetic options for my condition?



The table below summarises prosthesis types available for partial hand limb difference. This table is intended to introduce prosthesis types and manufacturers. Not all options or manufacturers are included in this table - you may wish to speak to your provider or research online to find out more.

Type	Alternative Terms	Image	Examples	
<b>Body-powered</b>	Body-driven	*insert graphic #3.3 	PIPDriver	Naked Prosthetics
<b>Myoelectric</b>	Muscle controlled, bionic, robotic	*insert graphic #3.2 	I-Digits	Ossur
<b>Mechanical</b>	Ratcheting	*insert graphic #3.4 	Point Digit	Point Designs
<b>Activity-specific</b>	Sports prosthesis	*insert graphic #3.7 	Paww	Koalaa
<b>Passive</b>	Cosmetic, silicone	*insert graphic #3.1 	Custom silicone partial hand prostheses	Ottobock
<b>Assistive device</b>	Opposition plate, tools	*insert graphic #3.6 	Custom made	Various
<b>No prosthesis</b>	N/A	*insert graphic of partial hands – same as graphic #2 in document 	N/A	N/A

## Types of Prostheses:

**Body-powered** prostheses use the function you may already have in your fingers, hand or wrist to move the prosthesis. This type of prosthesis does not require a socket.

**Myoelectric** prostheses use signals from muscles to control the prosthesis. The prosthesis responds to different muscle signals by creating various grips – such as pointing a finger or closing the device round an object.

**Mechanical** prostheses use mechanical systems, such as a ratcheting system, to move. You may use your other hand, or a surface such as a table, to move the fingers.

**Activity-specific** prostheses are designed for specific tasks like sports, work, hobbies or activities of daily living. Activity specific devices include tools for sports such as swimming or fixtures that allow you to hold objects such as hand tools.

**Passive** prostheses are designed to look like the missing body part can include details like hair and nails. These devices are not designed with a functional purpose. If your partial hand limb difference affects only one hand, this type of device may be modelled based on your other hand.

**Assistive** devices may not look like a hand and may not have fingers. Some attach to your residual limb and use features like plates or hooks. They may require you to use existing function in your residuum to press against an existing thumb or palm for example to create a grip.

**No prosthesis** is an option in which you choose not to use a device. You may perform tasks and feel satisfied without using a device.



- You may choose not to have a prosthesis
- You may use multiple devices

## What does the research show?



A review published in 2022 looked at and compared different prosthetic options for people with partial hand limb difference [1]. Another article from 2020 described types of partial hand prostheses available and explained options which might work best depending on the level of amputation [11].

## Advantages

Research shows that using a prosthesis regularly can improve health, increase quality of life and help people to adapt to life after amputation [2,4]. Some benefits of using a prosthesis include:

- **Increased independence:** Prosthesis use can help with carrying out daily activities, such as cooking, dressing and cleaning [3]
- **Returning to work and hobbies:** Being able to carry out such tasks independently can lead to better quality of life a higher level of satisfaction [5-7]
- **Pain and mental health:** Regularly using a prosthesis can also reduce pain and improve emotional wellbeing [8-10].

You don't have to wear a prosthesis all of the time to experience benefits. For example, you can remove it when you sleep or rest. Additionally, if you choose not to use a prosthesis, you may avoid relying on a device and be able to adapt to performing tasks with your residual limb.

## Challenges

### a. Limitations of prostheses

A prosthesis cannot replace a hand and can be limited in what it can do. A prosthesis is unlikely to achieve the same level of function as a hand. Additionally, you cannot feel objects through your prosthesis so may rely on other senses such as sight in order to use the device. You may find it easier to take off the prosthesis to perform some tasks, particularly tasks such as washing dishes or showering as some prostheses cannot get wet.

Training with a prosthesis may involve learning, practicing and assessing your progress which can take time. You may benefit from seeking support from other users or professionals to help you achieve your goals.

Wearing a prosthesis comes with some challenges. Sockets should be comfortable, but you may feel discomfort if your residual limb gets warm or sweaty inside. Your prosthetist may adjust or remake your socket, which can take time to get right.

#### **b. Limitations due to partial hand limb difference**

If you have congenital limb difference, or receive your prosthesis after a long period following amputation, you may have become used to not having a hand. You may have adapted to life with limb difference, which could make it challenging to get used to wearing a prosthesis.

If you choose not to use a prosthesis, you might rely more on your other hand, or other body parts, to do tasks. Over time, this could cause overuse injuries or issues with your balance and posture. You can consult with your provider to avoid issues and find solutions.

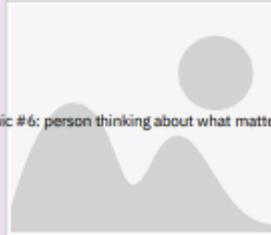


- Learning and training to use a prosthesis can bring many benefits
- A prosthesis can't produce the same level of functions as a hand, so can be limited



### What Matters Most to Me?

Thinking about what matters to you could help you choose which prosthesis could prove most beneficial to you. Additionally, what matters most to you could change over time. It may be useful to share this page this with your provider. You may wish to use the 'date' columns to revisit this section after you receive a prosthesis and track your journey.



Graphic #6: person thinking about what matters most to them

### What matters most to you right now?

Answer: \_\_\_\_\_  
date: \_\_\_\_\_

Answer: \_\_\_\_\_  
date: \_\_\_\_\_

Answer: \_\_\_\_\_  
date: \_\_\_\_\_



### What Matters Most to Me?

Thinking about what matters to you could help you choose which prosthesis could prove most beneficial to you. Additionally, what matters most to you could change over time. It may be useful to share this page this with your provider. You may wish to use the 'date' columns to revisit this section after you receive a prosthesis and track your journey.



Graphic #6: person thinking about what matters most to them

### What matters most to you right now?

Answer: \_\_\_\_\_  
date: \_\_\_\_\_

Answer: \_\_\_\_\_  
date: \_\_\_\_\_

Answer: \_\_\_\_\_  
date: \_\_\_\_\_



## Goal Setting



A prosthesis does not need to be worn for all tasks throughout the day. For example, you may use a prosthesis to carry out work, but find some tasks easier without the device.

**Step 1:** Think about how difficult it is to carry out the tasks listed and rate difficulty using the scale.

**Step 2:** Think about how important this task is to you and rate using the scale.

**Step 3:** Use the blank columns to list tasks that are specific to your daily life. Repeat steps 1 & 2.

**Step 4:** You may wish to revise this list to assess your progress as you adapt to life with/without a prosthesis.



Graphic #5: throwing a dart with a partial hand prosthesis towards a target

Activity	Difficulty	Importance
Cutting Food	1 2 3 4 5	1 2 3 4 5
Dressing	1 2 3 4 5	1 2 3 4 5
Washing	1 2 3 4 5	1 2 3 4 5
Tie Shoes	1 2 3 4 5	1 2 3 4 5
Driving a Car	1 2 3 4 5	1 2 3 4 5
Riding a Bike	1 2 3 4 5	1 2 3 4 5
Add your own		
Add your own		

Tip: Not at all difficult (1)  
Neither difficult or not difficult (3)  
Difficult (5)

Tip: Not important (1)  
Neither important or unimportant (3)  
Very important (5)



## Section 3 Further Support

### Check your understanding



Place a tick next to each key point to show you understand. Any key point(s) which you are unsure of should be discussed with your provider.

Key points	I understand
Partial hand prostheses can help people who have lost part of their fingers or hand	
Prosthetists can fit and assess prostheses - other occupations may be involved too	
You may benefit from having more than one prosthesis	
You may choose not to use a prosthesis	
Some people wear a prosthesis for a small part of the day, others may use it for long periods	
Setting goals can help you and your provider choose the best prosthesis for you	
You may not be a candidate for all prosthesis options	
Funding varies between individuals – speak to your provider to find out your options	
You can find support by joining online communities	

### How comfortable are you about making this decision?

1. I know enough about the advantages and limitations of prostheses **Y / N**
2. I am clear about what matters most to me **Y / N**
3. I have support and advice to make a decision **Y / N**
4. I feel able to make the best decision for me **Y / N**
5. I would like more information to help make a decision **Y / N**

I have questions for my provider:

- Q: \_\_\_\_\_
- Q: \_\_\_\_\_
- Q: \_\_\_\_\_

## Links to resources and communities



### 1. Resources

- Arm Dynamics | "Finger and Partial Hand Prosthetic Options" [armdynamics.com/our-care/finger-and-partial-hand-prosthetic-options-1](http://armdynamics.com/our-care/finger-and-partial-hand-prosthetic-options-1)
- O&P Virtual Library | "7C: Aesthetic Restoration" [oandplibrary.org/alp/chap07-03.asp](http://oandplibrary.org/alp/chap07-03.asp)
- Advance Medical Care | "Prosthetic Hand: What is it, Types, and Life-Changing Benefits" [advancemedical.ae/prosthetic-hand-what-is-it-types-and-benefits/#What\\_are\\_the\\_Benefits\\_of\\_Prosthetic\\_Hands](http://advancemedical.ae/prosthetic-hand-what-is-it-types-and-benefits/#What_are_the_Benefits_of_Prosthetic_Hands)

### 2. YouTube channels and videos

- Manufacturers and clinics:
  - @ArmDynamics | [Arm Dynamics - YouTube](https://www.youtube.com/channel/UC8mKjKjKjKjKjKjKjKjKjKj)
  - @OssurAcademy | [Ossur Academy - YouTube](https://www.youtube.com/channel/UC8mKjKjKjKjKjKjKjKjKjKj)
  - @HangerNews | [Hanger Clinic - Youtube](https://www.youtube.com/channel/UC8mKjKjKjKjKjKjKjKjKjKj)
- Prosthesis users:
  - [Jeffgivingahand Soelberg - YouTube](https://www.youtube.com/channel/UC8mKjKjKjKjKjKjKjKjKjKj)
  - <https://www.youtube.com/@stuartchasevideos>

### 3. Charities and support groups

- Finger and Partial-Hand Amputee Peer + Support Group | Facebook | [facebook.com/groups/fingerandpartialhandamputees/](https://www.facebook.com/groups/fingerandpartialhandamputees/)
- Finding Your Feet | [findingyourfeet.net/local-amputee-support-groups-directory/](http://findingyourfeet.net/local-amputee-support-groups-directory/) (England and Scotland)
- Jeff Giving a Hand | Facebook | <https://www.facebook.com/groups/Jeffgivingahand.org/>
- Community Connections | Amputee Coalition | [amputee-coalition.org/limb-loss-resource-center/community-connections/](http://amputee-coalition.org/limb-loss-resource-center/community-connections/) (USA)

This decision aid was created to support people with partial hand limb difference in making a decision about prosthesis prescription. Content for the decision aid was developed with input from prosthesis users, healthcare professionals and researchers in the field of partial hand prosthetics.

## References

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11. Graham EM, Hendrycks R, Baschuk CM, Atkins DJ, Keizer L, Duncan CC, Mendenhall SD. Restoring Form and Function to the Partial Hand Amputee: Prosthetic Options from the Fingertip to the Palm. *Hand Clinics*, 2021, Vol 37(1), p167-187