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DEPARTMENT OF BIOMEDICAL ENGINEERING

The epidemiology of limb amputation and congenital limb difference in Scotland

By

Sarah Day

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requirements for the degree of

DOCTOR OF PHILOSOPHY

Declaration of Author's Rights

This thesis is the result of the author's original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.

Signed:  Date: 4th May 2024

Foreword

Sarah Day, the author of this thesis, qualified as a Prosthetist Orthotist in 1999. A Prosthetist Orthotist is an allied healthcare professional who provides prosthetic and orthotic services for people with disabilities. Upon graduation, Sarah worked clinically in the UK, before travelling overseas to live and work in Ireland, Australia, Thailand, and Saudi Arabia. In 2012, Sarah returned to the UK where she works as an educator for people studying prosthetics and orthotics.

This work was inspired by the diverse populations that Sarah encountered during her career, and a realisation that in order to build and deliver effective clinical services a baseline knowledge about the number and characteristics of the service users is required. This knowledge was not freely available at the time, which made aspects of managing a clinical service – such as workforce planning, budgeting, and procurement – challenging. Sarah also became aware of variations in access to prosthetic services, and the impact which this had on people's physical and mental wellbeing.

Conducting this research has been a journey of personal development, and as a result Sarah has gained knowledge and developed skills in public health research, epidemiology, and data management, fields which are typically outside the scope of practice of a prosthetist orthotist. The research took longer to complete than expected due to many factors including challenges accessing data, legalities of data control, and the Covid-19 pandemic. An unexpected benefit from these delays has been an extended data collection period, enabling a larger cohort and longer follow-up of patients. This work has provided a baseline of information about people undergoing amputation in Scotland that can be used in decision-making within Scotland, and findings can be transferred to similar populations outside Scotland. There has been considerable interest from industry and other researchers about this piece of work and it is expected that the research will continue beyond the scope of this thesis.

Acknowledgements

I extend my gratitude to the many individuals who have supported me over the past decade in conducting this research. Firstly, I would like to thank my supervisor, Dr Arjan Buis, who has supported me throughout this journey, providing reassurance, challenging my limits, and always helping fight my battles. I would also like to thank Dr Tanja Mueller for her invaluable assistance with coding and for stepping in to co-supervise my research. I would not have reached this stage without either of you, and I am truly grateful for your mentorship.

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Financial support from the Centre for Excellence in Rehabilitation Research (CERR) for funding the data linkage and Safe Haven expenses encountered in Study 2 is gratefully acknowledged. Additionally, I am grateful for the Student Bursary provided by the FARR Institute of Health Informatics Research, which enabled my participation in their Doctoral Symposium and attendance at the 2017 Informatics for Health conference.

The research described within this thesis uses data provided by patients and collected by the NHS of part of their care and support. I am grateful that we live in a society where people understand the value of information and the benefits that can be achieved when information is shared. I would like to also acknowledge the eDRIS staff who have worked alongside me to conduct this research, and the various clinicians and academics who have generously shared their knowledge and insight.

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Finally, I want to thank my husband Kevin and my daughter Erin for their love, understanding, and belief in me. They have provided support, laughter, and endless hugs throughout this journey. I love you both and I hope the hugs never end. Thank you for being there.

Abstract

Literature highlights variability in the depth of information available about people living with limb difference, further compounded by challenges in comparing results across populations due to disparities in data collection methods and reporting practices. Epidemiological data are essential for comprehending the challenges encountered by individuals within a population. The International Society of Prosthetics and orthotics identified the absence of standardized data as a significant barrier to the development of prosthetic services.

The aim of this thesis was to further our understanding of individuals experiencing limb amputation or congenital limb difference (CLD) in Scotland. This was achieved through studies which used available data to characterise the epidemiology of limb amputation and CLD in Scotland.

A retrospective cohort study was conducted utilising routinely collected health data combined using data linkage techniques. The study examined Scotland's electronic health records to identify all limb amputations conducted between January 2012 and August 2022, and all births with CLD during the same timeframe. Descriptive analysis of clinical and demographic information was performed.

During the ten-year period 2012-2021, 17,255 lower limb amputation (LLA) procedures and 4,166 upper limb amputation (ULA) procedures were conducted on 15,974 patients, and 41 babies were born with 30 upper limb and 13 lower limb differences. Fifty-three percent of LLA were partial foot procedures. Ninety-seven percent of ULA were partial hand procedures. An analysis of demographic characteristics showed that the majority of people undergoing their first amputation were male, and a higher percentage lived in the most deprived areas of Scotland. Age of amputation and mean survival time varied according to the site, type, and level of amputation procedure.

The thesis provides baseline data which furthers our understanding of Scotland's limb different population. Recommendations are made for a national register to continue this work with an extended scope of monitoring clinical outcomes.

Conference presentations

1. Day, S. & Buis, A. Epidemiology of limb amputation in Scotland. International Society for Prosthetics and Orthotics 17th World Congress, online. Nov 2021
2. Day, S. & Buis, A. A retrospective review of all persons undergoing upper limb amputation in Scotland, 2012–2018. Trent International Prosthetic Symposium, Manchester, UK. Mar 2019.
3. Day, S. An exploratory analysis of factors influencing the quality of life of upper limb amputees living in Scotland. Informatics for Health 2017, Manchester, UK. Apr 2017.

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List of abbreviations

BSRM	British Society for Rehabilitation Medicine
CARDRISS	Conditions and Rare Diseases Registration and Information Service for Scotland
CARIS	Congenital Anomaly Register and Information Service
CCI	Charlson Comorbidity Index
CHI	Community Health Index
CHILI	CHI Linking and Indexing
CLD	Congenital limb difference
COMPASS	Consensus Outcome Measures for Prosthetic and Amputation Services
DARTS	Diabetes Audit and Research in Tayside Scotland
EHR	Electronic health records
EUROCAT	European Network of Population-based Registries for the Epidemiological Surveillance of Congenital Anomalies
FOI	Freedom of information
GBD	Global Burden of Diseases
GDPR	General Data Protection Regulation
HES	Hospital Episode Statistics
HR	Hazard ratio
ICD	International Classification of Diseases
ICRC	International Committee of the Red Cross
ISO	International Organization for Standardization
ISPO	International Society for Prosthetics and Orthotics
LEAD	Lower Extremity Amputation Data Set
LLA	Lower limb amputation
MARS	Mobility and Rehabilitation Service
NASDAB	National Amputee Statistical Database (UK)
NCARDRS	National Congenital Anomaly and Rare Disease Registration Service
NCEPOD	National Confidential Enquiry into Patient Outcome and Death
NRS	National Records of Scotland
NSS	National Services Scotland

OPCS	Office of Population Censuses and Surveys, Classification of Surgical Operation and Procedures
PAD	Peripheral arterial disease
PBPP	Public Benefit and Privacy Panel
PVD	Peripheral vascular disease
ReTIS	Rehabilitation Technology Information Service
SBR	Scottish Birth Record
SCI-DC	Scottish Care Information – Diabetes Collaboration
SHIP	Scottish Health Informatics Programme
SIMD	Scottish Indices of Multiple Deprivation
SLiCCD	Scottish Linked Congenital Condition Dataset
SMART	Southeast Scotland Mobility and Rehabilitation Technology
SMR	Scottish Morbidity Records
SPARG	Scottish Physiotherapy Amputee Research Group
TORT	Tayside Orthopaedic and Rehabilitation Technology Services
ULA	Upper limb amputation
WestMARC	West of Scotland Mobility and Rehabilitation Centre
WHO	World Health Organization

1. Introduction

1.1 Disability within society

It is estimated that around 1.3 billion people, 16 percent of the world's population, live with a disability (2022a). Disability refers to the interaction between a person with a health condition and their surrounding environment. People experience disability when environmental or personal factors affect their ability to function (World Health Organisation, 2022a; World Health Organization, 2011b). The extent of disability someone experiences is not solely based on the person's health condition but is also dependent on the environment and attitudes of society. This means that disability can be mitigated by managing environmental barriers.

In December 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities. This landmark convention, which was signed by 82 countries, came into force in May 2008. The purpose of the Convention was 'to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' (United Nations, 2006). The Convention describes disability as a human rights issue. This shift in attitude has changed the way people with disabilities are viewed and treated in society. Countries, or states, now have a legal obligation to modify or remove existing laws that are discriminatory against people with disabilities, while also protecting people against discrimination based on disability and adopting policies and activities to implement and support the rights of persons with disabilities. The Convention applies to all aspects of society. Participation and inclusion in society along with decision-making are highlighted as key principles. Accessibility to justice, independent living, information and communication services, education, health, rehabilitation, employment, protection of standards of living, and participation in political and cultural life are also listed as general principles.

Article 25 of the Convention states that:

> Persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability (United Nations, 2006).

> They are to receive the same range, quality and standard of free or affordable health services as provided other persons, receive those health services needed because of their disabilities, and not to be discriminated against in the provision of health insurance (United Nations, 2006).

Rehabilitation services were identified within Article 26 as an important element: 'To enable persons with disabilities to attain maximum independence and ability, countries are to provide comprehensive habilitation and rehabilitation services in the areas of health, employment and education' (United Nations, 2006).

Healthcare plays a crucial role in removing barriers that affect a person's ability to participate in society. People with a disability can experience higher levels of difficulty accessing healthcare than those without disabilities (World Health Organization, 2011b; Sakellariou and Rotarou, 2017; Kapadla et al., 2022). Women with disabilities, individuals from minority backgrounds with disabilities, and those with disabilities residing in rural areas experience more pronounced inequalities (Sakellariou and Rotarou, 2017; Matin et al., 2021). In the UK, women with a disability are 7.2 times more likely to have unmet health needs than men with no disability (Sakellariou and Rotarou, 2017).

Inequalities may be caused by barriers that prevent people from accessing or receiving the healthcare they require. The WHO has defined four barriers to accessing healthcare that people with disabilities may encounter. These barriers are categorised as attitudinal, physical, communication, and financial (World Health Organization, 2021). Attitudinal barriers include prejudice and stigma experienced at the hands of healthcare workers and policies that do not accommodate the needs of people with a disability. Physical barriers may include inaccessible facilities or services that are difficult to travel to or navigate around. Communication barriers include the limited availability of health information and communication in formats accessible to people with disabilities. Financial barriers include the costs associated with travel to hospitals, prescription charges, and lost income, and may be more pronounced for people who do not work, have limited income, or have financial reliance on others (Matin et al., 2021).

Removing barriers to equality is instrumental in reducing disability within society. Epidemiological data about a population can provide insight into barriers that may be present and can lead to a better understanding of the challenges that may arise for

an individual within that population. This understanding can and should be used to inform policy and decision-making.

1.2 Aims of the thesis

The overarching goal of this thesis is to deepen our understanding of individuals undergoing limb amputation or experiencing congenital limb differences (CLD) in Scotland. By shedding light on this demographic, the study aims to provide valuable insights that can inform policy formulation in Scotland. It is envisaged that these insights will not only contribute to reducing barriers and disparities within healthcare provision but also address broader societal structures.

This subject will be investigated through a three-step approach: initially, via a scoping review of existing literature, and then via two studies which utilise available data to measure frequency and characterise the epidemiology of individuals with limb difference in Scotland. Findings from the scoping review and the two retrospective studies, along with the methods used within the studies, are discussed with a view to providing recommendations for how future epidemiological studies about the limb different population in Scotland can be designed.

1.3 Outline of the thesis

Chapter 1 provides an introduction to the topic of disability and rationale for why an understanding of the population is important when considering health and social care policy. The chapter then introduces the population being studied and the nomenclature used throughout the thesis.

Chapter 2 describes the methods and findings from Study 1 which was a scoping review of the literature. The aim of the scoping review was to identify trends in amputation incidence, aetiology, and the prevalence of congenital limb difference, and determine the data sources which are used to obtain amputation data.

Chapter 3 provides a description of the Scottish population and healthcare system, and an introduction to electronic health records.

Chapter 4 describes the methods and findings from Study 2. The aim of Study 2 was to use publicly accessible data sources to establish how many limb amputations and CLD births occur in Scotland each year, and how many people are then referred to prosthetic services.

Chapter 5 discusses the methodology of data linkage, and then describes the methods used in Study 3. The objective for Study 3 was to create a dataset that could be used to investigate the frequency of amputation and CLD in Scotland, and the profile of the population undergoing amputation procedures, and analyse the data in terms of frequency of amputation and CLD, demographic profile, and clinical outcomes including survivorship.

Chapter 6 presents the results from Study 3 and provides a descriptive analysis of frequency of amputation and CLD at different levels and geographical distribution, demographic profile of the population in terms of sex, ethnicity, deprivation and age, and patient attendance at rehabilitation services following amputation. Survival probability after amputation and incidence/prevalence rates were calculated for various cohort. A discussion follows comparing findings to published literature.

Chapter 7 discusses the methods used within the thesis, including their strengths and limitations. The potential for a Scottish registry of limb difference is discussed.

Chapter 8 provides a conclusion of findings from the work presented in this thesis and explains its unique contribution to our knowledge in this field.

1.4 Limb difference

Limb differences can be congenital in origin or the result of limb amputation. Amputation of a complete limb or part of a limb is a surgical procedure performed to save or improve health or quality of life. Common reasons for amputation include infection, gangrene, or trauma.

Amputations are classed according to the level at which the limb is removed. In this thesis, the term ‘major amputation’ will be used to describe an amputation at or proximal to the ankle or wrist joint, and the term ‘minor amputation’ will be used when amputation occurs distal to the ankle or wrist joint. The term ‘lower limb amputation’ (LLA) will be used to describe the amputation of a leg, or part of a leg, and the term ‘upper limb amputation’ (ULA) will be used to describe the amputation of an arm, or part of an arm. Common levels of amputations and their nomenclature according to British Standard ISO 8S49-4:2020 are illustrated in figures 1.1–1.4. Nomenclature used to describe levels of amputation varies within published literature and clinical settings. A comparison of nomenclature currently recommended for use by the British Standards Institution, with commonly used terminology and Office of Population Censuses and Surveys OPCS-4 procedure codes is provided in Table 1.1.

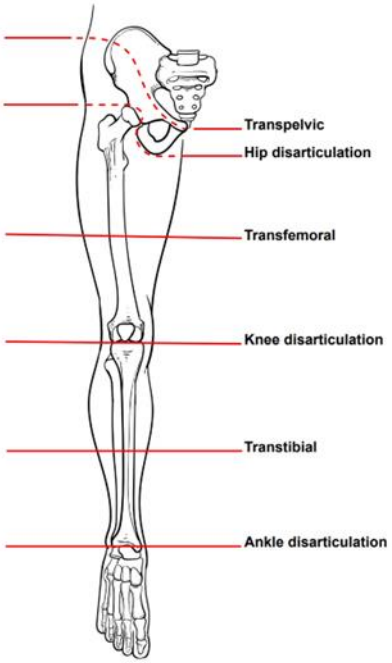


Figure 1.1 Amputation levels, leg.
Image by author

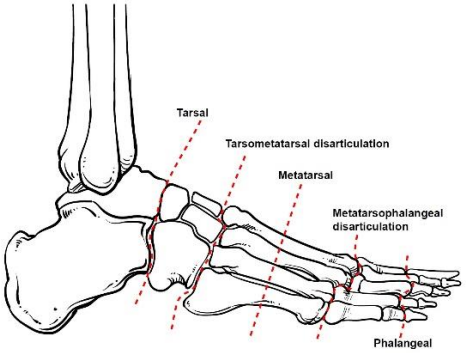


Figure 1.2 Amputation levels, foot
Image by author

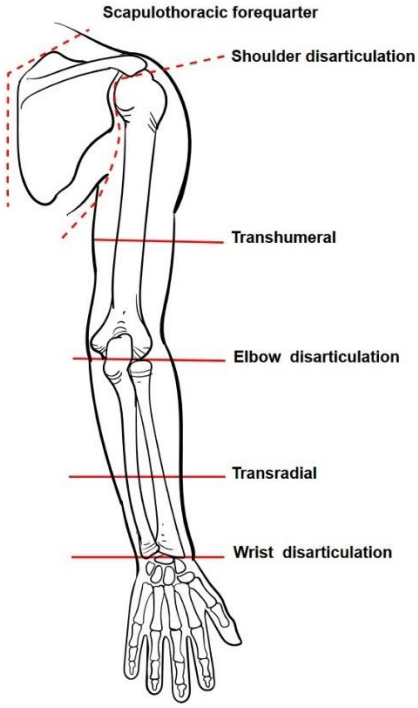


Figure 1.3 Amputation levels, arm
Image by author

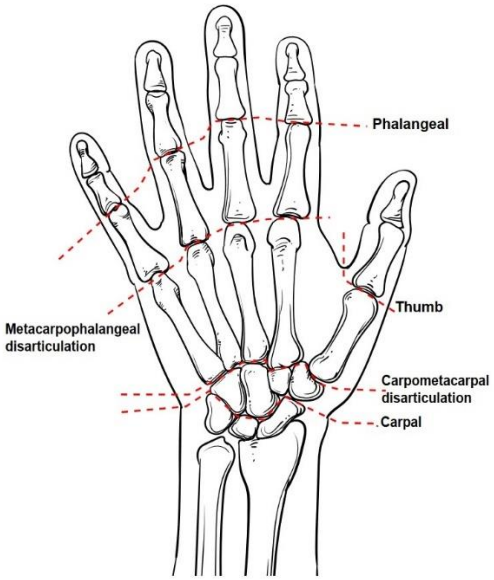


Figure 1.4 Amputation levels, hand
Image by author

Table 1.1 Amputation level nomenclature

Amputation level	BS ISO 8S49-4:2020		Common name	OPCS-4	
	Name	Definition		Name	Code
Major lower limb amputation levels	Transpelvic	Amputation of the whole lower limb together with all or part of the hemipelvis	Hemipelvectomy	Hindquarter amputation	X091
	Hip disarticulation	Amputation of the lower limb at the hip joint	Through hip	Disarticulation of hip	X092
	Transfemoral	Amputation of the lower limb between the hip joint and the knee joint	Above knee	Amputation of leg above knee	X093
	Knee disarticulation	Amputation of the lower limb at the knee joint	Through knee	Amputation of leg through knee	X094
	Transtibial	Amputation of the lower limb between the knee joint and the ankle joint	Below knee	Amputation of leg below knee	X095
	Ankle disarticulation	Amputation of the lower limb at the ankle joint	Symes	Amputation of foot through ankle	X101
	–	–	–	Other specified amputation of leg	X098
	–	–	–	Unspecified amputation of leg	X099
Minor lower limb amputation	Tarsal	Amputation of a part of the foot through any of the tarsal bones and/or joints	Chopart	Disarticulation of tarsal bones	X102
	Tarsometatarsal disarticulation	Amputation of part of the foot at one or more of the tarsometatarsal joints	Lisfranc	Disarticulation of metatarsal bones	X103
	Metatarsal	Amputation of a part of the foot through one or more metatarsals	–	Amputation through metatarsal bones	X104
	–	–	–	Other specified amputation of foot	X108
	–	–	–	Unspecified amputation of foot	X109
	Metatarsophalangeal disarticulation	Amputation of one or more toes	–	Amputation of toe	X111

	Phalangeal	Amputation of part of one or more toes	–	Amputation of phalanx of toe	X112
	–	–	–	Other specified amputation of toe	X118
	–	–	–	Unspecified amputation of toe	X119
Major upper limb amputation	Scapulothoracic forequarter	Amputation of the upper limb at the scapulothoracic and the sternoclavicular joints	Forequarter	Forequarter amputation	X071
	Shoulder disarticulation	Amputation of the upper limb at the shoulder joint	Through shoulder	Disarticulation of shoulder	X072
	Transhumeral	Amputation of the upper limb between the shoulder joint and the elbow joint	Above elbow	Amputation of arm above elbow	X073
	Elbow disarticulation	Amputation of the upper limb at the elbow joint	Through elbow	Amputation of arm through elbow	X074
	Transradial	Amputation of the upper limb between the elbow joint and the wrist joint	Below elbow	Amputation of arm through forearm	X075
	Wrist disarticulation	Amputation of the upper limb at the wrist joint	Through wrist	Amputation of hand at wrist	X081
	–	–	–	Other specified amputation of arm	X078
	–	–	–	Unspecified amputation of arm	X079
Minor upper limb amputation	Carpal	Amputation of a part of the hand through any of the carpal bones and/or joints	–	–	–
	Carpometacarpal disarticulation	Amputation of a part of the hand at one or more of the carpometacarpal joints	–	–	–
	Metacarpal	Amputation of a part of the hand through one or more metacarpals	–	–	–
	Metacarpophalangeal disarticulation	Amputation of one or more fingers	–	–	–

	Phalangeal	Amputation of part of one or more fingers	–	Amputation of phalanx of finger	X083
	Thumb	Amputation of the whole or part of the thumb	–	Amputation of thumb	X082
	–	–	–	Amputation of finger NEC	X084
	–	–	–	Other specified amputation of hand	X088
	–	–	–	Unspecified amputation of hand	X089

CLD, commonly referred to as limb reduction defect, is a congenital anomaly in which the limb has formed differently during foetal development. Congenital anomalies are diverse and complex in presentation, making their classification and nomenclature challenging. This thesis adheres to British Standard ISO 8548-1:1989 standards (International Organization for Standardization, 1989) when describing congenital anomalies. The classification system detailed in the standard was developed by the International Society for Prosthetics and Orthotics (ISPO) in 1973, and describes deficiencies according to the level of absence, identified as either transverse or longitudinal (Day, 1991).

The process for designating levels of transverse and longitudinal deficiencies, according to BS ISO 8548-1:1989, is illustrated in Table 1.2. When describing transverse deficiencies, the affected side (left or right), limb (upper or lower), and level of deficiency should be stated, as described. When describing longitudinal deficiencies the affected side (left or right), limb (upper or lower), and the name of the affected bone(s) should be stated, including the number of the bone where applicable, the state of deficiencies of the bone (total or partial absence), and the presence of hypoplasia, if appropriate, for any bone that has not been described as totally or partially absent.

Table 1.2 Terminology for describing transverse and longitudinal deficiencies

Plane	Affected side	Limb		Level of absence
		Lower limb	Upper limb	
Transverse deficiency	Left, right	Pelvis	Shoulder	Total
		Thigh	Upper arm	Total, upper third, middle third, lower third
		Leg	Forearm	Total, upper third, middle third, lower third
		Tarsal	Carpal	Total, partial
		Metatarsal	Metacarpal	Total, partial
		Phalangeal (toe)	Phalangeal (finger or thumb)	Total, partial
Longitudinal deficiency	Left, right	–	Ischium	Total, partial
		Scapula	Ilium	Total, partial

		Clavicle	Pubis	Total, partial
		Humerus	Femur	Total, partial
		Radius	Tibia	Total, partial
		Ulna	Fibula	Total, partial
		Carpus 1,2,3,4,5	Tarsus 1,2,3,4,5	Total, partial
		Metacarpals 1,2,3,4,5	Metatarsals 1,2,3,4,5	Total, partial
		Phalanges 1,2,3,4,5	Phalanges 1,2,3,4,5	Total, partial
		Rays	Rays	–

The terms ‘lower limb difference’ and ‘upper limb difference’ will be used in this thesis as general terms to describe a limb that either presents with a CLD or has undergone an amputation. It is commonly understood that people with limb differences will experience disability throughout their lives.

1.5 Summary of Chapter 1

Removing barriers to equality is instrumental in reducing disability within society. Epidemiological data about a population can provide insight into barriers that may be present and can lead to a better understanding of the challenges that may arise for an individual within that population. Chapter 1 explains that the aim of this thesis is to deepen our understanding of individuals undergoing limb amputation or experiencing CLD in Scotland and provides a description of the nomenclature used.

2. Study 1: Scoping review of the literature

This chapter explores the published literature to determine what is known about the people undergoing limb amputation or being born with a limb difference. Specifically, the chapter aims to map trends in amputation incidence and aetiology, the prevalence of congenital limb difference, and the data sources which are used to obtain amputation data. The chapter describes findings from a scoping review of the literature which was conducted in summer 2020 and was updated in 2023.

A scoping review was selected as the most appropriate method for exploring the literature to ascertain our current understanding of amputations. Such a review aims to map the literature on a broad topic to identify, for example, key concepts, types and sources of evidence, and gaps in knowledge (Pham et al., 2014). This differs from a systematic review which aims to summarise the best evidence in response to a specific research question (Arksey and O'Malley, 2005).

2.1 Method

The methods used for the scoping review were devised using the Scoping Review Protocol described by the Joanna Briggs Institute, and data reported using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) methods (Peters et al., 2020).

A systematic scoping review of published literature was conducted in June 2020 using a combination of keywords and Boolean operators (Table 2.1). Duplicates were removed, and titles and abstracts were manually screened against inclusion/exclusion criteria (Table 2.2). A broad criterion was used to minimize the risk of missing papers. Full text and conference abstract papers that discussed amputation incidence, patient demographics or registries (which include information about people with amputation or CLD) were included. Papers were excluded if a more recent paper using an updated version of the same dataset was available. Papers were also excluded if data was collected from a single site, unless the site was a national or regional centre.

Studies with small samples were also excluded with some exceptions. A summary of the filtering process used is illustrated as a PRISMA diagram in Figure 2.1.

Table 2.1 Search strategy showing keyword combinations

Search #	Search Term
1	amput*
2	“limb absen*”
3	“limb def*”
4	“limb diff*”
5	“cong* anomol*”
6	“cong* absen*”
7	“cong* abnormal*”
8	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7
9	limb
10	leg
11	arm
12	“lower limb”
13	“upper limb”
14	“lower-limb”
15	“upper-limb”
16	9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15
17	8 AND 16
18	registry
19	database
20	“data base”
21	epidemiology
22	incidence
23	prevalence
24	18 OR 19 OR 20 OR 21 OR 22 OR 23
25	17 AND 24

Table 2.2 Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Original research investigating demographics	Amputation or congenital deformity other than limbs
Studies using registries or repositories that report demographics	Case studies
Limb amputation	Single centre studies (unless national or regional hub)
Congenital limb difference	Small sample (~<75, dependant on number of years in sample and size of population)
Any date	More recent paper using same dataset with additional years
English language or translation into English	
Full text, conference abstract, report, systematic review, meta-analysis	

Papers were sub-divided into groups according to the population studied; global studies, lower limb amputation (LLA), upper limb amputation (ULA) or congenital limb difference CLD. Data was extracted, and papers were then analysed within their sub-groups. The following study characteristics were extracted from each paper; author, year of publication, date range of data examined, data source, country/region, population being examined, number of subjects, reported incidence, sex ratio, mean age at amputation. In addition, the presence of diabetes, and results corresponding to ethnicity and social deprivation was noted. LLA papers were then divided into groups according to the global populations examined; global reviews, UK & ROI, Scandinavia, Europe (excluding UK & ROI, North America, South America, Asia, Middle East, and Africa. These findings can be viewed in Appendix A.

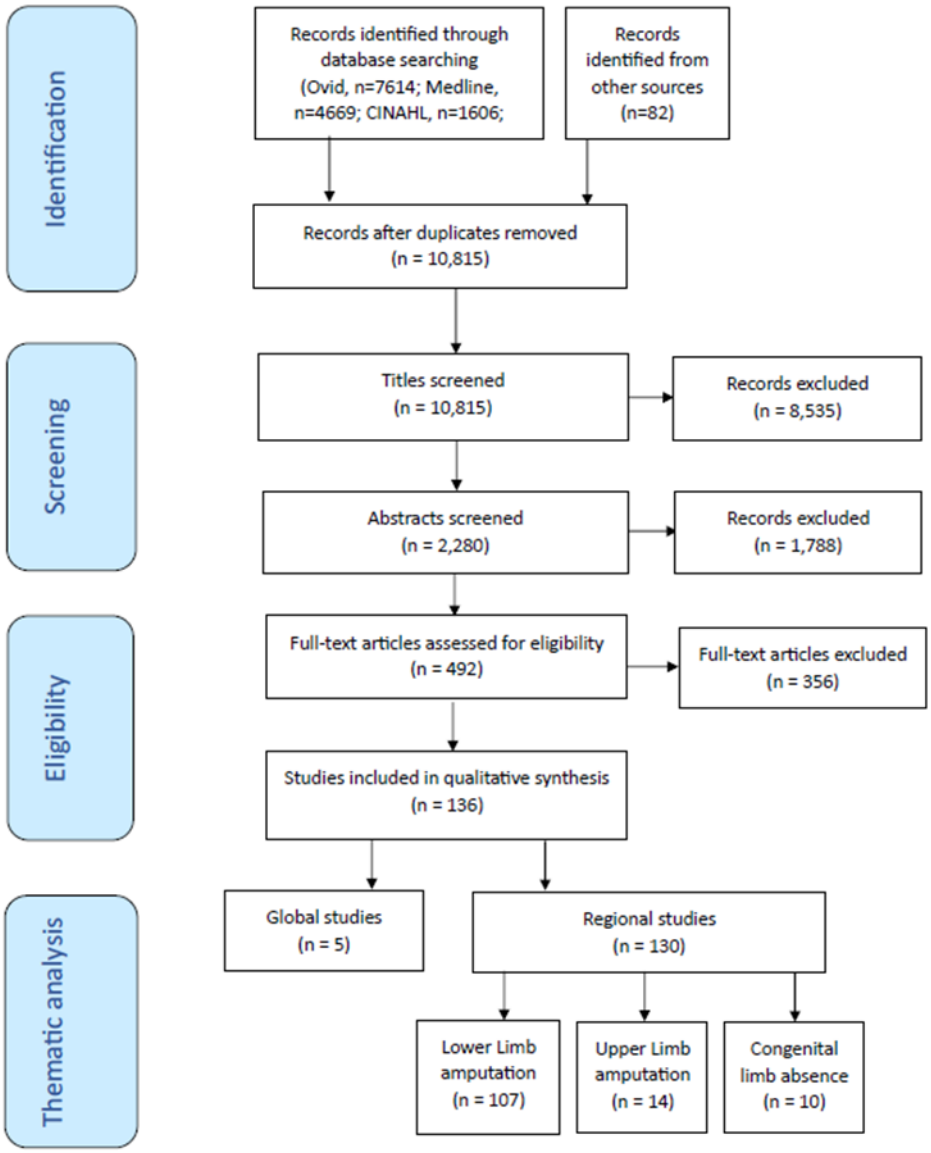


Figure 2.1 PRISMA flow diagram

2.2 Global incidence of limb difference

The global incidence of limb amputation and CLD is difficult to quantify due to differences in data collection methods and multiple variables within the population being observed. Findings from a literature review published in 2003 highlighted geographic variations in the incidence of amputation, and discussed how differences in the methods used to calculate rates limit the possibility of comparative analysis (Ephraim et al., 2003). An attempt to compare incidence rates across populations was made by Moxey et al. (2011), who performed a meta-analysis of literature published between 1989 and 2010 and reported that LLA ranged from 5.8 to 31 per 100,000 population. The LLA rate was, however, much higher in people with diabetes, ranging from 46.1 to 9,600 per 100,000 population (Moxey et al., 2011). Variations between incidence rates in diabetic and non-diabetic populations were also found by Narres et al. (2017) in their systematic review, with the authors noting that due to the heterogeneity of the data being examined it was not possible to conduct a meta-analysis.

Multi-national studies which examine the epidemiology of limb amputation are scarce and complex to administer. Differences in data collection methods among various centres or countries can result in discrepancies and potential errors in the data. An example of a multi-centre study is the work conducted in the 1990s by the Global Lower Extremity Amputation Study Group. Data was gathered from ten regional centres in England, Italy, Japan, North America, Spain, and Taiwan, with each centre providing demographic data about people undergoing an LLA at or above the subtalar joint. Differences were observed in incidence of LLA between the participating centres, with Navajo, USA, reporting incidence 15 times higher than Madrid, Spain. Most centres reported similar age distributions with over two-thirds of LLAs occurring in people aged over 60 years, and higher rates for males than females. Whilst useful, this study is limited by the low number of areas represented, and it only includes centres which responded to a recruitment advertisement. The authors discussed the limitations of the study and suggested that some differences in amputation incidence may be due to local differences in data interpretation (Unwin, 2000).

Recent studies by McDonald et al. (2021) and Yuan et al. (2023) reported the global prevalence of traumatic amputations. The two studies both used data collected in the Global Burden of Diseases (GBD) study, managed by the Institute for Health Metrics and Evaluation at the University of Washington, which is a collection of health data,

some of which can be accessed freely by the public. In the most recent output, morbidity and mortality data was collected from 204 countries (The Lancet; Institute for Health Metrics and Evaluation). Using data from the 2017 GBD study, McDonald et al. (2021) estimated that 57.7 million people were living with limb amputation caused by trauma, of which 38.7 percent were ULAs, and reported that the most common cause of traumatic amputation was falls (McDonald et al., 2021). Yuan et al. (2023) used the 2019 GBD to calculate incidence, prevalence, and burden of traumatic amputations across 204 countries. They found a 16.9 percent rise in incidence of traumatic amputations between 1990 and 2019 and reported that the burden of disability experienced by males varied widely across countries but there was less variance reported in females. In general, unilateral LLAs caused the greatest burden of disability, and the most common level for a traumatic amputation was the fingers (Yuan et al., 2023).

2.3 Study characteristics

Incidence of amputation was widely reported across a range of academic literature, and incidence rate of amputation was commonly used as a measure of effectiveness of surgical procedures or medical interventions. Most papers presented a demographic breakdown of patients based on gender and aetiology. Geographic location, ethnicity, and socioeconomic factors were also common themes. Comparisons between papers were difficult due to differences in methods, populations, and timeframes.

To facilitate reporting, findings have been presented within subgroups according to the population described within each paper (LLA, ULA, or CLD). Due to the high volume of papers which reported LLA, findings have been further divided into geographic regions.

2.4 Lower limb amputation

2.4.1 UK and Republic of Ireland

A variety of incidence studies have been conducted within the UK and Republic of Ireland which provide data on specific populations. Much of the literature has been focused on the diabetic and vascular populations. A comprehensive review of care received by people who have undergone major LLA due to vascular disease or diabetes was conducted by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) in 2014. Recommendations from the review included the

importance of a best practice clinical care pathway, minimising delays, and timely access to rehabilitation services (Gough et al., 2014).

Peripheral arterial disease (PAD) and diabetes are the most common cause of LLA. In Scotland, 84.7 percent of all persons undergoing major LLA had PAD (Smith, Scott and Hebenton, 2019). In England, 39.4 percent of those undergoing major LLA and 50 percent undergoing minor LLA had diabetes (Moxey et al., 2010). The risk for LLA was found to be ten times higher for people with diabetes than those without diabetes (Holman, Young and Jeffcoate, 2012).

Prevalence of vascular and diabetic LLA has been investigated by several teams across the UK and Republic of Ireland, varying from single centre to regional or nationwide studies. Evidence points towards a reduction in major LLA in patients with diabetes and vascular patients. Reported incidence of major LLA decreased in the early 2000s compared with earlier studies (Krishnan et al., 2008; Schofield et al., 2009; Vamos et al., 2010; Yu et al., 2010; Kennon et al., 2012). A reduction of 40.7 percent in incidence of major LLA in Scotland was observed between 2004 and 2008 (Kennon et al., 2012). In addition, an 82 percent reduction in diabetic major LLA was found over an 11-year period in a study of inpatients at a single-site hospital in England (Krishnan et al., 2008).

The reduction in major LLA may be a result of enhanced diabetic footcare, an opinion supported by Paisey et al. (2018), who reported that diabetes-related major LLA in south-west England was inversely related to delivery of diabetic footcare services. Rossi et al. (2010) also support this opinion, reporting a 53 percent reduction in diabetic major LLA since improvements to the diabetic care pathways were implemented in 2005.

Whilst most results indicate a reduction in LLA, there are exceptions. No change in minor or major LLA was found in a three-year review in Leicester, England (Macriyiannis et al., 2015) or a nationwide review of English major LLA (2003–2007) (Moxey et al., 2010). In addition, several studies noted increases in minor LLA (Krishnan et al., 2008), including Vamos et al. (2010), who reported a two-fold increase in type 2 diabetic minor LLA.

Geographic variances in incidence of amputation in the UK have been reported including regional variations of up to ten times (Moxey et al., 2010; Holman, Young and Jeffcoate, 2012). When the relationship between LLA and revascularisation in

patients aged over 50 in England (2003–2009) was examined, it was found that the likelihood of having an LLA with revascularisation was increased for people living in the north of England. Although a difference in social deprivation was reported this did not explain the difference (Ahmad et al., 2014a).

Social deprivation has been linked to higher incidence of LLA. Most studies investigating this have used the Indices of Multiple Deprivation or Scottish Indices of Multiple Deprivation (SIMD) for this comparison. Increased LLA rates in the most deprived areas were found in a study of 327 persons with PAD undergoing LLA (2003–2009) (Ferguson et al., 2010). In Scotland, a link between higher rates of LLA and social deprivation was reported (Davie-Smith et al., 2019). Davie-Smith et al. (2019) found that 67 percent of people with LLA lived in the most deprived 40 percent of areas, and that there were significantly more transfemoral amputations in the most deprived 20 percent of areas compared with the least deprived. They also found that people living in more deprived areas had higher prevalence of smoking and lower rates of participation and mobility than those in less deprived areas.

Differences in incidence have also been found in relation to race and ethnicity. When ethnicity and amputation in the diabetic and non-diabetic populations living in Leicestershire, England, was examined, lower incidence rates were found in both groups in patients of Asian origin than in those who are White (Gujral et al., 1993). Similar findings were reported by Holman, Young and Jeffcoate (2012). No ethnic differences were found in a study comparing diabetes-related amputation amongst African Caribbean and European women in London. A difference was found, however, in males, with African Caribbean males having a reduced risk of LLA (Leggetter et al., 2002).

There is consensus that the majority of LLAs are performed on males. Ahmed et al. (2014b, 2016b) and Davie-Smith et al. (2019) report this figure to be 75 percent and 68.5 percent, respectively.

2.4.2 Scandinavia and the Nordic countries

Scandinavian countries have produced a wealth of literature describing the occurrence of amputation in various cities and regions. Incidence studies have been conducted across the region using hospital amputation and governmental records, dating from as early as 1930. These studies allow convenient tracking of amputation rates throughout the mid to late 20th century and beyond.

Alaranta et al. (1995) and Pohjolainen and Alaranta (1988) both compared their results from studies in Helsinki, Finland, with earlier studies, and found an overall increase in incidence since 1984 but a decrease in traumatic amputations, and a higher mean age of persons undergoing amputation. A higher proportion of persons with vascular disease and an older population may explain the increase in mortality rate observed between the studies. Pohjolainen and Alaranta (1988) predicted that the rate of LLA in Finland would continue to rise by 50 percent within 20 to 30 years. This rise, however, has not been demonstrated in a more recent study where a marked decrease in incidence of major amputations in Finland was found during the period 1997–2007 amongst groups both with and without diabetes. A high mortality rate amongst those undergoing major amputation was also noted (Ikonen et al., 2010).

The high prevalence of type 1 diabetes and the increasing prevalence of type 2 diabetes in the region may contribute to a high incidence of major and minor LLAs. Many papers from the region examine the effect of surgical and medical procedures on the incidence of amputation and level of amputation. Revascularisation procedures and multidisciplinary foot clinics have been shown to reduce the incidence of LLA within the diabetic population (Eskelinen et al., 2006). Rates of amputation are generally higher in regions where foot clinics are not commonplace, suggesting the importance of their role in preventing LLA. Eskelinen et al. (2006) reported a 23 percent decrease in diabetic major LLA in Helsinki, Finland, from 1990 to 2002. This reduction may be linked to the establishment of diabetic foot centres in the region, which occurred during the early period of study. A 40 percent decrease in incidence of non-diabetic major LLA was also reported over the same period (Eskelinen et al., 2006). Decreases in incidence of first LLA occurring between 1997 and 2007 were also observed (Winell et al., 2013). Other Scandinavian countries have demonstrated a similar decline in the number of major amputations being conducted since the late 1990s. In Denmark the LLA incidence rate amongst patients aged over 50 with diabetes and atherosclerosis decreased from 41.67 per 100,000 in 1997–2002 to 32.53 per 100,000 in 2009–2014 (Londero et al., 2019). During the same period, access to vascular surgeons was increased although there was no increase in the number of revascularisation procedures performed prior to amputation. These results were supported by findings from a 20-year review of Danish amputation data, 1997–2017, that reported significant decreases in LLA incidence amongst both the diabetic and non-diabetic populations. This decrease was evident in amputations both above

and below the ankle, and the authors suggest that the decrease could be partly due to the implementation of specialist foot clinics (Roikjer et al., 2020).

Similar results were found in Norway where, to evaluate the effect of regional diabetic foot clinics on the amputation rate, amputation data from 2004–2007 was compared with previously collected data from 1994–1997, which was prior to foot clinics being set up. The amputation rate decreased both in the patient group with diabetes and among patients with peripheral vascular disease (PVD) (Witso, Lium and Lydersen, 2010).

A reduction in the rate of major amputations is also evident in literature from Sweden. Larsson et al. (2008) reviewed 628 amputations which occurred over a 20-year period, from the time of implementing a multidisciplinary foot clinic in 1982. They noted a decrease in the incidence of major amputation from 16 to 6.8 per 100,000 inhabitants. Notably though, they also reported a rising proportion of amputations at or distal to the ankle joint over the review period, and a reduction in re-amputation. This infers that the foot clinic may have influenced treatment and surgical decisions resulting in fewer proximal LLAs.

Reviewing amputation data is made possible within Scandinavian countries due to the established registries which collect and process medical data from governmental hospitals and services. In addition to general surgical and medical data, two notable specialist amputation registries exist in the region. The Danish Amputee Register was established in 1972 (Ebskov, 1986) and more recently SwedeAmp was established in 2011 (Kamrad et al., 2020). Both registries are government funded and collect amputation, medical, and prosthetic data related to LLA. These registries will be discussed in more detail within Section 2.7.

It can be concluded that there is a vast quantity of amputation data within Scandinavian countries which demonstrates that the prevalence of LLA rose until the late 20th century. This rise can be attributed to the increased prevalence of diabetes within the population. Specialist multidisciplinary foot clinics were established within the region which appear to have been influential in improving foot care and reducing the rate of LLA.

2.4.3 Europe (excluding UK and Republic of Ireland)

Diabetes and PVD are prevalent in mainland Europe and the rate of LLA rose during the mid to late 20th century. Following changes to the healthcare model to promote

good foot care and wound healing, a reduction or stabilisation in diabetic LLA incidence was observed in Germany (Trautner et al., 2007), the Netherlands (Van Houtum et al., 2004; Fortington et al., 2013; Nijenhuis-Rosien et al., 2017), Spain (Calle-Pascual et al., 2001; Lopez-de-Andres et al., 2015; Jimenez et al., 2017), Hungary (Kolossvary et al., 2020), Italy (Lombardo et al., 2014), and Czech Republic (Pit'hova et al., 2015). The ratio of minor LLA to major LLA increased and the rate of re-amputation decreased as foot care services become more widely accessible (Malyar et al., 2014; Heyer et al., 2015; Kröger et al., 2017). Kröger et al. (2017) reported that, whilst the major amputation rate fell in Germany by over 30 percent between 2005 and 2014, the rate of minor amputations rose by 25 percent.

Analysis of LLA has been identified as an important component of healthcare monitoring. In addition to the European countries mentioned above, baseline LLA incidence figures have been estimated for Portugal (Sequeira and Martins, 1996), France (Fosse et al., 2009), Slovakia (Petrasovic et al., 1996), and Poland (Nazim, 2001). Similar patterns to those seen in Scandinavia are evident in Europe. The published data reports that whilst the rate of diabetes has increased, preventative medicine has been effective in stabilising, or in some cases reducing, the number of LLAs, particularly major LLA. Variations in LLA incidence occur across the different geographic areas of the region. Several authors comment on such variations and attribute high incidence in rural areas to less access to specialist preventative medicine clinics (Lindegard, Jonsson and Lithner, 1984; Dózsa et al., 2020).

2.4.4 North America

The Medicare system was a source of data for many of the studies conducted in the USA. Medicare is a USA government-run health insurance programme which provides health insurance for older and disabled persons, and those on low incomes. Approximately 18.4 percent of people in the USA are enrolled in the Medicare programme (Vankar, 2023). Data is collated about all services paid for through the Medicare system. Other sources of data included pathology specific registries and surgical databases. In Canada, amputation incidence was calculated using hospital admissions and discharge data from a national database (Hussain et al., 2016; Kayssi et al., 2016; Imam et al., 2017).

Geographic variances in LLA incidence have been reported in the USA (Wrobel, Mayfield and Reiber, 2001; Peacock et al., 2011; Stevens et al., 2014). The rate of LLA across the USA was more variable in the diabetic population than in the non-

diabetic population (Wrobel, Mayfield and Reiber, 2001). Geographic variances in LLA incidence exist between rural and urban areas, and between areas of differing socioeconomic wealth. Incidence of LLA is higher in rural communities (Peacock et al., 2011) and areas of low income (Stevens et al., 2014). The LLA rate for people with diabetes living in lower income regions of California was twice as high compared with those living in higher income regions (Stevens et al., 2014).

Socioeconomic variation in amputation rate was also evident in literature from Canada. Despite universal access to healthcare, Amin et al. (2014) found a correlation between low socioeconomic status and diabetes-related LLA and reported that LLA was more prevalent in males than females (Amin et al., 2014).

Limb ischemia is a common cause of LLA in North America (Prasad et al., 2018). LLA incidence has decreased in the vascular population since limb salvage procedures became more frequent (Nowygrod et al., 2009). Many of the papers which reported LLA incidence within the region discussed racial and socioeconomic disparities within the population. A study which examined the medical records of patients with PVD who underwent an LLA in New York state during the period 1999–2014 determined that Black patients were significantly more likely than White patients to undergo an LLA rather than a limb salvage procedure (Stapleton et al., 2017). Similar findings were reported by Rowe et al. (2010), who reviewed nationwide data collected from 1998 to 2006 (Rowe et al., 2010), and Traven et al. (2020), who reviewed national surgical data 2011–2017 (Traven et al., 2020). Racial disparities were also reported by Rizzo et al. (2016, 2018), who found that LLA rates for African Americans with PAD were up to 50 percent higher than for Caucasians (the term used in the study) with PAD. In their study, Caucasians had a lower LLA rate than all other racial and ethnic groups (Rizzo et al., 2016; Rizzo et al., 2018). Higher rates of LLA were also seen in American Indians (the term used in the study) compared with the overall US population (O'Connell et al., 2010).

Racial disparities in LLA were not isolated to cases of limb ischemia. Weber et al. (2011) reported that race and age are factors when determining the risk of amputation following fracture. Older Black people have a higher risk of amputation than other racial groups, but younger Black people have a lower risk (Weber et al., 2011). No conclusive reason is given for this disparity, although suggestions are made that injury type and limb salvage practices may be contributing factors. When examining cancer

care practice, Player et al. (2017) found that Black and Hispanic people were more likely to undergo amputation.

In summary, studies based on North American data show that geographic, socioeconomic, and racial disparities exist in the medical and surgical procedures associated with limb salvage. These disparities may contribute to an increased risk of LLA for people living in rural or low-income communities, and for people from racial and ethnic groups other than White.

2.4.5 South America

Compared with other regions, there are fewer publications detailing the rates of LLA in South America. Analyses of regional LLA have been conducted in Costa Rica (Lacle and Valero-Juan, 2012), Mexico (Jesus Ascencio-Montiel, Kumate-Rodriguez and Cisneros-Gonzalez, 2017), and Brazil (Cascão, Costa and Kale, 2012; Barbosa et al., 2016; Montalvo Tinoco et al., 2017). Montalvo Tinoco et al.'s (2017) seven-year review of LLA data in Brazil found evidence of geographic and socioeconomic variances throughout the country.

2.4.6 Asia and Oceania

Australia and New Zealand have national healthcare systems with registries and databases for recording hospital procedures. These have been used as data sources in several studies describing LLA in the region. Baseline regional data from the 1980s was published by Jones (1990), and many papers have since followed, allowing trends in amputation incidence to be observed. The reviewed papers present similar findings and patterns, particularly in relation to the effect of limb salvage procedures, as those described for Europe and Scandinavia. Dillon et al. (2014) reported no overall change in the LLA incidence from 2000 to 2010, although the ratio of minor to major LLA shifted with increases in the number of minor LLA procedures being conducted (Dillon, Kohler and Peeva, 2014). This was further confirmed by Wright et al. (2019), who found that whilst the rate of revascularisation procedures and minor LLA had increased during the period of review, 2001–2015, major LLA had decreased (Wright, Steffens and Huilgol, 2019). Decreases in diabetic major LLA were also reported by other research teams (O'Rourke et al., 2012; Baba et al., 2015).

A study of diabetic LLA in New Zealand found that ethnic disparities existed within the country, with Maori people most at risk of amputation (Robinson et al., 2016).

Results from studies in East and South-East Asia show that diabetes related minor LLA has increased, whilst major LLA has decreased. This trend is evident in South Korea (Kim et al., 2019a) and Taiwan (Chen, Ho and Li, 2006; Lai et al., 2015; Sheen et al., 2018; Li et al., 2020).

Several studies have been conducted using universal health insurance data from Taiwan. Baseline data collected in 1997 indicated a higher incidence for males than females but highlighted that females and young people with diabetes had an increased risk of non-traumatic LLA (Chen, Ho and Li, 2006). A longer observational study, from 2001 to 2010, showed that the incidence of diabetic LLA had decreased (Lai et al., 2015). A continued decrease is also reported in later studies (Li et al., 2020). Higher incidence of LLA was observed in rural and suburban areas (Li et al., 2020) and amongst people of lower socioeconomic status (Sheen et al., 2018). These findings are in line with trends seen in other countries and support the evidence that improved access to diabetic care reduces LLA incidence.

In a review of patients with PAD in Japan, women were found to undergo LLA at higher levels than males (Kumakura et al., 2011).

The data collection methods used in studies from East and South-East Asia varied. Whilst countries such as Taiwan have established national insurance systems from which data can be extracted, other countries are less well set up for epidemiological studies. Data sources used by studies in Japan included a government disabled person insurance scheme and surveys with populations identified through manual searching of hospital records (Nagashima, Inoue and Takechi, 1993; Ohmine et al., 2012). A community-based survey by Ohmine et al. in 2012 showed that amputation had increased in comparison to baseline data collected in 1968–1992. In Thailand, a baseline dataset of diabetic patient data was established using medical records collected from hospitals over a nine-month period, and a separate study describes the implementation of a national programme for monitoring care of amputees across Thailand (Suvapan et al., 2015).

There were no studies found from India using registry or national data. Single-centre studies give an indication of the causes of amputation in the region. A review of attendance at a rehabilitation centre over a 25-year period from 1954 to 1978 reported that 7.3 percent of civilian amputees were female, and 67 percent of disabilities were due to trauma (Narang and Jape, 1982). Train accidents were the most common

cause of traumatic LLA in both the adult and paediatric populations in India (Narang and Jape, 1982; Ahmad et al., 2016a).

2.4.7 Middle East

The Middle Eastern countries have a high prevalence of diabetes (Elhadd, Al-Amoudi and Alzahrani, 2007; Al Busaidi, Shanmugam and Manoharan, 2019). Despite this, there are limited studies reporting LLA incidence in the region. Of the literature that has been published from the region, most report data from single-site hospitals.

A study of amputees from 1977 to 1990 at a single hospital in Saudi Arabia found that the main cause for LLA was trauma (52.9 percent) (al-Turaiki and al-Falahi, 1993). The timing of this study, however, was before the increase in diabetes in the region. It can be assumed that the ratio of traumatic amputations to vascular disease may have since altered since. In contrast, a more recent study at a single hospital found that 40.2 percent of existing patients with LLA had diabetes (Shahine et al., 2022), and results from a study at a single hospital in Qatar from 2000 to 2014 found that 75.86 percent of the amputations were conducted on people with diabetes (Al-Thani, Sathian and El-Menyar, 2019). Similar findings were seen in a review of 47 amputations in the small neighbouring country of Bahrain, where 84.4 percent of LLAs were due to complications of diabetes (Agha et al., 2017).

LLA figures have been published for hospitals in Riyadh (Alshehri et al., 2022) and Jeddah (Badri et al., 2011), Saudi Arabia. The amputation figures from Jeddah hospitals were used along with diabetes prevalence rates and a national census to predict incidence of amputation in Saudi Arabia. The resulting figure for all LLA was 2.6 per 10,000 population (Alzahrani, 2012). A male to female ratio of 3:1 was found in the Riyadh study with 53 percent of LLAs being performed due to vascular causes (Alshehri et al., 2022).

A review of LLA data in Amman, Jordan, did not report diabetic status, but found that the incidence of major LLA was greater than minor LLA (Salman and Laporte, 2010). This differs from the Qatari study, where minor LLA outnumbered major LLA with a ratio of 2:1 (Al-Thani, Sathian and El-Menyar, 2019). The Jordanian study found that the risk of LLA was greater in males and peaked at age 60–70, although the risk of major LLA continued to rise in the 80+ age group. A similar risk was found in Lebanon, where 50 percent of patients were in the 60–79 age bracket (Yaghi et al., 2012). The

authors of the Lebanese study reported that 59 percent of all amputations (ULA and LLA) were due to vascular disease.

A high male to female ratio was noted in a study of traumatic amputations (LLA and ULA) in northern Iran, where more than 80 percent of patients were male (Janmohammadi and Bijani, 2008).

2.4.8 Africa

Published incidence statistics for LLA in Africa are scarce, with data only found for Nigeria, Ghana, and South Africa.

Trauma is a main cause of major limb amputation in Nigeria (Solagberu, 2001a; Ajibade, Akinniyi and Okoye, 2013). Akinyoola et al. (2006) reported that trauma accounted for 74.3 percent of paediatric amputations (Akinyoola et al., 2006). There are, however, variances according to the amputation centre being studied, as a review of LLA records (n=127) at a single centre in Lagos found that 55.14 percent of amputations were due to diabetic gangrene (Enweluzo et al., 2010).

In a five-year review at a single centre in north Nigeria (n=132), it was found that 86.4 percent of adult patients undergoing amputation were male and 70.5 percent were under the age of 40 (Ajibade, Akinniyi and Okoye, 2013). Similar findings were found in Lagos, Nigeria (Enweluzo et al., 2010). The risk of complications following trauma is high, with traditional bone setters gangrene accounting for many amputations (Akinyoola et al., 2006; Ajibade, Akinniyi and Okoye, 2013). Complications after amputation were also high (31.1 percent) (Ajibade, Akinniyi and Okoye, 2013).

Whilst trauma has been documented as the main cause of major LLA in Nigeria, it is apparent that diabetes is also problematic within the region. An increase in the incidence of diabetes-related LLA was found in Ghana (Sarfo-Kantanka et al., 2019). LLA incidence rose from 0.6 to 10.9 per 1,000 follow-up years from 2010 to 2015. The majority of LLAs were classes as major amputations. The authors suggested that lack of resources for diabetic care alongside an increase in life expectancy may be partly responsible for this increase.

Diabetes and atherosclerosis were found to be the main cause of LLA in South Africa. A five-year review (n=348) at a single centre found that access to foot care, particularly in rural communities, was a contributing factor (Khan et al., 2020). Variances in aetiology are discussed by Solagberu and Onawola (2001), who

suggests that West Africa LLA statistics are similar to those for other developed countries.

2.5 Upper limb amputation

The incidence of ULA is less well documented than LLA, and many of the published studies which report incidence were conducted in the 20th century. Prevalence of acquired major ULA has been calculated at 11.6 per 100,000 adults (Østlie et al., 2011) and 13.5 per 100,000 population (Ziegler-Graham et al., 2008). The incidence of ULA decreased by 41.4 percent between 1997 and 2012 in the US paediatric population (Vakhshori et al., 2019).

Most papers discussing incidence and prevalence of ULA are based on single-centre reviews with only a small number of regional or national studies available. Overall figures indicate that ULA is a less common procedure than LLA. In the Netherlands in 1969 there were 103 ULAs compared with 935 LLAs (Bakker, 1973), and in Denmark, 75 ULAs were reported annually compared with 2,164 LLAs (Andersen-Ranberg and Ebskov, 1988). In single-centre studies in South Korea and Saudi Arabia, the percentage of ULA was 32.3 percent (Kim et al., 1996) and 21 percent (Alshehri et al., 2022), respectively.

There is consensus within the published literature that males are more likely to undergo ULA than females (Liang et al., 2004; Østlie et al., 2011; Pomares et al., 2018; Toma et al., 2018; Kim et al., 2019b; Ro et al., 2019). The male to female ratio for major ULA has been estimated to be 5:1. The percentage of males is as high as 97 percent in studies investigating manual-work-related injuries (Østlie et al., 2011; Kim et al., 2019b).

The average age at amputation varied within the literature. An average age of 29.6 years was found in a review of acquired ULA in Norway (Østlie et al., 2011), 39 years in work-related ULA in Taiwan (Liang et al., 2004), and 59 years in traumatic ULA in France (Pomares et al., 2018). This variance may be due to differences within the populations being examined and methods used to collect data. It is clear, however, that the average age of ULA is lower than that of LLA.

The gender difference and younger age may be due to the high occurrence of trauma-related ULA. Trauma was reported as the cause of amputation in 84.5 percent of cases studied in the Netherlands (Østlie et al., 2011), and 78 percent of cases studied in South Korea (Kim et al., 1996). A ten-year review of traumatic ULA in France found

that work-related trauma was the most common cause, with a male to female ratio of 3.1:1 (Pomares et al., 2018). Liang et al. (2014) also reported that in the work-related injuries in Taiwan that they examined, males were more commonly affected than females. Østlie et al. (2011) found that males were more likely than females to undergo ULA due to work-related trauma, whilst the main cause of traumatic ULA in women was road traffic accidents.

Hand amputations are the most common level of ULA. Forty percent of ULAs conducted at a single-centre hospital in Saudi Arabia were partial hand amputations (Alshehri et al., 2022). In a Korean study, 584 hand amputations were reported compared with 478 transradial and 397 above elbow amputations (Kim et al., 1996). Vakhshori et al. (2019) reported that 92.54 percent of traumatic ULAs in the paediatric US population they studied were finger amputations. A review of all trauma injuries in Iran found that finger amputation was the most common level of trauma-caused amputation (Moini et al., 2009).

When work-related traumatic amputation trends in South Korea were examined, it was found that whilst ULA increased in frequency the number of finger amputations decreased from their peak in 2006–2007 (Ro et al., 2019). The authors felt that the reduction may be due to the introduction of policies to reduce industrial injuries, and that these were more effective at reducing minor ULA than major ULA.

Methodological problems that exist when reporting and comparing ULA studies have been discussed in the literature. Differences in collection methods, categorisation, and over/under-reporting have resulted in wide differences between studies (Østlie et al., 2011).

2.5.1 ULA in the UK

There is a lack of information about the number of ULAs carried out in the UK. There are currently no studies which describe incidence or prevalence of ULA in the UK.

A small number of studies have reported the number of people with ULA attending limb-fitting centres in the UK. A study which examined the profile of patients attending a single prosthetic centre reported that 59 percent of attendees were adult males, 28 percent adult females, and 13 percent were aged under 16 (Kyberd, Beard and Morrison, 1997). More recent data about persons with ULA who are referred to prosthetic clinics in the UK is included within the published reports of the National Amputee Statistical Database (UK) (NASDAB) and Limbless Statistics. According to

NASDAB, from 1997/98 until 2005/06, the rate of new upper limb referrals remained constant, with around 250–300 new referrals each year (NASDAB, a-i). Most new referrals in 2010–2011 were due to CLD (40 percent) or amputation following trauma (40 percent). The remaining 20 percent of referrals were due to amputation following pathology, such as meningococcal septicaemia, meningitis, PVD, frostbite, tumour, and self-mutilation. Of all upper limb referrals to UK prosthetic clinics in 2010–2011, 66 percent were aged under 55 (Limbless Statistics, 2013d).

2.6 Congenital limb difference

The prevalence of CLD has been reported as 3.5 per 10,000 births (Canada) (Irvine, Luo and Leon, 2015), 5.6 per 10,000 (Canada) (Bedard et al., 2015), 4.4 per 10,000 (Norway) (Klungsøyr *et al.*, 2019b), and 4.15 per 10,000 births (Japan) (Mano et al., 2018). Longitudinal surveillance indicates that CLD prevalence has decreased since the 1980s. A 25-year review of birth records from New York State reported a 2.79 percent decrease in upper limb CLD and 3.15 percent decrease in lower limb CLD (Kim et al., 2013). Significant decreases in upper limb CLD were observed in the non-Hispanic Black population and where maternal age was over 35 years. Contrary to this, a 33-year review of CLD in Alberta, Canada, showed that whilst fluctuations occurred the overall rate since 1980 was stable (Bedard et al., 2015). Stable rates of CLD during the same period were also observed in Norway (Klungsøyr et al., 2019b).

Syndromes and associated defects are often present in children with limb reduction. Associated major anomalies are present in 53.2 percent of pregnancies with CLD (Klungsøyr et al., 2019a). A lower risk of 33 percent was reported in a single-centre review in Israel (n=24) (Makhoul et al., 2003). Risk of low birth weight has been found to be an associated factor (Kallen, Rahmani and Winberg, 1984).

Risk of stillbirth, neonatal death, and infant mortality are elevated by the presence of birth defects (Klungsøyr et al., 2019b; Heinke et al., 2020). In a review of 19,170 neonates in the USA, the presence of longitudinal limb deficiencies was found to increase the risk of stillbirth from 6 per 1,000 to 11 per 1,000; transverse limb deficiency to 26 per 1,000; and defects associated with amniotic bands to 110 per 1,000 (Heinke et al., 2020). Klungsøyr et al. (2019) reported that in Norway after 1999, 26 percent of pregnancies with identified CLD were terminated, and of these 90 percent had presented with associated major anomalies. Autopsy studies can provide information about prevalence of limb deficiencies and associated defects in stillborn neonates. In an autopsy study in Greece, CLD was found in 1.97 percent of cases

and, of those, associated defects were present in 50 percent of the autopsy examinations (Goutas et al., 1993).

2.6.1 Congenital limb difference in the UK

Literature is scarce regarding persons in the UK with a CLD. A single-centre study reviewed referrals to the Dundee Limb Fitting Centre from 1965 to 1994, and concluded that during this time 68 patients, with 80 congenital anomalies, had been referred for treatment, 40 of which were upper limb anomalies. This accounted for only 1.8 percent of people born with anomalies in the area during this period, suggesting that a low percentage of persons born with limb anomalies are referred for prosthetic fitting (Stewart and Jain, 1995).

Data about congenital births in England is collected by the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). In 2019, NCARDRS reported a limb anomaly incidence of 29 per 10,000 births. Incidence of congenital limb difference was not published in the report (Public Health England, 2021).

2.7 Data sources

Data sources for studies reporting limb difference vary depending on the scale of the study, country and population being examined. Hospital records or national health records were used within many studies. Other data sources included insurance schemes. Data obtained from prosthetic clinics, or about prosthetic provision, is of limited use as it provides information only about the people accessing services rather than the entire population.

2.7.1 Data sources in UK studies

The Health Episode Statistics (HES) database has been used as a source of data for multiple studies conducted in England (Moxey et al., 2010; Jones et al., 2011; Holman, Young and Jeffcoate, 2012; Ahmad et al., 2014b; Ahmad et al., 2016b)). HES is a database operated by NHS Digital which contains details of all hospital admissions, outpatient appointments, and accident and emergency attendances in England.

Other data sources which have been used include the UK National Vascular Register (Ambler et al., 2019), UK Joint Theatre Trauma Registry (Brown and Clasper, 2013), SCI-DC register (a national diabetes register for Scotland) (Kennon et al., 2012), Diabetes Audit and Research in Tayside Scotland database (Morris et al., 1998), and

SPARG (Scottish Physiotherapy Amputee Research Group) database (Smith, Scott and Hebenton, 2019). Hospital records were used as the data source in single-site (Ericson, Kallen and Winberg, 1977) and regional studies (Graham and Parke, 2004; Kanade et al., 2007; Krishnan et al., 2008; Ferguson et al., 2010). The Clinical Practice Research Datalink, which collects data from (general practitioner) GP practices, was found to be less reliable than HES when reporting major LLAs (Meffen et al., 2022). Limbless Statistics, and its predecessor NASDAB, have reported the number of people referred to UK prosthetic centres between 1997 and 2012 (NASDAB, a-j; Limbless Statistics, 2013a-d).

2.8 Registries

In 2002 the World Medical Association's Declaration on Ethical Considerations regarding Health Databases declared that databases are a valuable source of information for health research and quality assurance (Aitken et al., 2016). Registries and databases are useful sources of data and have been used in studies reporting amputation and CLD incidence.

A database is a structured collection of data arranged for ease of use. A registry is an organised collection of data from multiple sources which is maintained over time. Patient registries are typically a collection of standardised observational data about a group of people with a similar medical condition. They can be organised on a local level, e.g. a single research institution, or can have a wider reach involving multiple institutions or global organisations.

There has been a rise in the number of registries and databases established to monitor health conditions, and vast differences have been found in the quality of data collection techniques used (Black, Barker and Payne, 2004). Databases and registries can be initiated by any interested party. To improve their efficiency and usefulness, organisations such as the Clinical Audits and Registries Management Service in England and the European Medicines Agency have been established, which monitor the management and use of registries (NHS England; Michalowski and Newsome).

Studies which report incidence of CLD often obtain data from established large-scale registries. These registries are populated using health data of the mother and child, which is routinely collected at birth by health authorities and submitted to regional

surveillance systems. Examples of such registries can be found in Section 2.8.3 and include regional, national, and international registries.

Analyses of registry datasets are regularly performed and published in the public domain, which enables longitudinal monitoring of congenital anomalies and comparisons between regions. However, issues can occur with the quality of data and inconsistencies in data input. Under-reporting by around 6 percent was found when a national register in Sweden was compared with a clinic-based register (Hermansson, Bodin and Wranne, 2001). These results are an improvement on an older Swedish study that estimated an 11 percent under-reporting (Ericson, Kallen and Winberg, 1977). Monitoring of congenital birth deficits requires accurate and consistent classification of conditions. Conditions which are not noticed at birth, misdiagnosed, or part of a defined syndrome may lead to under-reporting (Hermansson, Bodin and Wranne, 2001). Inconsistencies in classifying deformities may also lead to misreporting, and the experience of the person classifying deformities may influence accuracy (Kallen et al., 2001).

Comparing results across studies and different registers can be problematic due to differences in collection and reporting. Whilst most registries presently use International Classification of Diseases 10 (ICD-10) for classification, differences in how conditions are grouped can occur. For example, some studies include conditions such as proximal femoral focal deficiency and hip dysplasia within the CLD reports whilst others exclude these conditions (Mano et al., 2018). Differences were also observed in whether only live births were reported, or if stillbirths, foetal death (≥20, 24, or 28 weeks), and terminated pregnancies (where a diagnosis of CLD had been given) were also counted. Differences with classification were highlighted as sources of error when comparing datasets (Bedard et al., 2015).

2.8.1 Existing registries

There is no central international register for collecting data about people with limb difference. There are, however, several regional and in-house registries and databases. Comparing results across different registers can be problematic due to differences in collection methods and reporting.

In 2021, the LEAD (Lower Extremity Amputation Data Set) and COMPASS (Consensus Outcome Measures for Prosthetic and Amputation Services) project conducted a scoping review of existing LLA registries and semi-structured interviews

to establish what registries exist and the types of data that they collect. The scoping review failed to find all existing registries. Additional registries, known to the investigators, were added for later parts of the study. The report highlights that it is likely other registries exist, perhaps managed by governments or organisations, which are unknown to the scientific community and difficult to find. The project team highlighted difficulties when contacting registries and receiving responses (International Society for Prosthetics and Orthotics, 2021). This suggests that knowledge gained from analysing registry data may not be getting published, and that globally there is an uncoordinated approach to data management in this field.

Here follows some examples of existing registries which collect data about people with limb difference.

2.8.2 Amputation registers

The Nordic countries are pioneers in establishing and managing amputation databases. The Danish Amputee Register was established in 1972 (Ebskov, 1986), and in 2011 SwedeAmp was established (Kamrad et al., 2020). Both registries are government funded and collect amputation, medical, and prosthetic data related to LLA. SwedeAmp collects data about people who have undergone LLA, including partial foot amputations. Data is provided by healthcare professionals in clinics across Sweden. In 2019, 62 percent of regions and 70 percent of prosthetic clinics provided data to the registry. Results from a validation study of SwedeAmp data in 2019 show 90 percent coverage and an error of 1.3 percent. The types of data collected include personal and amputation data, details of any prosthesis provided, baseline and follow-up patient-reported outcome measures, and mobility outcome measures. SwedeAmp claims to be the world's only register to follow the patient journey from amputation to rehabilitation. Since 2012 annual reports, with English language versions for 2019 and 2021, have been published on the SwedeAmp website and have been used to inform national guidelines (SwedeAmp, 2021; SwedeAmp, 2023).

SPARG collected data about patients undergoing post-operative physiotherapy following major LLA until January 2024. Data was collated on paper by the treating physiotherapist until patient discharge from physiotherapy services, then uploaded to a web-based database, and included information about demographics, aetiology, post-operative therapy, treatment timelines, and discharge information including whether the person was fitted with a prosthesis at time of discharge. Data collection began in 1994, with reports published annually. The dataset did not include persons

undergoing palliative amputations (Davie-Smith, Hebenton and Scott, 2020). Since January 2024, SPARG no longer uses a web-based database, and collects data only from vascular clinics.

In 2018, the need for a national limb loss registry in the USA was identified and a registry project, jointly funded for five years by the National Center for Medical Rehabilitation Research and the Department of Defense, was launched (NIH Medline Plus, 2019; Limb loss and preservation registry). A multi-stakeholder group consisting of patients, healthcare providers, insurance companies, and manufacturers was established. This led to the launch of the Limb Loss Prevention Registry in 2022. Data on amputations and hospital stays, prosthetic fittings, and patient-reported outcome measures are collected from clinics and patients, who manually enter information into an electronic portal. Between its launch in March 2022 and December 2022, 92 prosthetics and orthotics facilities and 17 hospitals had enrolled to share information with the registry (The O&P Edge, 2023).

2.8.3 Congenital anomaly registers

The European Network of Population-based Registries for the Epidemiological Surveillance of Congenital Anomalies (EUROCAT) was established in 1979 with the aim of collecting epidemiological data about congenital anomalies and becoming a resource for information. Data is currently collected from 20 European countries. A large network is beneficial, particularly when studying rare conditions, because data can be pooled, compared, and shared.

Using defined guidelines and coding, incidences of congenital anomalies, including limb reduction defects, are reported. EUROCAT collates and analyses the data and produces regular reports about the findings. Prevalence of conditions is updated two times each year.

Within the UK, NCARDRS and the Congenital Anomaly Register and Information Service (CARIS) are currently full members of EUROCAT. The Scottish Linked Routine Data Congenital Anomaly Register is an associate member, which means that they submit an aggregated file containing the total number of cases in each subgroup rather than case data on every incidence (European Commission).

Data about people born with congenital anomalies living in England, including limb difference, is collated by NCARDRS (Broughan, 2022). NCARDRS was establish by Public Health England in 2015, merging information from seven regional and one

national disease specific registers into a central database. The registration service has since been expanded to cover all areas of England (Ward-Platt, Stevens and Miller, 2018). Suspected or confirmed cases of congenital anomalies are reported to the registration service by healthcare workers. To report a case the healthcare worker completes a data collection form and provides supporting evidence such as scans, clinic letters, or laboratory reports. These are then sent electronically to a regional office for processing (Broughan, 2022).

CARIS collects data on babies with congenital anomalies born to mothers normally resident in Wales. Data collection started in 1998 and has been managed by Public Health Wales since 2009. Reporting of congenital anomalies is voluntary through sources such as antenatal clinics, delivery units, and paediatric departments. The register reports prenatal diagnoses and diagnoses in babies up to one year of age (European Commission).

The Scottish Linked Routine Data Congenital Anomaly Register was established in 2018 and is managed by Public Health Scotland, which is a governmental organisation. The registry is formed using linked routinely collected data and covers all mothers delivering in Scotland since 2000 including live births, stillbirths, and termination of pregnancy. Congenital anomalies up to age 1 year are reported within this register. The registry acknowledges that the 1-year cut-off will under-ascertain anomalies that do not require hospital admission within the first year of life, and over-ascertain some anomalies where diagnosis is confirmed at a later age (European Commission).

2.8.4 In-house company registers

Large providers of prosthetic clinical care, such as Otto Bock, Opcare, and International Committee of the Red Cross (ICRC), have in-house registries which collect data about patient demographics, componentry, fitting dates, and patient outcomes. Data is commonly used within audit processes, and findings shared internally. In 2021, ICRC published findings from an analysis of demographic and clinical data of 28,446 patients attending ICRC rehabilitation services in five countries over a nine-year period (Barth et al., 2021).

2.9 The need for standardised data

A lack of standardised data was identified as a barrier to the further development of prosthetic services (International Society for Prosthetics and Orthotics, 2021). In

September 2021, ISPO released a report detailing two initiatives which could help address this issue. LEAD is an initiative to establish a core dataset of information to be included in all LLA databases or registries. Following a consultation process a list of essential information to be included in an LLA database or registry was published. The desire for an international registry and the methods and challenges for managing this were also discussed (International Society for Prosthetics and Orthotics, 2021).

Article 31 of the Convention on the Rights of Persons with Disabilities states that parties should collect information, including statistics, to enable them to formulate and implement policies related to the Convention. Despite this obligation, very little is known about the population of persons living with limb difference in the UK. Literature shows that there have been attempts to measure incidence of LLA in parts of the UK and lower limb immediate post-amputation rehabilitation in Scotland, and that registries exist where occurrences of CLD in the UK are recorded.

There is currently no mechanism, however, for recording or tracking the progress of people with amputation or CLD over their lifetime. Prosthetic centres collect data about the patients that they treat, but there is currently no system for combining this with data from other sources. A nationwide registry about all people with limb difference would enable the gathering of data related to rehabilitation and disability throughout a person's life. This information could be used to inform government policy and monitor health and social care provision within the country.

When planning a registry, it is recommended that initial work is conducted to determine the feasibility and scope of the registry (Gliklich, Dreyer and Leavy, 2014). The aim of this thesis is to explore the methods available for data collection within Scotland to establish if setting up a national registry of persons with limb differences would be feasible. Using existing data collection methods, baseline data about the population of persons living in Scotland with limb difference will be obtained. The baseline data derived from this thesis can inform the scope and methodology of a future registry.

2.10 Chapter 2 Summary

This chapter reported the findings from a scoping review which aimed to map trends in amputation incidence and aetiology, the prevalence of congenital limb difference, and the data sources which are used to obtain amputation data. There are many published studies which report incidence and prevalence of amputation; however,

making comparisons is challenging due to variations in included populations and the methods used to collect data. Common causes of LLA are PVD and diabetes, and LLA is more common in males. Geographic variances in LLA incidence exist between rural and urban areas, and between areas of differing socioeconomic wealth. ULA is not reported as frequently. The main cause of ULA is trauma, with hand amputations being the most common level. ULA is more common in males, and the average age of people undergoing ULA is lower than for those undergoing LLA. CLD is a rare condition that is often associated with other congenital defects. Common sources of data about limb amputations include hospital statistics and medical insurance records. There is no central international register for collecting data about people with limb difference. Comparing results across regional registers can be problematic due to differences in collection methods and reporting.

3. Thesis rationale

This chapter outlines the rationale, aims, and objectives for the thesis, and describes the setting for the studies which follow providing a description of the Scottish population and healthcare system, and an introduction to electronic health records.

3.1 Thesis rationale

A scoping review of the literature has shown that it is challenging to compare incidences of amputation or CLD due to inconsistencies in the way that data is collected and processed. The number of people living in Scotland with limb difference is unknown and limited information is available about the amputations which are conducted in Scotland every year. Without this knowledge it is difficult to accurately evaluate the service which people with limb difference receive within NHS Scotland, and the effect of disability on their daily lives.

As far as the author is aware, there have been no attempts to quantify the frequency of amputations conducted in Scotland, examine the demographic and clinical profiles of individuals undergoing amputation, or investigate the post-amputation outcomes experienced by the population.

Detailed information about the people undergoing amputation, or being born with a limb difference, should be considered when planning service delivery, estimating future workforce needs, and establishing areas for future research.

3.2 Study aims and objectives

The overarching goal of this thesis is to deepen our understanding of the population of people who undergo limb amputation or experiencing congenital limb differences (CLD) in Scotland. The objectives of this thesis are to:

- Quantify the incidence of limb amputation and the prevalence of congenital limb difference in Scotland
- Determine the referral rate to prosthetic services after amputation of birth with a CLD
- Determine frequency of the different levels of limb amputation in Scotland
- Investigate the geographical spread of amputation across Scotland
- Determine the age at which people undergo their first amputation

- Determine the frequency of people undergoing amputation with regards to the independent variables of sex, ethnicity and deprivation
- Determine the frequency of comorbidities at the time of first amputation
- Investigate clinical outcomes after amputation including survivorship.

3.3 Study setting

Scotland, a constituent country of the United Kingdom of Great Britain and Northern Ireland (UK), occupies the northern region of the island of Great Britain, sharing a land border with England to the south. With a landmass spanning approximately 30,414 square miles, Scotland boasts a diverse landscape. A striking contrast exists between the predominantly rural character of its land, covering 98 percent of its territory, and the concentration of its population in non-rural areas. According to data from the 2011 Scottish Census, approximately 83 percent of Scotland's population resides in urban or suburban locations (Scotland's Census).

3.3.1 Demographics

The population of Scotland, as recorded in the 2011 census, stood at 5,295,403 individuals, with 51.5 percent identifying as female. Notably, 16.8 percent of the population was aged over 65, while 16.1 percent were under 15 years old at the time of the census, reflecting a diverse age distribution within the populace. The overwhelming majority of Scotland's population, accounting for 96 percent, identified their ethnic group as White. Linguistically, English proficiency is widespread, with 98.6 percent of individuals aged 3 years and over reporting the ability to speak the language, with 93.8 percent proficient in both speaking and writing English (Scotland's Census). Initial findings from the 2022 census show that Scotland's population has grown by 2.7% to its highest recorded level, with an estimated 5,436,600 people (National Records of Scotland, 2023b).

Despite its cultural and linguistic cohesion, Scotland experiences health disparities and challenges. Notably, the country's life expectancy figures are among the lowest in Europe, with a marked discrepancy between genders. In the period 2018–2020, life expectancy at birth was estimated at 76.8 years for males and 81 years for females, with a gradual increase observed over the decades, albeit tempered by the impact of the Covid-19 pandemic (National Records of Scotland, 2021). The variation in life expectancy is further pronounced across geographic regions, with rural areas

generally exhibiting higher life expectancy compared with urban counterparts. For instance, individuals residing within the NHS Shetland area boast the highest life expectancy for males (80.6 years) and in the NHS Orkney area for females (83.5 years), contrasting with the lowest figures recorded within the NHS Greater Glasgow and Clyde region (National Records of Scotland, 2021).

Life expectancy is intricately linked to socioeconomic factors, with disparities observed between the most and least deprived areas of Scotland. Those residing in the 10 percent most deprived regions face considerably lower life expectancy, with males averaging 68.9 years compared with 82.4 years for their counterparts in the least deprived areas (National Records of Scotland, 2021) Furthermore, healthy life expectancy, an indicator of overall wellbeing, mirrors these disparities, exhibiting a declining trend across the country, particularly evident in areas characterised by higher deprivation levels. In the period 2018–2020, healthy life expectancy stood at 60.9 years for males and 61.8 years for females, with a significant disparity of over 24 years observed between the most and least deprived areas (National Records of Scotland, 2022a). These findings demonstrate the intricate relationship between the demographic, socioeconomic, and health-related factors which influence Scotland's population health landscape and the need for targeted interventions to address underlying disparities and promote equitable health outcomes across all segments of society.

3.3.2 Health system

Scotland is a democratic nation governed by the UK Parliament. Since 1999 the power to make laws on a range of issues, including health, has been devolved to the Scottish Parliament (The Scottish Parliament).

Healthcare provision in Scotland is primarily delivered by NHS Scotland, a publicly funded healthcare system that ensures access to healthcare services free of charge at the point of delivery. As of 2016, approximately 82 percent of healthcare expenditure in Scotland was funded by the government, reflecting a commitment to universal healthcare access and affordability (OECD, 2016). Central to the operation of NHS Scotland is the allocation of a unique registration number, known as the Community Health Index (CHI) number, to every individual residing in Scotland. The CHI number serves as a key identifier and is recorded whenever an individual accesses NHS Scotland services, facilitating efficient and coordinated healthcare delivery. Patients typically register with a local GP, who serves as their primary point

of contact for healthcare needs and coordinates referrals to specialist services within NHS Scotland. However, patients also have the option to self-refer into certain services and can access emergency healthcare directly when needed.

NHS Scotland operates through a decentralised structure, comprising 14 regional NHS boards, seven special NHS boards, and one public health board. Each of these boards is accountable to the Scottish Ministers and is supported by the Scottish Government Health and Social Care Directorate, which oversees strategic planning, policy development, and resource allocation within the healthcare system.

3.3.2.1 Amputation and prosthetic rehabilitation services in Scotland

Limb amputation may be conducted as an emergency or a planned surgical procedure. Following surgery, patients require comprehensive rehabilitation to optimise their functional outcomes and quality of life. This rehabilitation pathway typically involves a multidisciplinary approach, encompassing physiotherapy, occupational therapy, counselling, and prosthetic fitting.

NHS prosthetic services in Scotland are located within five rehabilitation centres: West of Scotland Mobility and Rehabilitation Centre (WestMARC) in Glasgow, South-east Scotland Mobility and Rehabilitation Technology (SMART) centre in Edinburgh, Tayside Orthopaedic & Rehabilitation Technology (TORT) centre in Dundee, Mobility and Rehabilitation Service (MARS) in Aberdeen, and Raigmore Hospital in Inverness. These centres play a pivotal role in providing prosthetic care and support to individuals undergoing limb amputation or requiring prosthetic devices to enhance their mobility and function. Specialist prosthetic limbs, such as microprocessor knees and ankles, multi-articulating hands, and sporting prostheses, are provided to eligible patients at WestMARC and SMART under the National Specialist Prosthetic Service.

3.4 Electronic health records

In 2005, the publication of *A National Framework for Service Change*, commonly referred to as the Kerr Report, marked a pivotal moment in NHS Scotland's strategic planning. The report aimed to address the evolving needs of an aging population and outlined key recommendations to steer healthcare delivery in Scotland. Among these recommendations was the urgent implementation of a national system of electronic patient records, signalling a shift towards digital healthcare infrastructure. Additionally, the report emphasized the importance of delivering healthcare locally and proposed the establishment of a telehealth system to enhance accessibility and efficiency (Kerr,

2005). Building on these recommendations, the Scottish Executive developed detailed plans to prioritise local NHS care, provide systematic support for individuals with long-term conditions, narrow inequalities in healthcare access, and manage hospital admissions. At the core of these plans lay the implementation of a national eHealth strategy, leveraging electronic health records (EHRs) to streamline healthcare delivery and improve patient outcomes (DHI News Team, 2005; Scottish Executive, 2005)}. Implementation efforts commenced in 2007, marking the beginning of a transformative journey towards digital healthcare integration in Scotland.

An EHR is a digital document that contains information about a person's health or care needs. A system of EHRs is a digital version of health records that are maintained over time. EHR systems are intended to replace traditional paper-based record keeping. Patient information is uploaded directly to the EHR by a clinician or medical coder at the time of the intervention, or shortly after. Uploaded information can then be accessed by authorised personnel using the system, meaning that health records can be reviewed remotely (Office of Information Security, 2020).

The need for an improved health record system in Scotland was made clear in the Scottish Executive's *Delivering for Health* document, which reported that 'one in seven hospital admissions occurs because care providers do not have access to previous hospital records', '20% of laboratory tests are requested because the results of previous investigations are not accessible', and '15% of hospitalisations are complicated by medication error' (Scottish Executive, 2005). EHR systems have been shown to improve legibility, reduce medical error, and improve access to diagnostic test results and prescription records (Menachemi and Collum, 2011; Hoover, 2016).

Scotland's EHR is a nationwide digital system that was implemented as part of eHealth 2008–2011. It is a decentralised clinical portal system that provides clinicians a single point of access to secure information. The phased implementation of EHR clinical portals commenced with the establishment of ePharmacy, enabling electronic transmission of prescriptions to pharmacies since 2007 (Whitehouse, Giest and Artmann, 2010). To ensure the effective utilisation of the system and adherence to data management standards, the Data and Intelligence section of Public Health Scotland, previously Information Services Division Scotland, offers guidance on terminology and coding, and provides training and support to users.

Electronic patient record systems have been shown to reduce the time spent documenting care, improve the quality of record keeping, and improve clinical

outcomes, financial and operational benefits, and benefits to society through improved ability for research (Menachemi and Collum, 2011; NHS Research Scotland; Healthcare Improvements Scotland, 2021).

3.5 Routinely collected data

Data is routinely collected by the health service as part of their normal operational business. The purpose of collecting routine data is not for research; it is primarily used for other purposes, which may include service evaluation monitoring, quality monitoring, and audit. Routinely collected data is often uploaded directly into EHRs or databases by clinical staff at, or shortly after, the time of clinical contact, or it can be uploaded later by a clinical coder.

Routinely collected data is obtained after every clinical intervention which means that the NHS collects a vast amount of information. This data can be a useful information source for researchers interested in monitoring health conditions in the real world rather than under laboratory conditions. Data which is collected from real-world scenarios is reported to better represent the population being studied (Hemkens, Contopoulos-Ioannidis and Ioannidis, 2016). This is, however, dependent on the source of the data and the methods by which it was collected. Large, national datasets rather than smaller, local datasets are likely to represent the national population and therefore be more use when generalising about a population. Using routinely collected data can have other benefits; for example, the costs associated with a study using routinely collected data can be much lower than with using other methodologies such as randomised controlled trials (Wachtell et al., 2016; Lensen et al., 2020)}. Further benefits can include a lower burden on the participants and lower attrition rates (Lensen et al., 2020).

3.6 Use of routinely collected data within this thesis

This thesis contains two studies which use routinely collected data to gain a better understanding of the population of people undergoing limb amputation or being born with limb difference in Scotland.

The first study is an investigation using publicly available information to determine the number of amputations being conducted in Scotland, and the referral rate of patients to prosthetic services. Details of this study are provided in Chapter 4.

The second study is an in-depth retrospective review of all persons who have undergone a limb amputation, or been born with a limb difference, between 2012 and 2021. The study uses routinely collected linked data. The methodology and methods for this study are described in Chapter 5, with the results and discussion presented in Chapter 6.

Finally, the methods used within this thesis to obtain information about the people living with limb difference and the case for a Scottish Registry of Limb Difference are discussed in Chapter 7.

3.7 Summary of Chapter 3

Chapter 3 provides contextual social and health information about Scotland, the country whose population will be investigated in the studies within this thesis. The chapter described Scotland's national system of EHRs and how data is routinely collected after every clinical intervention. Finally, the chapter outlines the remaining chapters within the thesis and introduces two studies which used routinely collected data to investigate the epidemiology of limb amputation and congenital limb difference in Scotland.

4. Study 2: Limb amputation, congenital limb births, and referrals to prosthetic services – a preliminary investigation

This chapter describes an investigation which was conducted to find out how much information could be obtained about amputation incidence and prosthetic referral in Scotland using publicly available data sources. The chapter describes the methods which were used, and the results obtained. It also highlights the limitations of the methods used and poses areas for further investigation.

4.1 Aims

The aim of this study was to establish how many limb amputations and CLD births occur in Scotland each year, and how many people are then referred to prosthetic services. By obtaining this information, a better understanding of the incidence of amputation and limb absence can be obtained. A further aim of this study was to establish how much detail can be obtained by using publicly accessible data.

4.2 Methodology and methods

Study 2 was a retrospective analysis of surgical data, birth data, and prosthetic centre referral data. The study involved the secondary use of health data, which is described by the WHO as 'the processing of health data for purposes other than the initial purposes for which the data were collected' (World Health Organisation, 2022b). The reported benefits of this technique include reductions in cost and time compared with experimental research (World Health Organisation, 2022b) and improved access to data which would be otherwise difficult to collect (Naher et al., 2023).

Data for this study was accessed through a freedom of information (FOI) request and from publicly available published reports.

4.2.1 Freedom of information request

An FOI request is a formal request for information that is made to a public authority. In the UK, a public authority is described as a public body that can exercise public functions, such as providing services, regulating industries, or holding records. Examples of public authorities include government departments and agencies, the armed forces, the NHS, and educational institutions (House of Commons Library, 2023). FOI requests play an important role in ensuring the transparency and accountability of organisations that use public funding and are permitted within Scotland under the Freedom of Information (Scotland) Act 2002 (Lauber, 2022; *Freedom of Information (Scotland) Act 2002*, 2002). The Act provides a means where members of the public can access information that has been collected by organisations which receive public funding. Any individual person, or group of people, can make a formal FOI request. Whilst any information can be requested, a public authority can refuse to provide it there is a risk to disclosing the information, such as identification of individuals, or if it would cost more than £450 (£600 for central government) to find and extract the information (*Freedom of Information (Scotland) Act 2002*, 2002). In practice this means that only small amounts of information can be requested at a time.

Since the Act came into practice FOI requests have been used primarily by investigative journalists (Savage and Hyde, 2014; Clifton-Sprigg, James and Vujic, 2020). However, there is a growing recognition of the role of FOI requests in research and data analysis, contributing to the democratisation of research processes (Savage and Hyde, 2014; Lauber, 2022).

Data obtained from an FOI request can be used alone or combined with other research techniques through a mixed methodology approach to provide a deeper understanding of the issues being investigated (Savage and Hyde, 2014).

4.2.2 Data sources

Three data sources were used within this study; NHS Scotland routinely collected data, and reports published by the National Amputee Statistical Database (UK) (NASDAB) and Limbless Statistics.

Limbless Statistics is a national repository for quantitative information about persons with limb difference referred to prosthetic centres in the UK. The repository is managed by the University of Salford and replaced NASDAB, which ceased operation

in 2010 due to lack of funding. NASDAB, and more recently Limbless Statistics, have published annual reports containing non-identifiable quantitative data about people referred to each prosthetic centre in the UK. Variables such as sex, age range, ethnicity, and level of amputation are included within the report. Annual reports are available from 1997/98 to 2006/07 from NASDAB, and 2007/08 to 2011/12 from Limbless Statistics.

4.2.3 Method

An FOI request (FOI INFO-2014-000144) was made to NHS Scotland on 5th August 2014 requesting the following information:

1. Since records began until present, the number of lower limb amputations performed each year in Scotland
2. Since records began until present, the number of upper limb amputations performed each year in Scotland
3. Since records began until present, the number of children born each year in Scotland with lower limb absence
4. Since records began until present, the number of children born each year in Scotland with upper limb absence.

NHS National Services Scotland (NSS) used the following criteria to provide the response:

1. The statistics were derived from data collected on discharges from non-obstetric and non-psychiatric hospitals (SMR01) in Scotland. Only patients treated as inpatients or day cases were included. The specialty of geriatric long stay was excluded.
2. Data was based on date of discharge.
3. Data relates to all patients treated by the NHS in Scotland.
4. Figures are episode based – an SMR01 episode is generated when a patient is discharged from hospital but also when a patient is transferred to a different hospital, significant facility, specialty or to the care of a different consultant.
5. Up to four procedures (one main procedure and three secondary procedures) may be recorded per hospital episode using the UK classification of Operative Procedures OPCS-4 (Office of Population Censuses and Surveys, Classification of Surgical Operation and Procedures). All four procedure positions were used to identify the relevant cases.

6. Congenital absences were identified from the Scottish Birth Record using the following ICD-10 codes:
   Q710: Congenital complete absence of upper limb(s)
   Q711: Congenital absence of upper arm and forearm with hand present
   Q712: Congenital absence of both forearm and hand
   Q713: Congenital absence of hand and finger(s)
   Q720: Congenital complete absence of lower limb(s)
   Q721: Congenital absence of thigh and lower leg with foot present
   Q722: Congenital absence of both lower leg and foot
   Q723: Congenital absence of foot and toe(s)
   Q730: Congenital absence of unspecified limb(s)
   Q731: Phocomelia, unspecified limb(s).

A Microsoft Excel sheet containing the agreed dataset was received by email on 2nd September 2014. Due to the level of data recorded at the time it was not possible to separate ULA and LLA prior to 1989, and therefore only the total number of amputations per year was provided for 1981–1989.

A further request was made by email on 4th June 2015 for amputations of duplicate or supernumerary digits to be excluded from the dataset. This was processed by NSS as a separate FOI request (IR2015-01123). When compiling the response for the second request, NSS also excluded all episodes with a diagnosis of polydactyly from this dataset. Due to the level of data recorded it was not possible to exclude these categories from the data prior to 1989. The second dataset was received by email, as a Microsoft Excel sheet on 13th July 2015.

Data from both FOI requests were analysed using Microsoft Excel. Incidence of amputation per 100,000 population was calculated using the formula below. For this calculation, population was derived from mid-year population estimates from National Records of Scotland (NRS).

*Incidence = (number of amputations / population) * 100,000*

Birth prevalence per 10,000 live births was calculated using the formula below. For this calculation the number of live births was obtained from the Births Time Series Data published by NRS (National Records of Scotland).

*Birth prevalence = (number of live birth cases with CLD / total number of live births) * 10,000*

Amputation and CLD birth data were compared against the referral rate to prosthetic services. To calculate the referral rate to prosthetic services the number of referrals to Scottish prosthetic services was extracted from NASDAB and Limbless Statistics reports 1997–2011.

An assumption was made that patients undergoing amputation of supernumerary digits would not normally be referred to a prosthetic service; therefore, the dataset which excluded supernumerary amputations was used in the calculation of referral rate after amputation. A further assumption was made that referrals normally occur within a reasonable time after the amputation, as The British Society of Rehabilitation Medicine (BSRM) recommend that all patients should be offered a referral to a Prosthetic Centre during the post-operative phase of rehabilitation (British Society of Rehabilitation Medicine, 2018) and so, for example, amputations occurring anytime in 2010 were compared with referral data from April 2010 to April 2011.

In cases of CLD, an assumption was made that referral would take place shortly after the child's birth, as the BSRM recommend that children identified with a congenital limb difference should be referred to a Limb Deficiency Clinic as early as possible, ideally within the first month of life (British Society of Rehabilitation Medicine, 2018). However, as it was not possible to identify newborn patients from the NASDAB or Limbless Statistics data, birth data was compared against the number of referrals for patients with congenital absence aged under 16 for years up to 2006, and against the number of referrals for all patients with congenital absence for all years. Therefore, 2010 births were compared with 2010/11 referrals aged under 16.

Referral rate after amputation was calculated using the formula below.

*Referral rate after amputation = (number of referrals / number of amputations) * 100*

Referral rate for children born with a CLD was calculated using the formula below.

*Referral rate after CLD birth = (number of referrals / number of CLD births) * 100*

4.3 Results

4.3.1 Number of amputations

Between 1981 and 2013 the mean number of amputations conducted each year was 2,054 (standard deviation (SD) 153). LLAs were performed more frequently than ULAs at a ratio of 4:1. The mean number of LLAs performed each year was 1,595 (SD 124) compared with 459 (SD 57) ULAs. Eliminating amputations of

supernumerary digits reduced the total number of amputations by a mean of 80 (SD 17) (3.81 percent) per year. Of the supernumerary amputations, 73 percent were of the upper limbs.

The number of amputations for each year are shown in figures 4.1 and 4.2 and Table 4.1.

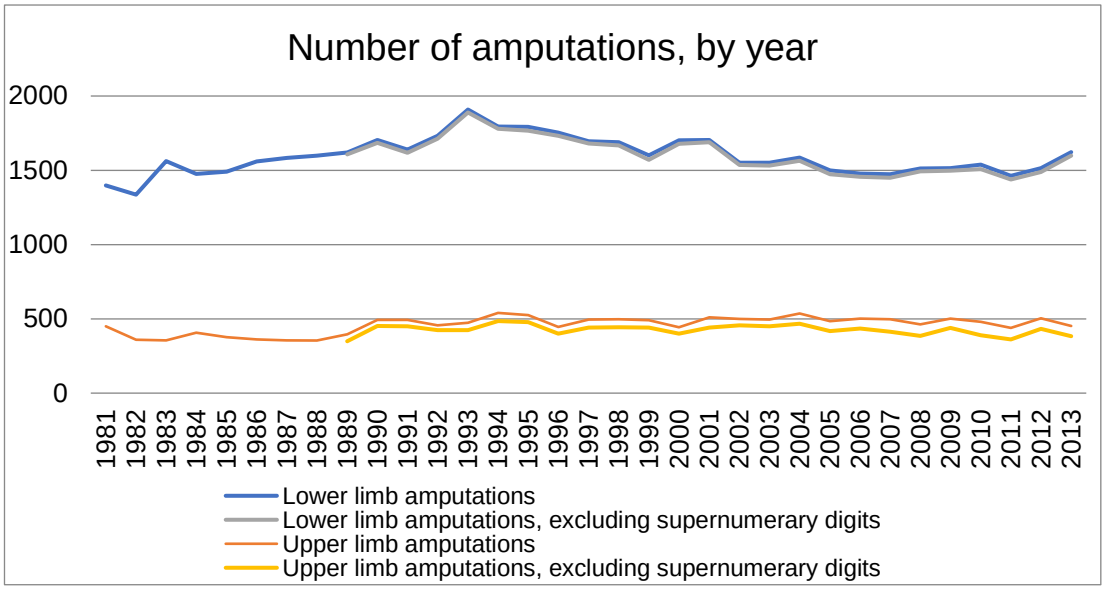


Figure 4.1 Number of amputations in Scotland

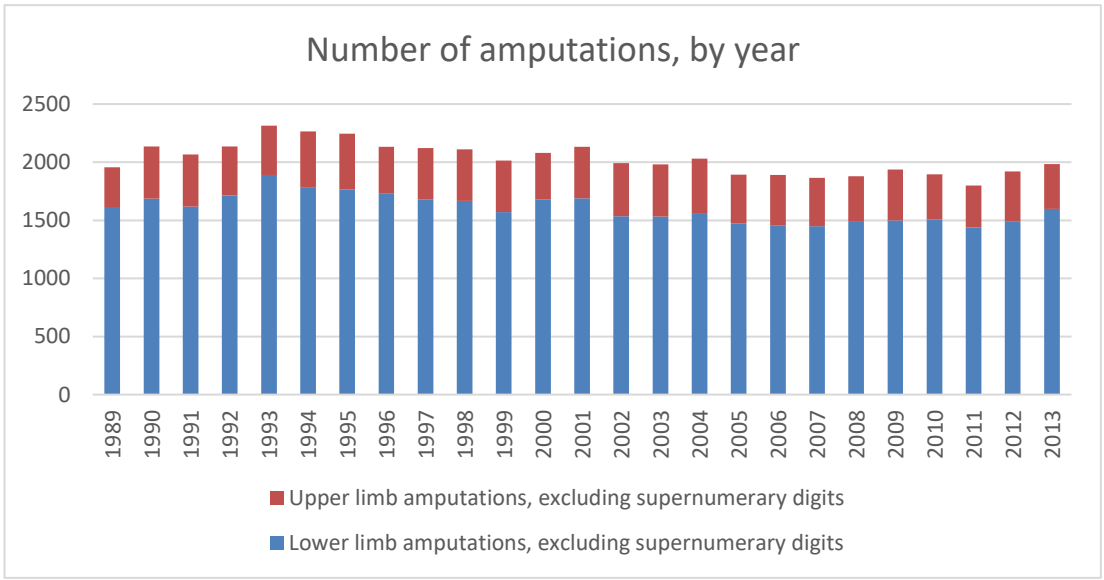


Figure 4.2 Number of amputations in Scotland, by year

Table 4.1 Number of amputations in Scotland and incidence of amputations per 100,000 population, per year, 1981–2013

Year	Number of amputations								
	LLA	LLA*	Diff** %	ULA	ULA*	Diff** %	All	All*	Diff** %
1981	1399	–	–	450	–	–	1849	–	–
1982	1336	–	–	359	–	–	1695	–	–
1983	1562	–	–	356	–	–	1918	–	–
1984	1476	–	–	407	–	–	1883	–	–
1985	1490	–	–	376	–	–	1866	–	–
1986	1559	–	–	361	–	–	1920	–	–
1987	1583	–	–	356	–	–	1939	–	–
1988	1598	–	–	354	–	–	1952	–	–
1989	1621	1607	0.86	397	349	12.09	2018	1956	3.07
1990	1703	1685	1.06	493	451	8.52	2196	2136	2.73
1991	1639	1618	1.28	493	449	8.92	2132	2067	3.05
1992	1731	1713	1.04	456	423	7.24	2187	2136	2.33
1993	1909	1889	1.05	474	424	10.55	2383	2313	2.94
1994	1794	1779	0.84	540	485	10.19	2334	2264	3.00
1995	1793	1766	1.51	525	478	8.95	2318	2244	3.19
1996	1754	1732	1.25	446	401	10.09	2200	2133	3.05
1997	1695	1681	0.83	496	441	11.09	2191	2122	3.15
1998	1690	1667	1.36	497	443	10.87	2187	2110	3.52
1999	1601	1571	1.87	491	442	9.98	2092	2013	3.78
2000	1701	1679	1.29	444	400	9.91	2145	2079	3.08
2001	1705	1690	0.88	510	442	13.33	2215	2132	3.75
2002	1551	1535	1.03	500	456	8.80	2051	1991	2.93
2003	1551	1532	1.23	496	450	9.27	2047	1982	3.18
2004	1586	1563	1.45	537	467	13.04	2123	2030	4.38
2005	1499	1474	1.67	485	418	13.81	1984	1892	4.64
2006	1477	1457	1.35	502	434	13.55	1979	1891	4.45
2007	1474	1450	1.63	498	414	16.87	1972	1864	5.48
2008	1513	1492	1.39	463	386	16.63	1976	1878	4.96
2009	1514	1498	1.06	501	438	12.57	2015	1936	3.92
2010	1538	1507	2.02	481	389	19.13	2019	1896	6.09
2011	1463	1438	1.71	438	362	17.35	1901	1800	5.31
2012	1515	1488	1.78	503	433	13.92	2018	1921	4.81
2013	1623	1599	1.48	451	384	14.86	2074	1983	4.39

**Excluding supernumerary digits*

***Diff = difference between number of amputations and number of amputations with supernumerary digits excluded*

4.3.2 Incidence of amputation

Incidence of amputation was calculated using the dataset which excluded supernumerary amputations. As supernumerary amputations could not be identified within the data prior to 1989, incidence was only calculated from 1989 onwards.

The number of amputations (supernumerary amputations excluded) and incidence per year can be viewed in Table 4.2.

Between 1989 and 2013, the mean annual incidence of limb amputation per 100,000 population was 39.59 (SD 3.05). The mean annual incidence of LLA was 31.28 (SD 2.6) and the mean annual incidence of ULA was 8.31 (SD 0.7). Incidence rates peaked in 1993 (Figure 4.3).

Table 4.2 Incidence of amputation, 1989–2013

Year	Population	No. amputations*			Incidence per 100,000 population		
		LLA*	ULA*	All*	LLA	ULA	All
1989	5,078,190	1607	349	1956	31.65	6.87	38.52
1990	5,081,270	1685	451	2136	33.16	8.88	42.04
1991	5,083,330	1618	449	2067	31.83	8.83	40.66
1992	5,085,620	1713	423	2136	33.68	8.32	42.00
1993	5,092,460	1889	424	2313	37.09	8.33	45.42
1994	5,102,210	1779	485	2264	34.87	9.51	44.37
1995	5,103,690	1766	478	2244	34.60	9.37	43.97
1996	5,092,190	1732	401	2133	34.01	7.87	41.89
1997	5,083,340	1681	441	2122	33.07	8.68	41.74
1998	5,077,070	1667	443	2110	32.83	8.73	41.56
1999	5,071,950	1571	442	2013	30.97	8.71	39.69
2000	5,062,940	1679	400	2079	33.16	7.90	41.06
2001	5,064,200	1690	442	2132	33.37	8.73	42.10
2002	5,066,000	1535	456	1991	30.30	9.00	39.30
2003	5,068,500	1532	450	1982	30.23	8.88	39.10
2004	5,084,300	1563	467	2030	30.74	9.19	39.93
2005	5,110,200	1474	418	1892	28.84	8.18	37.02
2006	5,133,000	1457	434	1891	28.38	8.46	36.84
2007	5,170,000	1450	414	1864	28.05	8.01	36.05
2008	5,202,900	1492	386	1878	28.68	7.42	36.10
2009	5,231,900	1498	438	1936	28.63	8.37	37.00
2010	5,262,200	1507	389	1896	28.64	7.39	36.03
2011	5,299,900	1438	362	1800	27.13	6.83	33.96
2012	5,313,600	1488	433	1921	28.00	8.15	36.15
2013	5,327,700	1599	384	1983	30.01	7.21	37.22

**Excluding supernumerary digits*

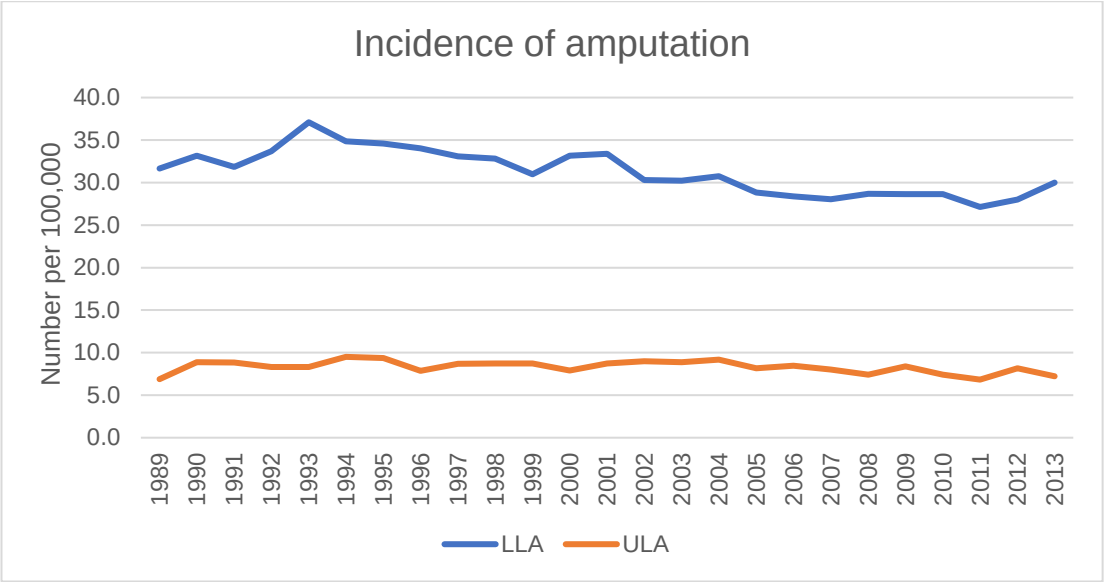


Figure 4.3 Incidence of amputation, 1989–2013

4.3.3 Referral to prosthetic services following amputation

The mean number of people referred to lower limb prosthetic services per year was 468 (SD 43). The number of referrals per year increased during the observation period (Figure 4.4). The referral rate for LLA ranged from 24.1 to 35.5 percent, increasing steadily over the period being examined (Figure 4.5).

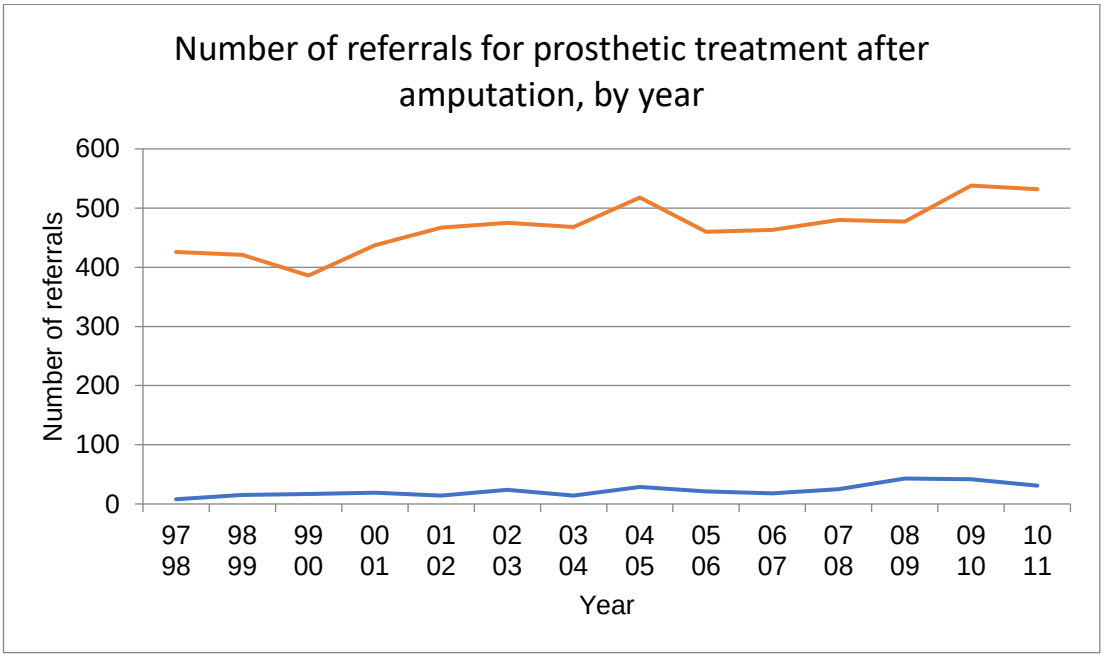


Figure 4.4 Number of referrals to prosthetic services

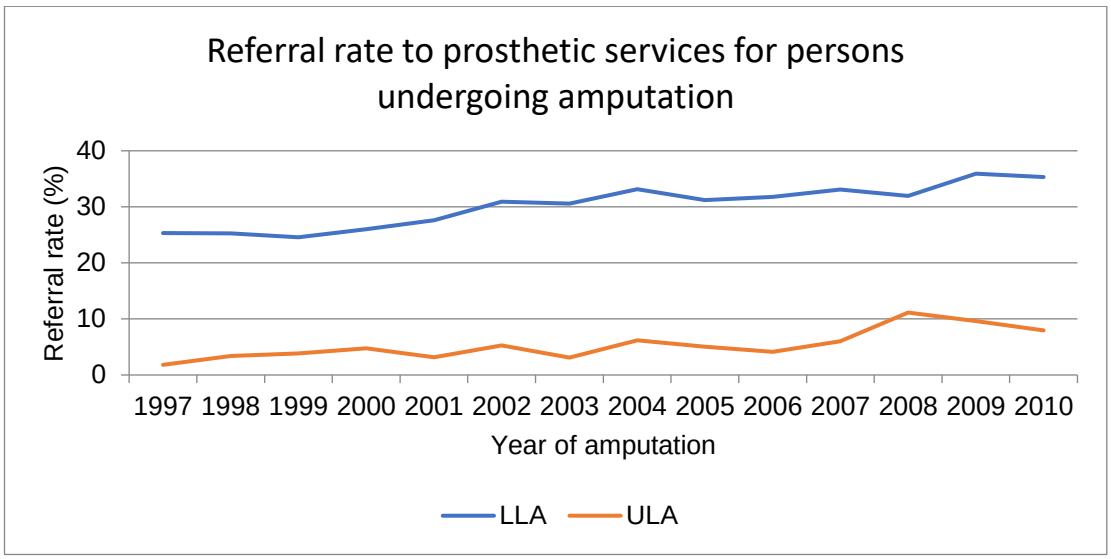


Figure 4.5 Referral rate to prosthetic services after amputation

The mean number of people referred to upper limb prosthetic services per year was 23 (SD 10). The number of people referred quadrupled between 1997/98 and 2009/10 (Figure 4.4, Table 4.3). The referral rate for ULA was lower than for LLA and ranged from 1.6 to 11.14 percent. There was a general increase in referral rate over the period being examined, reflecting the increase in number of referrals (Figure 4.5).

Table 4.3 shows the comparison between number of amputations per year and number of referrals, and the referral rate.

Table 4.3 Number of amputations, referrals to prosthetic services, and referral rate per year, 1997–2010

Year of amputation	LLA*			ULA*		
	LLAs	Referrals	Referral rate %	ULA	Referrals	Referral rate %
1997	1681	426	25.34	441	8	1.81
1998	1667	421	25.25	443	15	3.39
1999	1571	386	24.57	442	17	3.85
2000	1679	437	26.03	400	19	4.75
2001	1690	467	27.63	442	14	3.17
2002	1535	475	30.94	456	24	5.26
2003	1532	468	30.55	450	14	3.11
2004	1563	518	33.14	467	29	6.21
2005	1474	460	31.21	418	21	5.02
2006	1457	463	31.78	434	18	4.15
2007	1450	480	33.10	414	25	6.04
2008	1492	477	31.97	386	43	11.14
2009	1498	538	35.91	438	42	9.59
2010	1507	532	35.30	389	31	7.97

**Excluding supernumerary digits*

4.3.4 Birth prevalence of congenital limb absence in Scotland

Due to small frequency numbers, data about congenital upper and lower limb differences were grouped together to protect anonymity of the people being examined. The data supplied was extracted from the Scottish Birth Record (SBR) for the years ending 31st March 2003–2013. Four values were supressed due to low numbers (<3). The number of births with CLD per year ranged from less than three to nine (Figure 4.6). The birth prevalence of CLD in the years where data was available ranges from 0.53 to 1.53 per 10,000 live births, as shown in Table 4.4.

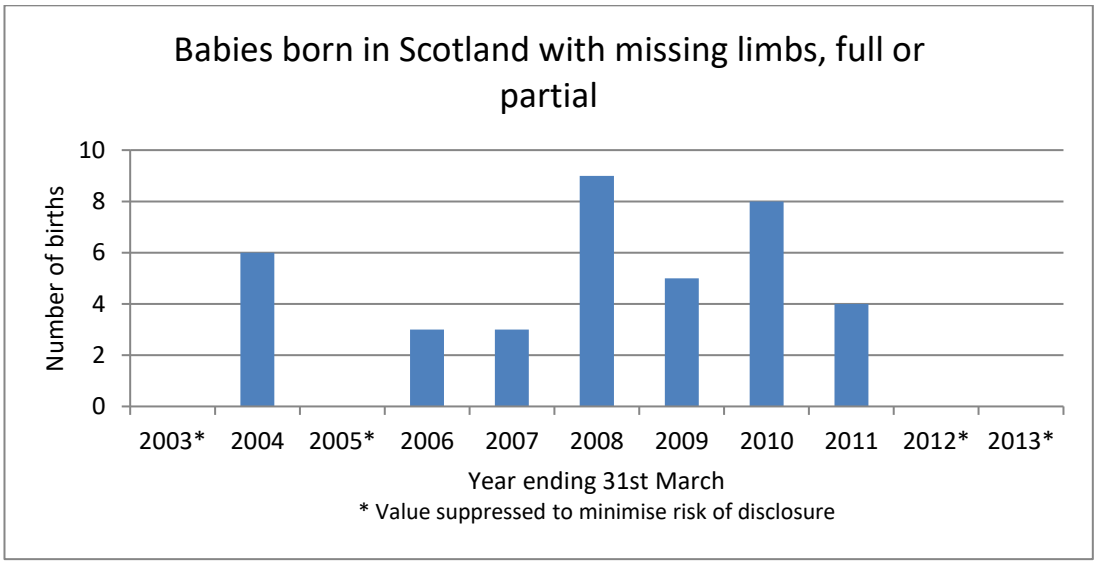


Figure 4.6 Number of children born with CLD

Table 4.4 Birth prevalence of CLD

Year ending 31st March	Total number of live births	Number of CLD births	Birth prevalence, per 10,000 live births
2002/03	51,660	<3	–
2003/04	53,127	6	1.13
2004/05	53,854	<3	–
2005/06	54,598	3	0.55
2006/07	56,331	3	0.53
2007/08	58,678	9	1.53
2008/09	59,440	5	0.84
2009/10	59,210	8	1.35
2010/11	58,735	4	0.68
2011/12	58,749	<3	–
2012/13	57,117	<3	–

4.3.5 Referral to prosthetic services following birth

The number of referrals each year to prosthetic services for people with CLD varied from zero to 18 (Figure 4.7).

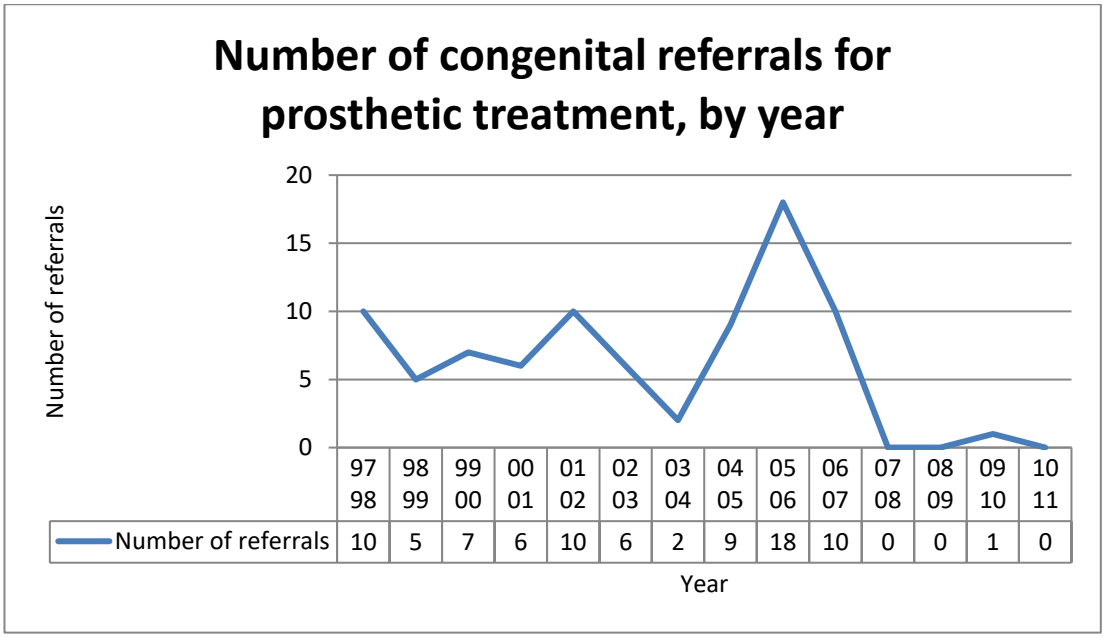


Figure 4.7 Number of congenital referrals to prosthetic services

The referral rate for congenital limb absence ranged from 33 to 550 percent. Figure 4.8 shows the comparison between the number of births and the number of referrals each year. For every year except 2003/04, the total number of referrals to prosthetic services for people born with limb absence exceeded the number of children born with limb absence in that year. Figure 4.9 shows a breakdown of the number of referrals to prosthetic centres by age of the patient. This shows that some of the CLD referrals were for older patients, not newborns.

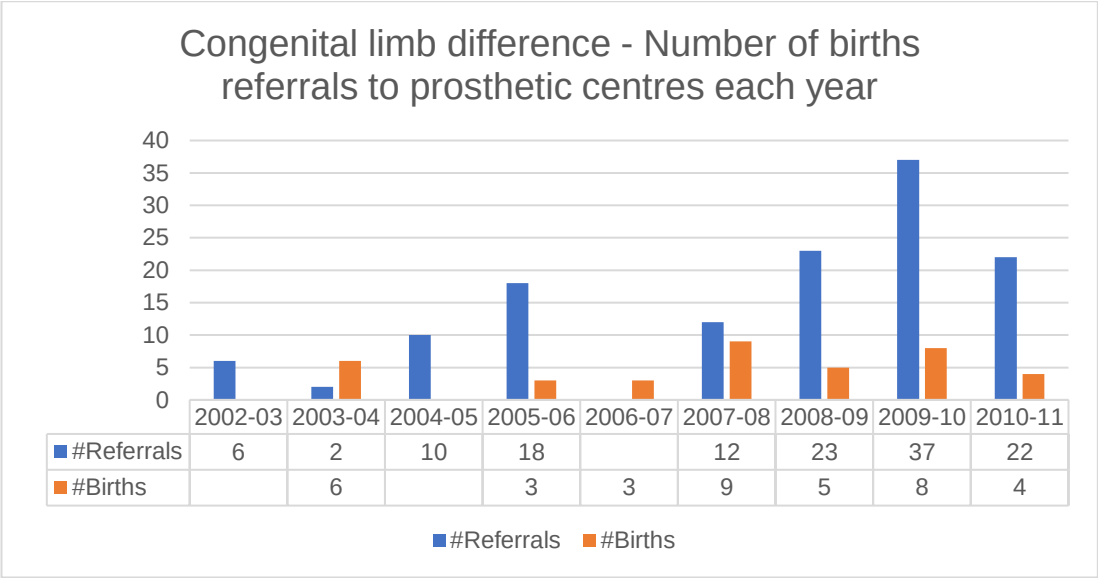


Figure 4.8 Number of CLD births and number of referrals to prosthetic services per year

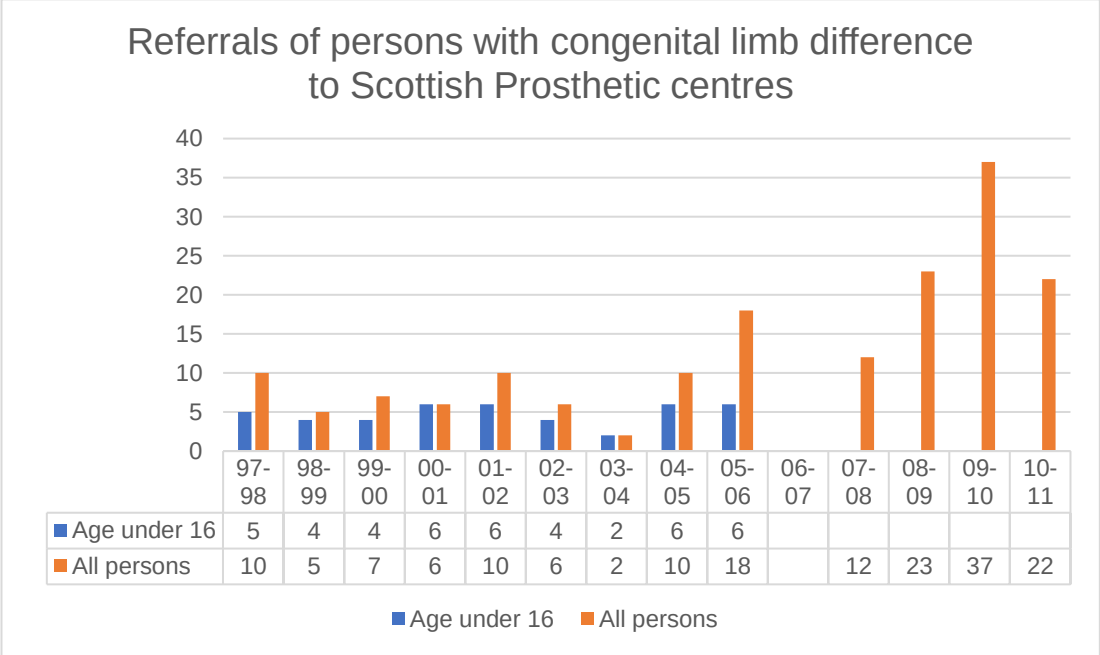


Figure 4.9 Number of referrals to Scottish prosthetic services per year, by age of patient

4.4 Discussion

4.4.1 Limb amputations in Scotland

The incidence of limb amputation rose during the 1980s and early 1990s, peaking in 1993. A decrease in the number of LLAs between 1993 and 2011 resulted in a total decrease in the number of amputations during this time. As identified in Chapter 2,

similar trends have been noticed in other European countries with researchers suggesting that this decrease coincides with increased measures to improve foot care within the diabetic population.

In 2002, NHS Scotland introduced the Scottish Diabetic Framework as part of their commitment to the Our National Health: A Plan for Action, a Plan for Change strategy. Clinical Standards Board for Scotland standards 4 and 7 of the Framework stated that people with diabetes are at high risk of developing lower limb complications and should be offered more frequent examinations to monitor their condition and specialist assessment when required. The importance of feet checks was identified, with guidance provided about what this should entail (NHS Scotland, 2002). The implementation of improved foot care services for people with diabetes, as recommended in this strategy, may explain the reduction of LLAs seen in the 2000s. However, as this study did not investigate diabetic status or access to footcare services, it is not possible to state this definitively.

Results from this study can be compared with data presented in SPARG reports. SPARG collects LLA data which has been entered locally on the SPARG database by NHS physiotherapists. SPARG data excludes amputations distal to the ankle joint and patients who receive amputation for palliative care.

According to NHS NSS, there were 1,507 LLAs excluding supernumerary digits in 2010 (Table 4.1), and the LLA referral rate calculated in this study for the same period was 35 percent (n=532). This amputation figure is higher than the 763 LLA procedures reported by SPARG in the same period. SPARG reported that in the same year 315 (43.1 percent) of patients were fitted with a prosthesis, with a further 15 patients abandoning use of a prosthesis before discharge.

It can be assumed that many of the 744 procedures unaccounted for in the SPARG report were partial foot LLAs. The absence of minor LLAs in the figures could explain the difference in the number of amputations reported in the two studies.

There is also a difference between the number of people referred to prosthetic services, as published in Limbless Statistics, and the number of people fitted with a prosthesis. This difference will partly be because not all people referred for treatment will be provided with a prosthesis. Another reason for the discrepancy could be that Limbless Statistics figures may include people with existing amputations. These

differences in methodology mean that comparing findings across studies is challenging.

Unlike LLA there are no published findings which can be used to compare the number of ULAs. Incidence of ULA is generally reported in the literature according to type (major or minor) or level. The mean incidence of ULA calculated in this study was 8.31 (SD 0.7). This figure is lower than the published incidence figures described in Section 2.5, many of which consider major ULA only.

The referral rate calculated in this study after ULA was much lower than for LLA. In 2010, 389 ULAs were performed in Scotland, but only 31 patients were referred to Scottish prosthetic clinics during the same period (7 percent referral rate) (Table 4.3). It is unclear from the information available within this study why the referral rate after ULA is so low.

This study considered only the referral rate to prosthetic services. In Scotland, prosthetic services focus primarily on rehabilitating people with major amputations. People with minor amputations are also treated within the prosthetic service but can often receive treatment from other medical services, e.g. podiatry, occupational therapy. Prosthetic and/or orthotic devices provided by other services are not captured within this study. When examining the Limbless Statistics data, it is evident that most of the patients with ULA referred to prosthetic services had major ULA. It may be the case that patients with minor amputations are less likely to be referred to prosthetic clinics, and this could explain the low referral rates.

Prevalence of CLD could only be calculated for seven out of the 11 years examined due to data being supressed to protect patient identity. Prevalence varied between 0.53 and 1.53 per 10,000 births, and it can be assumed that in the years where CLD birth data was supressed, prevalence would be even lower. These figures are low compared with the incidence figures discussed in Section 2.6. Reasons for this difference could be related to the methods by which incidence has been calculated. This study has only considered births included in the SBR. Whilst the SBR includes stillbirths, pregnancies which have ended before 24 weeks gestation are not included, and this may partially explain the low prevalence found in this study. It is possible that the prevalence of CLD in Scotland could be higher as some CLDs may not have been detected at the time that the birth was registered.

The referral rate to prosthetic services for children with CLD was in most instances higher than the number of recorded births with CLD in that year. This indicates that this comparison was, in this instance, not appropriate. Reasons for this inaccuracy may include children being referred to limb-fitting centres at older ages or repeat referrals.

4.4.2 Methods discussion and future work

This study involved the secondary use of data that is available to the public to investigate the number of amputations being conducted each year and the number of children born each year with CLD. Data was obtained from Scottish Government websites, published reports, and an FOI request.

The process of requesting information through an FOI request was straightforward. Guidance about how to request data is provided online and this was easy to follow. NHS NSS responded to the FOI request quickly, discussed over email what they were able to provide, and released the data in a timely manner.

Whilst using an FOI request proved to be an effective method of obtaining amputation numbers, this method is limited as to the depth of information that can be provided. Preserving patient anonymity was a factor when investigating CLD births. The quality of data received was compromised through combining lower and upper limb absence, and by suppressing several years' figures where the frequency of cases was under three. This combined with insufficient detail on referrals led to a referral rate calculation which seems impossible. As discussed in Section 4.4.1 above, LLA figures differ from those published by SPARG, and an assumption is made that the additional amputations may be minor LLA. To confirm this, detailed amputation data which includes the level of amputation is required, and this level of detail falls outside the remit of the Freedom of Information Act.

An observation to be aware of when using an FOI request within research is that requests and responses can be published on the public authority website. Archives of data outputs generated for FOI requests can be a useful resource for researchers and beneficial for the public.

The method used to calculate referral rates to prosthetic services was not optimal but was selected for use as an objective of this study was to utilise only publicly available data sources. The methods involved the secondary use of data provided by prosthetic

centres but as no metadata was available certain assumptions were made. A lack of metadata meant that it was also not possible to verify the quality of data in the reports.

As described in Section 4.2.3, assumptions were made about the timeframe from amputation to referral. This may have led to inaccuracies when calculating the referral rate to prosthetic services. In addition, as NASDAB/Limbless Statistics data included all new referrals in their figures, patients with existing amputations who, for example, had recently moved into the area may have been included. This may mean that the number of referrals for people who had undergone a new amputation was lower than reported in NASDAB/Limbless Statistics, and the resulting referral rate may be an over-estimation. A lack of detail about the people included in NASDAB/Limbless Statistics reports and the inability to track individual cases means that the referral rates calculated in Study 2 have limited value.

4.4.3 Further studies

The aim of Study 2 was to use publicly accessible data sources to establish how many limb amputations and CLD births occur in Scotland each year, and how many people are then referred to prosthetic services. Whilst it is acknowledged that the results of this study are limited due to the methods used, the study did produce several key findings. Prior to this study, there was no published data about amputation numbers in Scotland. Following the release of the requested FOI data to the requester, in accordance with NHS NSS policy, the data was also published on the NHS NSS website and has been cited in other publications.

The findings from Study 2 have raised additional research questions including why the number of LLAs reported in Study 2 was higher than has been reported in other reports, such as those of SPARG or Limbless Statistics. Whilst it is suspected that this may be due to differences in methods, especially the exclusion of minor amputations in other studies, this theory has not been tested. Obtaining detailed information about the level of amputation will help answer this question, and this was a consideration when developing Study 3.

4.5 Conclusions and recommendations

Through the secondary use of data, it was possible to report the number of amputations that occurred in Scotland from 1997 to 2010. Incidence of LLA was estimated at 27.1–34.9 per 100,000, and ULA was estimated at 6.8–9.5 per 100,000.

Amputation incidence peaked in the mid-1990s before dropping to lower levels by 2010. The birth prevalence of CLD ranged between 0.53 and 1.53 per 10,000 births.

The referral rate to prosthetic services ranged from 24.1 to 35.5 percent after LLA, and 1.6 to 9.3 percent after ULA. As no patient-level data was used, it was not possible to examine the characteristics of individuals to determine reasons why referral rates were low.

To answer the questions raised from this investigation, a robust methodology must be devised which tracks individual patient data from the point of amputation/birth through to referral and treatment. Capturing all amputations, both major and minor, is essential to understand the needs of the people with limb difference living in Scotland.

4.6 Summary of Chapter 4

Chapter 4 details a study that utilized data acquired from Freedom of Information requests in conjunction with publicly available datasets to investigate the incidence of amputation in Scotland from 1989 to 2013, as well as the birth prevalence of congenital limb differences from 2002 to 2013. Subsequently, this data was integrated with information from prosthetic centres to ascertain the rate of referral to prosthetic services.

5. Study 3: A retrospective review of limb amputation and congenital limb difference using linked data

The scoping review in Chapter 2 showed that there is insufficient information about the amputee population in Scotland available within the literature. Study 2 used publicly accessible data to determine frequency of amputation and congenital limb difference, and referral rates to prosthetic services, but detailed information, including the level of amputation procedure, geographic locations, sex and age of patient was not available. To investigate this further a retrospective data linkage study was devised to obtain detailed information about the people undergoing amputation or being born with limb difference in Scotland, and the medical services which they receive.

The objective for Study 3 was to create a dataset that could be used to investigate the frequency of amputation and CLD in Scotland, and the profile of the population undergoing amputation procedures, and analyse the data in terms of frequency of amputation and CLD, demographic profile, and clinical outcomes including survivorship.

Whilst a comprehensive and detailed statistical analysis of the gathered data is beyond the scope of the thesis the potential of the data set will be demonstrated by a descriptive analysis of frequency of amputation and CLD at different levels and geographical distribution, demographic profile of the population in terms of sex, ethnicity, deprivation and age, and patient attendance at rehabilitation services following amputation. Survival probability after amputation and incidence/prevalence rates were calculated for various cohort.

The methodology and methods for Study 3 are described within this chapter. The results for Study 3 are presented and discussed in Chapter 6.

5.1 Study overview

A retrospective cohort study was conducted using multiple sources of routinely collected health data combined using data linkage techniques. The study examined

Scotland's EHRs to identify all limb amputations conducted between 2012 and 2022, and all births with CLD during the same timeframe. Descriptive analysis of clinical and demographic information was performed.

The study was designed and collaboratively managed with the Electronic Data Research and Innovation Service (eDRIS), a specialist team within Public Health Scotland. eDRIS is a single point of contact for researchers conducting studies which use linked NHS data.

5.2 Methodology

5.2.1 Data linkage as a research method

Data linkage is the process of bringing together two or more records about an individual person, place, organisation, or event to form a new dataset. Records from different sources are paired using identifiers which could include a unique person-specific identifier (deterministic method) or a combination of information e.g. name, address, date of birth, ID number, and sex (probabilistic method) (Kelman, Bass and Holman, 2002). Through the joining of multiple records, a new dataset is formed which is considered broader in scope and may contain multiple factors, variables, or outcomes. The linkage of datasets can provide context to the subject being examined, which assists in the interpretation of existing data, thus enriching understanding of the topic.

The use of data linkage within medical research has evolved over recent decades. The potential for linking data was recognised in the 1960s by the Oxford Record Linkage System. Researchers tested its feasibility and went on to conduct a large study utilising multiple sources of health records (Acheson, 1967; Baldwin, 1972). The advancement of computing technology and mathematical matching techniques simplified processing and storage, which led to an expansion of interest in the field (Smith and Flack, 2021). The practice of sharing health data for secondary analysis has increased dramatically over the past 20 years (Black, Barker and Payne, 2004; Bohensky et al., 2010; Aitken et al., 2016).

Data linkage studies commonly use existing administrative datasets. This reduces the burden on clinicians and patients as new data does not need to be collected. A key benefit of data linkage is that it enables cost-effective longitudinal tracking of non-identifiable data throughout life (Holman et al., 2008). The technique has proved useful for evaluating effects of preventative care; a subject matter that has previously

been challenging to analyse (Rowe et al., 2019). Linking databases can also help fill in blanks where there is missing data. For this reason, it is agreed that the new combined dataset is more complete than the individual unlinked sources (Holman et al., 2008).There are, however, some disadvantages to this methodology, which centre around public perception and ensuring data quality (Brook, Rosman and Holman, 2008; Holman et al., 2008).

5.2.2 Public perception of data linkage

Concern about the use of big data is widespread within the general public. This mistrust centres around a fear that personal data may be misused or sold to third parties. The importance of public acceptability has been acknowledged as critical for the future of data linkage studies (Aitken et al., 2016). However, low levels of public awareness about methods and uses of shared data have been found within the literature (Aitken et al., 2016).

The Scottish Government published findings from a study conducted in 2012 to examine public acceptance of data linkage in Scotland (Davidson et al., 2012). There was general acceptance amongst participants that data linkage has potential benefits, but concerns were raised that data linkage could result in negative 'labelling' of individuals. There was also concern that data would be identifiable and compromise individuals' privacy, and that the data linkage process could pose a security issue or be shared for commercial gain. Public understanding of data linkage was also highlighted as an issue in the 2017–2018 study of public attitudes towards data linkage, commissioned by University College London (UCL). They reported that understanding of data linkage was not consistent amongst participants in the study and some participants were not aware of the differences between data linkage and data sharing. Concerns were raised by participants of the UCL study about consent, particularly de-identification, and transfer of data. Despite this, most participants could see benefit in data linkage 'if there was either a personal or societal benefit to doing so' (National Centre for Social Research, 2018).

As data linkage often involves secondary use of data, the process of linkage and analysis can be conducted without explicit informed consent from the individuals to whom the data relates (Kelman, Bass and Holman, 2002; Smith and Flack, 2021). Consent for use of data is a complex issue covered within the legal and ethical framework of the country processing the data. Recommendations such as regulation and improved public dialogue have been made to ensure that data sharing is

optimised for public benefit (Aitken et al., 2016; Kennedy et al., 2020). The challenge of balancing benefit against risk to individuals has been well documented (Mourby et al., 2019; Smith and Flack, 2021).

To protect an individual's privacy, and gain public trust, it is essential that steps are taken to reduce risk of identification (Brook, Rosman and Holman, 2008). For this reason, it is best practice for administrative data to be provided to researchers in an anonymised form. The definition of anonymised data under UK and European data protection law is that the data has been processed and protected in such a way that it no longer relates to an identifiable individual (The European Parliament and the Council of the European Union, 2016; Mourby et al., 2019; Information Commissioner's Office).

Anonymisation is the processing of personal data so that it is impossible to identify individuals. It is permanent and data cannot be converted back to its original form. This differs from pseudonymisation where individuals can potentially be identified if data is combined with additional information held elsewhere (e.g. a code key).

The UK General Data Protection Regulation (GDPR) does not apply to personal data that has been anonymised but does apply to data that has been pseudonymised (UK Parliament, 2018). It is recommended that personal data used in data linkage studies be anonymised.

The use of anonymised data has been shown to reassure public opinion about data-sharing studies (Aitken et al., 2016; Tully et al., 2020). In addition to this, transparency and openness are recommended good practice when conducting research studies using patient information (Broughan, 2022).

5.2.3 Quality of data

A second challenge for data linkage studies is maintaining quality within the study. The quality of a linked dataset will be compromised if the source data is inaccurate or incomplete, or if errors have occurred during the linking process. Methods of dealing with inconsistent or missing data must be determined before analysis begins with rules consistently applied.

To reduce the risk of identifying individuals, data linkage and data analysis are considered separate processes and are commonly conducted by different people. Identifiers are normally removed before the analyst has access to the linked dataset.

To minimise error, it is essential that the data linker and data analyst communicate so that the data linker understands the context of the study, and the data analyst understands the degree of linkage uncertainty.

The Guidance for Information about Linking Data Sets recommends that detailed information about methods is made available at each stage of data linkage to help reduce miscommunication and errors. False matching and mismatching can occur when there is no unique identifier across the datasets. This can happen, for example, when NHS and non-NHS datasets are linked. For this reason, it is normal to use more than one factor as an identifier, e.g. NHS number and date of birth. Issues can occur if source databases do not supply multiple identifiers as this can make it difficult to trace or decode errors (Gilbert et al., 2018).

Data needs to be cleaned prior to linking to remove inconsistencies such as spaces or format changes as these can increase the likelihood of false matches. Details about the methods used to clean the data, a report on the proportion of missing data before and after cleaning, and the number excluded or changed should be provided to the analyst.

Data-sharing agreements between data controllers and data owners are recommended best practice. The agreement may include minimum standards to ensure data protection, confidentiality, security, and quality (Health Economics Unit, 2022).

5.2.4 Data linkage in Scotland

Scotland considers itself to be a leader in health data linkage. Following public consultation, the Scottish Government published a series of strategies, guides, and frameworks related to data linkage research. The documents provide guidance on aspects such as public interest, privacy and consent, anonymisation, transparency, data handling, and governance (The Scottish Government, 2012a; The Scottish Government, 2012b; The Scottish Government, 2015a; The Scottish Government, 2015b).

Amongst the government's initiatives was the establishment of the Scottish Health Informatics Programme (SHIP) in 2009 to develop expertise in all aspects of data linkage. This initiative evolved into the similarly named Scottish Informatics Programme, a collaboration between the universities of Dundee, Edinburgh, Glasgow, and St Andrews, and the NHS Information Services Division. Jointly funded

by the Wellcome Trust, Medical Research Council, and Economic and Social Research Council from 2009 to 2013, SHIP provided a research platform and training to support data linkage studies which use EHRs (The Scottish Government, 2015a; The Scottish Government, 2015b; SHIP). Scotland's National Safe Haven and the eDRIS portal, a service that supports research using health data and EHRs, became operational in 2013 (The Scottish Government, 2015a).

The documents published by the Scottish Government have formed the framework for the methodology used within this study.

5.3 Methods

A data linkage study was developed using routinely collected health and administrative data. The process used in Study 2 is illustrated in Figure 5.1.

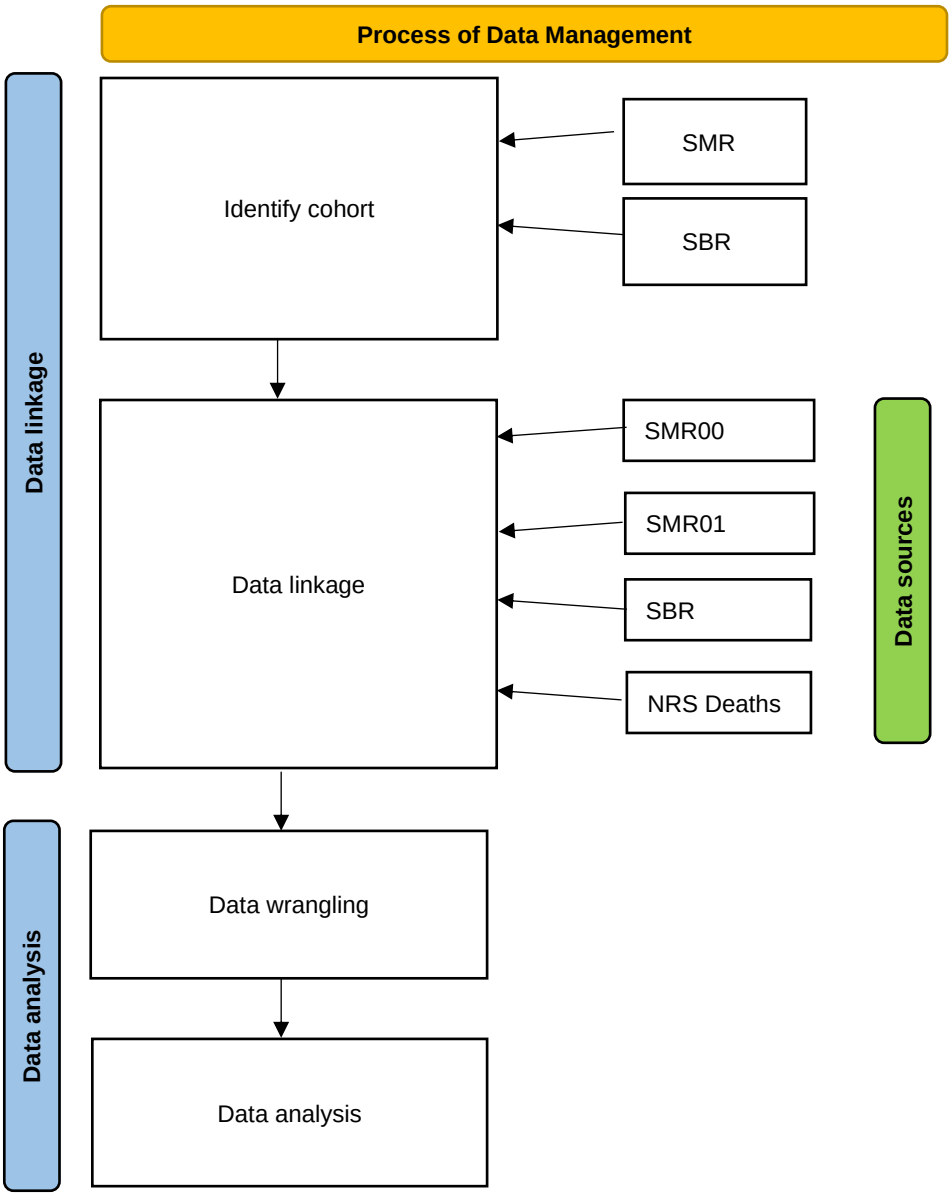


Figure 5.1 Process of data management

5.3.1 Data sources

Four sources of data were used within this study: the Community Health Index (CHI), Scottish Morbidity Records (SMR), Scottish Birth Record (SBR) and National Records of Scotland (NRS). CHI was used only in the identification of the cohort.

5.3.1.1 Community Health Index

The CHI is a register of all patients registered with NHS Scotland. The CHI number is a unique ten-character identifier which is allocated to everyone at birth or on their first

registration with NHS Scotland. It forms part of Scotland's EHRs and is used each time a patient accesses an NHS Scotland service. This allows information about health services to be associated with an individual person.

5.3.1.2 Scottish Morbidity Records

Episodes of healthcare received by individuals in Scotland are recorded in the SMR. Information is presented within separate datasets. The datasets, known as SMR record types, are shown in Table 5.1.

Table 5.1 SMR datasets

Hospital activity SMRs	00	Outpatient attendance (excluding accident and emergency attenders, ward attenders, and bedside consultations)
	01	General/acute inpatient and day case
	02	Maternity inpatient and day case
	04	Mental health inpatient and day case
Other SMRs	06	Cancer registration
	25	Scottish Drugs Misuse Database

SMR datasets contain information about the patient and the episode of treatment. Patient identifiers and demographic information collected within SMR datasets include patient name, date of birth, sex, CHI number, postcode, and ethnic group. Episode management data includes, amongst other variables, location, medical specialty, name of consultant, diagnostic and procedural codes, admission date, and discharge date. This study used SMR data from SMR01 and SMR00.

SMR01

SMR01 collects episode level data about all hospital inpatient and day case discharges from acute specialties. It contains information about the treatment episode including admission type, patient condition, operations, and location as well as patient identifiers such as name, date of birth, CHI number, postcode, and ethnicity. Patient conditions within SMR01 are currently coded using ICD-10 format, and operations are currently coded using OPCS-4 format. SMR01 data collection started in 1960 and covers all regions of Scotland (Public Health Scotland, a).

SMR00

SMR00 collates information related to outpatient attendance such as referral date, referral source, reason for referral, clinic date, and attendance status (Public Health Scotland, b).

5.3.1.3 Scottish Birth Record

The SBR is a part of the EHR and is completed for all births in Scotland including stillbirths and home births. The SBR started collecting data in 2002 and is a web-based system which allows real-time national data collection and updating of information and enables a baby to be registered with CHI shortly after birth. It consists of two parts: the clinical module, which is normally completed by midwifery, neonatal, or paediatric staff; and the coding module, which is completed by medical record staff. The SBR differs from other SMRs as it is based on individuals rather than episodes of care (Public Health Scotland, c).

5.3.1.4 National Records of Scotland

NRS, established in 2011, is a non-ministerial department of the Scottish Government. Their purpose is to 'collect, preserve and produce information about Scotland's people' (National Records of Scotland). NRS has a broad remit including maintaining historical records, managing public records, administering the registration of life events (births, marriages, deaths, divorces, adoptions), and maintaining the Scottish Register of Tartans. In addition, the NRS is responsible for administrating Scotland's census. The census is a household questionnaire which is conducted every ten years. It collects information about the characteristics of people and households.

NRS publishes annual mid-year population estimates which are considered the official estimate of the Scottish population. The process used to determine the estimates is detailed within a report that is published annually (National Records of Scotland, 2022c).

In addition to mid-year population estimates, two datasets managed by NRS are used within this study: SIMD and NRS Deaths Data (NRS Deaths).

Scottish Index of Multiple Deprivation

The SIMD is Scotland's measure of how deprived a geographic area is. Reviewed annually, the SIMD is used by the Scottish Government to identify areas of multiple deprivation. SIMD is a measure of relative deprivation and does not mean that everyone living in an area is experiencing deprivation equally. It is calculated using data related to income, employment, education, health, access to services, crime, and housing.

To calculate SIMD, Scotland is divided into small 'data zones' each containing seven hundred to eight hundred people. The data zones are then ranked in order of deprivation. In 2020, there were 6,976 data zones which were then ranked from 1 (most deprived) to 6,976 (least deprived). For ease of interpretation, data zones are commonly divided into deciles, where each decile contains 10 percent of Scotland's data zones. It is common for researchers to focus on data zones below a particular rank, for example SIMD10 refers to areas falling into decile one, the 10 percent most deprived data zones. SIMD20 refers to areas falling into deciles one and two, the 20 percent most deprived data zones. SIMD data is used in this study as an indicator of deprivation (The Scottish Government, 2020).

NRS Deaths

The NRS Deaths database records information about all deaths registered in Scotland since 1974. Examples of information collected include cause of death, duration of illness, age at death, place of death, occupation, marital status.

5.3.2 Variables

5.3.2.1 Identifying the cohort

Individuals were identified for inclusion in the study if their SMR contained an episode of care or record with a procedure code and/or diagnostic code that indicated limb amputation or limb difference. EHRs were then linked using the person's unique CHI number, which allowed data from multiple sources to be combined into one dataset.

Procedure codes

Procedure codes are the clinical codes describing hospital interventions and procedures. They enable statistical classification. NHS Scotland currently uses OPCS-4 for the clinical coding of procedures and interventions (NHS Digital, 2019; Public Health Scotland, d). OPCS-4 was adopted by Public Health Scotland in 1989 and replaced OPCS-3, which was used from 1977 to 1988.

Up to four pairs of procedure codes can be recorded against an episode of care within an SMR dataset; these are listed as a 'Main Operation' and up to three 'Other Operations'. A pairing code is used to record two procedures carried out within a single theatre visit (Public Health Scotland, e; Public Health Scotland, f).

Procedure codes were used to identify the cohort for Study 2 and were also used during the data analysis process. OPCS-4 codes were used in this study to identify people who had undergone amputation within the timeframe being examined. In

addition, OPCS-3 codes were used to enable the identification of pre-existing amputations in those individuals.

The procedure codes used in this study to identify the cohort of people who had undergone limb amputation are listed in Table 5.2. This list was created using information gained from Study 1, from the investigator's prior knowledge of amputation levels, and under advice from the eDRIS coordinator.

Table 5.2 Procedure codes used for identification of cohort

OPCS-3		OPCS-4			
861	8712	X07	X08.2	X09.5	X11
862	8713	X07.1	X08.3	X09.8	X11.1
863	8714	X07.2	X08.4	X09.9	X11.2
864	872	X07.3	X08.8	X10	X11.8
865	873	X07.4	X08.9	X10.1	X11.9
866	874	X07.5	X09	X10.2	X21.5
867	875	X07.8	X09.1	X10.3	X21.6
870	8751	X07.9	X09.2	X10.4	X27.3
871	8752	X08	X09.3	X10.8	
8711	8755	X08.1	X09.4	X10.9	

Diagnostic codes

Diagnostic coding is a method of translating medical information from a patient's medical notes into a series of characters which describe diagnoses or procedures (Aalseth). Diagnostic coding systems are groups of codes that correspond to individual procedures and diagnoses. The ICD, published by the WHO, is a classification system that is used internationally, allowing standardised recording, analysis, and comparison of mortality and morbidity data. It is used worldwide and is the most widely used diagnostic coding system (World Health Organization, 2022). Since the ICD was established in 1948, various versions have been released. This study uses ICD-10, which came into effect in 1993. A more recent revision, ICD-11, which came into effect in January 2022 (World Health Organization, 2022) was not available for use at the time of data extraction.

The ICD-10 diagnostic codes used in this study to identify people who have either undergone limb amputation or been born with a limb difference are listed in Table 5.3. This list was created using the investigator's prior knowledge of amputation and under advice from the eDRIS coordinator.

Table 5.3 Diagnostic codes used for identification of cohort

Congenital diagnostic codes	Other relevant diagnostic codes
Q710	ICD10 codes for traumatic amputations
Q711	
Q712	S48
Q713	S58
Q720	S68
Q721	T05.0, 5.1, 5.2, 5.6
Q722	T11.6
Q723	S78
Q730	S88
Q731	S98

5.3.2.2 Clinical variables

Comorbidity

Comorbidity is related to mortality, quality of life, functional status, and healthcare, and can be used as a predictor of these factors (Gijsen et al., 2001; Charlson et al., 2022). The Charlson Comorbidity Index (CCI) is a validated assessment tool designed to predict long-term mortality. Originally developed in the 1980s, the index has since been updated and validated for use with ICD-10 codes (Charlson et al., 2022). The original version considers 19 conditions, which are weighted and combined with age to predict mortality (Charlson et al., 1987; Charlson et al., 2022). Variations of the original index include the Age-Comorbidity Index, which is suitable for small sample groups, and adaptions using ICD-9 and ICD-10 codes (Charlson et al., 2022).

The CCI is used within this study as a measure of comorbidity. It was calculated by searching SMR for the presence of 19 conditions within the five-year period preceding the amputation. Conditions were identified using ICD-10 codes. The findings were then weighted and the CCI was calculated.

Other clinical variables

Clinical data was extracted from SMR01 (inpatients), SMR00 (outpatients), SBR, and NRS Deaths. Table 5.4 details the variables retrieved from each source. Date of birth was retrieved as a partial date (mm/yyyy) to reduce the risk of identification.

Table 5.4 Clinical and socio-demographic variables retrieved from data sources

SMR00	SMR01	NRS Deaths	SBR

CHI number Clinic date Attendance status Referral type Specialty	CHI number Date of admission Date of discharge Date of birth Sex Postcode Ethnic group Location Specialty Admission type Main condition Other condition 1 Other condition 2 Other condition 3 Other condition 4 Other condition 5 Main operation Other operation 1 Other operation 2 Other operation 3 SIMD 2012 quintile SIMD 2012 decile	CHI number Date of death	CHI number Date of birth Sex Ethnic group Hospital of birth Congenital anomaly Routine exam, arms Routine exam, hands Reason for admission Date of main operation Main operation code Other operations 1 Other operations 2 Other operations 3 Main condition Other condition 1 Other condition 2 Other condition 3 Other condition 4 Other condition 5 Postcode SIMD 2012 quintile SIMD 2012 decile

Socio-demographic variables

Socio-demographic data pertaining to the individual was retrieved from SMR01 and SBR. Dates of birth were retrieved as mm/yyyy and postcode was retrieved at sector level (e.g., G2, E12, AB6) to reduce the risk of identification of the individual.

5.3.3 Data management

An independent data analyst was appointed by eDRIS to retrieve the requested data from the data sources and create the dataset for this study. Data transfer took place using the secure National Safe Haven Serv-U STFP.

The process of retrieving data from sources and preparing it for release to researchers was conducted by eDRIS using deterministic matching techniques. The PHS CHI Linking and Indexing team (CHILI) created a master index of the cohort members, using a list of CHIs provided by the eDRIS analyst. Files were loaded into the National Safe Haven and run through the Linking Agent in there, creating one consistent master index. The look-up file for the master index was uploaded by the CHILI team directly into the Safe Haven, bypassing the eDRIS team to maintain separation of

function and avoid the possibility of eDRIS personnel seeing a personal identifier. Data cleaning was performed on the NRS Deaths extract. A Data Sharing Agreement in the form of a User Agreement was signed by representatives from the University of Strathclyde and eDRIS.

The process of linkage data is illustrated in Figure 5.2.

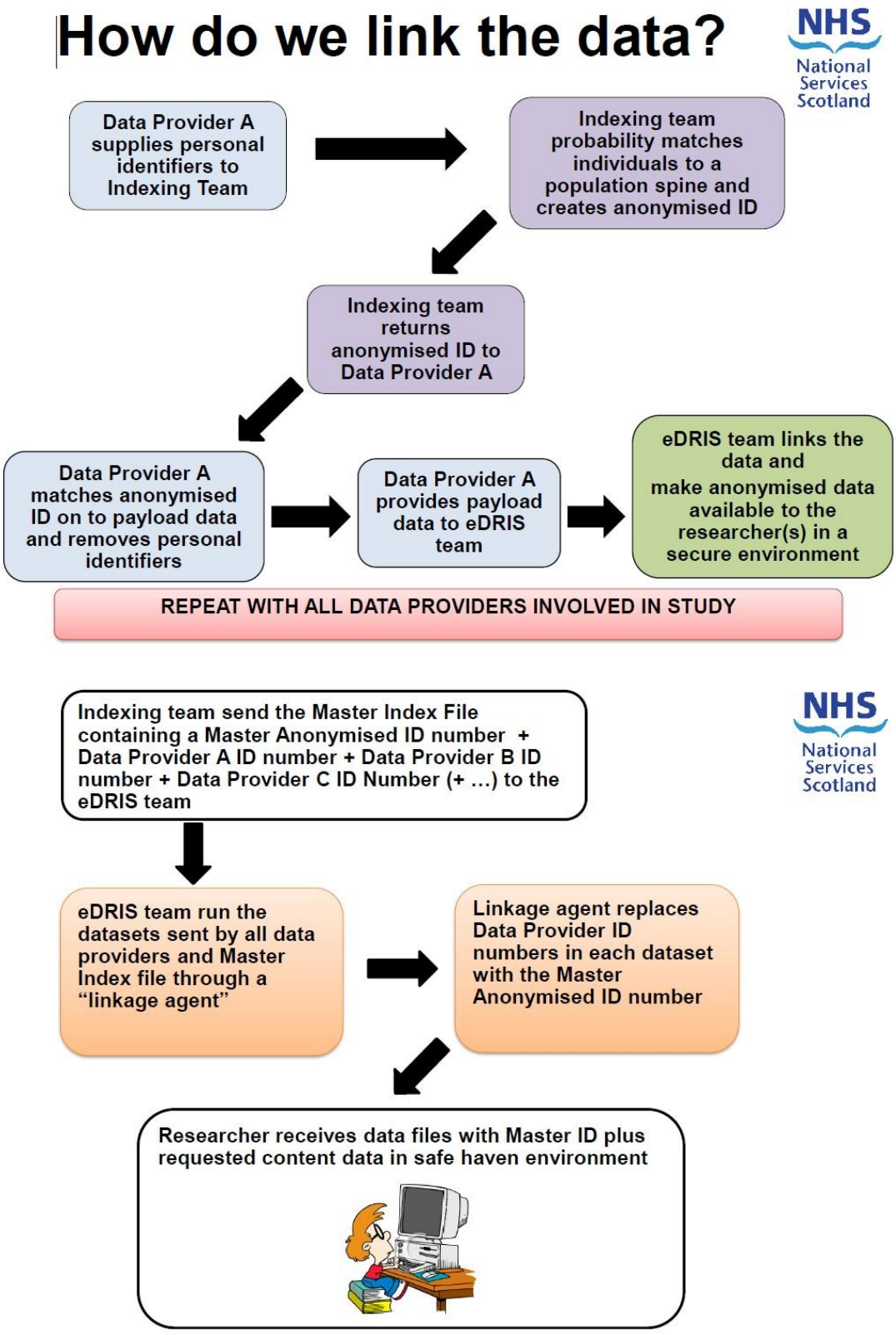


Figure 5.2 Process of data linkage used within Study 2. Image supplied by eDRIS

5.4 Ethical considerations

5.4.1 Local review

Prior to applying for ethical approval, advice was sought from the West of Scotland Research Ethics Service. After reviewing details of the proposed study, it was advised that the Integrated Research Application System was not required and the following comment was made:

> Generally we would regard this as a very safe way to access linked data with virtually no risk of individual patient identification. In the past we have taken the view that this type of data does not require a formal ethical review. If the PBPP [Public Benefit and Privacy Panel] require ethical review then I recommend that you go for Proportionate Ethical Review but otherwise the project would appear to be of extremely low ethical risk if it is to be carried out via the National Safe Haven.

Current data protection legislation was considered during the preparation of the study, and throughout. The method was updated to comply with GDPR legislation, which was introduced during the scope of this study.

The study used data routinely collected by NHS Scotland. NHS patients have access to widely available patient information on their right to confidentiality including information about how to ‘opt out’ of patient data being used for research. In addition, information about the types of data collected and processed by NHS Scotland, and the legal basis for doing so, is detailed on the NHS Inform website (NHS Inform).

To reduce the risk of identification of individuals, the data minimisation principle was adhered to. Data was minimised to ensure that only the essential data required to meet the objectives of the study were requested. Individuals unlikely to experience impact from amputation, such as those undergoing amputation of supplementary digits, were excluded from the cohort. To protect identity, date of birth was requested as month/year and postcode was requested at sector level.

5.4.2 Information governance

All researchers involved in the study were required to complete information governance training every two to three years. Evidence of completion was provided to eDRIS, and Safe Haven access revoked if certification lapsed.

Potentially identifiable data held in the National Safe Haven was archived and retained in line with eDRIS policy. Data disposal will be conducted in line with National Safe Haven policy. Processed non-identifiable data will be kept indefinitely in accordance with the University of Strathclyde Research Data Policy, and disposed of once obsolete, normally after a period of ten years.

5.4.3 Project approval

This study was reviewed and granted ethical approval by the NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (PBPP). PBPP is a patient advocacy panel and a governance structure of NHS Scotland. Their role is to scrutinise and consider applications for access to NHS Scotland data to ensure that public benefit and privacy implications, and information governance requirements, have been considered (NHS Scotland).

Full approval for this study was granted in July 2016. Amendments were subsequently approved in 2017, 2018, 2019, and 2022. Reasons for amendments included extending the original scope of the study and extension of study duration. Table 5.5 shows the PBPP approval dates.

Table 5.5 PBPP approval dates

Ethics application Ref: 1516-0094	Approval date
Original (with conditions)	06/05/16
Original (conditions met)	27/07/16
Amendment 1	23/06/17
Amendment 2	19/09/18
Amendment 3	19/09/19
Amendment 4	05/08/22

5.5 Data analysis

While numerous potential research topics could be explored, this study will specifically focus on answering the following research questions.

1. Determine how many amputations are conducted in Scotland, and at which levels. Determine at which facilities the amputation surgeries are performed, and the medical speciality in charge of the episode of care.
2. Investigate the profile of persons undergoing amputation, including sex, age, geographic location, and comorbidities
3. Investigate outcomes for people undergoing amputation

4. Determine the number of children born in Scotland with CLDs and identify the specific levels of limb difference
5. Calculate the incidence of amputation and birth prevalence of CLD in Scotland.

5.5.1 Data access

Data was accessible to researchers exclusively through the National Safe Haven, a secure digital environment accessible through secure access points. A secure access point is described as ‘a dedicated computer in a physically secure area where no external devices can be used or connected. The secure access point does not connect to the internet nor can it be accessed remotely’ (Public Health Scotland, f).

Datasets containing linked data, in the form Excel spreadsheets, were deposited into the National Safe Haven, to be accessed by the analyst. For the purposes of this study, the analyst was Sarah Day, the author of this thesis. Dr Tanja Mueller, one of the student’s supervisors, was also granted permission to access data on the Safe Haven. The data was accessed through secure access points on campus at the University of Strathclyde, and temporarily during the Covid-19 pandemic, through a virtual private network connecting to a secure access point. Access was controlled via a two-factor authentication process which included receipt of an access code sent to a pre-registered mobile telephone. Access to the National Safe Haven was time limited, with automatic disconnection if the screen lay dormant for five minutes.

The National Safe Haven is a secure environment from which data cannot be added or removed by the end user. It is a high-powered computing platform containing a range of analytic and word processing software. All data processing by the analyst was conducted within the Safe Haven. Release of outputs from the Safe Haven is only possible following a series of checks. To release study outputs, the analyst made written requests via their eDRIS research coordinator. The research coordinator then assessed the requested outputs to ensure that they did not include any information which could be used, either on its own or in conjunction with other data, to identify an individual. Requested outputs were also checked by a supervisor within eDRIS who had no detailed knowledge of the study. Once cleared, permitted outputs were placed in an accessible file for the analyst to download.

5.5.2 Data wrangling

Linked data which was deposited in the Safe Haven was imported by the data analyst into R Studio, a statistical software package for analysis. R Studio is an integrated development environment for R, an open-source programming language for statistical computing and graphics.

Data wrangling is the process of reorganising and preparing the data to facilitate analysis. This included reassigning categories of variables, and merging and filtering datasets to produce datafiles which could be used for data analysis.

For the purposes of analysis, a ten-year cohort was created containing the details of amputations conducted between 1st January 2012 and 31st December 2021. The full-term dataset, containing data until 31st August 2022, was used in patient outcomes and comorbidities analyses.

Datafiles were created to enable analysis based on surgery site (upper or lower limb), type of amputation (major or minor), and level of amputation. To facilitate the analysis of demographic data, datasets were created based on an individual's first amputation during the timeframe of the study (2012–2022). Other datasets that were created include those related to survival, comorbidities, and subsequent amputations.

When conducting the data wrangling, procedure codes were assigned into groupings to indicate the level, type, and site of the amputation. Similarly, diagnostic codes used to identify congenital limb absence were assigned into groups to indicate the site of limb difference. The amputation and CLD groupings that were used through the analysis are shown in tables 5.6 and 5.7 below.

Table 5.6 Amputation groupings used in analysis

Site	Type	Body segment	Level	Procedure codes	
Lower limb	Major	Leg	Transpelvic	OPCS-3	–
				OPCS-4	X091
			Hip disarticulation	OPCS-3	–
				OPCS-4	X092
			Transfemoral	OPCS-3	871, 8711, 8712, 8713, 8714
				OPCS-4	X093
			Knee disarticulation	OPCS-3	872
				OPCS-4	X094
			Transtibial	OPCS-3	873
				OPCS-4	X095
			Ankle disarticulation	OPCS-3	–
				OPCS-4	X101
			Other (leg)	OPCS-3	870
				OPCS-4	X098, X099
	Minor	Foot	Tarsal	OPCS-3	–
				OPCS-4	X102
			Tarsometatarsal disarticulation	OPCS-3	–
				OPCS-4	X103
			Metatarsal	OPCS-3	–
				OPCS-4	X104
			Other (foot)	OPCS-3	874
				OPCS-4	X108, X109
		Digit	Hallux	OPCS-3	
				OPCS-4	X111
			Phalangeal (toe)	OPCS-3	875
				OPCS-4	X112
			Other (toe)	OPCS-3	
				OPCS-4	X118, X119
Upper limb	Major	Arm	Scapulothoracic forequarter	OPCS-3	–
				OPCS-4	X071
			Shoulder disarticulation	OPCS-3	–
				OPCS-4	X072
			Transhumeral	OPCS-3	–
				OPCS-4	X073
			Elbow disarticulation	OPCS-3	–
				OPCS-4	X074

			Transradial	OPCS-3	863
				OPCS-4	X075
			Wrist disarticulation	OPCS-3	864
				OPCS-4	X081
			Other (arm)	OPCS-3	861, 862, 867
				OPCS-4	X078, X079
	Minor	Hand	Other (hand)	OPCS-3	–
				OPCS-4	X088, X089
		Digit	Thumb	OPCS-3	865
				OPCS-4	X082
			Phalangeal (finger)	OPCS-3	866
				OPCS-4	X083
			Other (finger)	OPCS-3	–
				OPCS-4	X084

Table 5.7 CLD groupings

Site	Coding system	Diagnostic code	Description
Upper	ICD-10	Q710	Congenital complete absence of upper limb(s)
	ICD-10	Q711	Congenital absence of upper arm and forearm with hand present
	ICD-10	Q712	Congenital absence of both forearm and hand
	ICD-10	Q713	Congenital absence of hand and finger(s)
Lower	ICD-10	Q720	Congenital complete absence of lower limb(s)
	ICD-10	Q721	Congenital absence of thigh and lower leg with foot present
	ICD-10	Q722	Congenital absence of both lower leg and foot
	ICD-10	Q723	Congenital absence of foot and toe(s)
Unspecified	ICD-10	Q730	Congenital absence of unspecified limb(s)

5.5.2.1 Geographic

Postcodes were supplied within the datasets at sector level. Postcodes were grouped according to the health board where they were located.

5.5.2.2 Specialty

Specialty of the health professional in charge of the patient episode was analysed as reported and not grouped.

5.5.2.3 Comorbidity

There is variability within the literature in the way that aetiology and comorbidities are grouped and reported. The presence of diabetes was identified from 'Main Conditions' and 'Other Conditions' listed in SMR01 using the ICD-10 codes listed in Table 5.8. The presence of PVD was identified from the CCI datafile.

Table 5.8 Diabetic codes

Diabetic Codes
E10, E100, E101, E102, E103, E104, E105, E106, E107, E108, E109, E11, E110, E111, E112, E113, E114, E115, E116, E117, E118, E119, E12, E120, E121, E122, E123, E124, E125, E126, E127, E128, E129, E13, E130, E131, E132, E133, E134, E135, E136, E137, E138, E139, 14, E141, E142, E143, E144, E145, E146, E147, E148, E149

5.5.2.4 Ethnic groups

The codes for ethnicity were grouped as shown in Table 5.9. This method is similar to the format used in the NRS 2011 Scottish census (Public Health Scotland, 2023b; The Scottish Government, 2021).

Table 5.9 Ethnicity codes

Grouping	Code
Group A	1A White Scottish
	1B White other British
	1C White Irish
	1K White Gypsy/Traveller
	1L Polish
Group B	2A Any mixed or multiple ethnic groups
Group C	3F Pakistani, Pakistani Scottish, or Pakistani British
	3G Indian, Indian Scottish, or Indian British
	3J Chinese, Chinese Scottish, or Chinese British
	3Z Other Asian, Asian Scottish, or Asian British
	3F Pakistani, Pakistani Scottish, or Pakistani British
Group D	4D African, African Scottish, or African British
	4Y Other African
Group E	5C Caribbean, Caribbean Scottish, or Caribbean British
	5D Black, Black Scottish, or Black British
	5Y Other, Caribbean, or Black
Group F	6A Arab, Arab Scottish, or Arab British
	6Z Other ethnic group
Unknown	98 Refused/Not provided by patient
	99 Not known

5.5.2.5 Patient referrals

Records for the following disciplines relevant to amputation rehabilitation were used to analyse patient referrals after amputation:

- Physiotherapy
- Occupational therapy
- Podiatry
- Prosthetics
- Clinical psychology.

5.5.3 Methods of analysis

Data was analysed using R Studio and Microsoft Excel. All analyses were conducted within the National Safe Haven secure environment.

Whilst a comprehensive and detailed statistical analysis of the gathered data is beyond the scope of the thesis the potential of the data set was demonstrated by a

descriptive analysis of the data acknowledging that a robust inferential analysis is appropriate to fully address the questions raised.

Descriptive statistics were used to report the frequency of amputation surgeries at the different sites, types, and levels, medical specialty, amputating hospital, and subsequent amputations. Patient information, such as sex, age at amputation, and level of deprivation, were also described using descriptive statistics.

Survival status and survival time from first amputation were calculated for each patient who underwent their first amputation during the period 2012–2021. Survival status was designated as ‘event occurred’ for patients who died during the follow-up period which ended on 31st August 2022. This information was obtained from NRS Deaths. Patients who were still alive on 31st August 2022 were treated as ‘censored’. Survival time was calculated from the date of first amputation until either the date of death or 31st August 2022, depending on the patient’s survival status.

Median survival time (days), and probability of survival at 30 days, one year, two years, five years, and ten years were calculated for different univariates. Probability of survival was visualised using Kaplan–Meier curves, and the distribution of the survival curves for different samples was compared using log-rank tests. Log-rank tests were conducted using the null hypothesis that the samples have identical Kaplan–Meier curves and an alternative hypothesis that the samples have different curves, and the level of significance was set at 5 percent. Where significant differences were found relationships were investigated using Cox proportional hazard regression analysis. Wald statistic (z), regression coefficient (β coef), hazard ratio (exp(coef)), and hazard ratio confidence interval were reported from the Cox proportional regression calculations. Global statistical significance was assessed using the likelihood-ratio test, Wald test, and score log-rank statistics.

Incidence of amputation per 100,000 population was calculated using the formula below. For this calculation, population was derived from mid-year population estimates from NRS (Scotland ('Mid-year population estimates: time series data,' 2022; National Records of Scotland, 2022d). Birth prevalence was calculated using the formula below. For this calculation, the number of live births was obtained from the Vital Events Data Tables published by NRS (National Records of Scotland, 2022b).

*Incidence = (number of amputations / population) * 100,000*

*Birth prevalence = (number of live birth cases with CLD / total number of live births) * 10,000*

5.7 Summary of Chapter 5

Chapter 5 discussed how data linkage techniques can be utilised in research to determine a deeper understanding of a population without the need for further data collection. The chapter then outlined the methods which were used in Study 3, and the steps taken to protect the confidentiality of the population being examined.

6. Study 3 results

This chapter will present the findings from Study 3. Six Excel worksheets containing data relating to all amputation surgeries conducted in Scotland between 1st January 2012 and 31st August 2022 were uploaded to the Safe Haven for analysis, providing >7.3 million data entries (Table 6.1).

Table 6.1 Datafiles uploaded to Safe Haven for analysis

File name	Number of records	Number of variables
SMR01	245,572	27
SMR00	55,902	5
SBR	2,154	24
Deaths	6,997	2
Charlson	11,008	19
Cohort	19,707	6

In total 22,627 amputation procedures were conducted during the 128-month duration of the study. For the purposes of analysis, a ten-year cohort was created containing the details of amputation procedures conducted between 1st January 2012 and 31st December 2021, and this was used to calculate the findings presented in this chapter. The full-term dataset was used in death and treatment analyses to enable a minimum of eight months follow-up for each patient.

Whilst a comprehensive and detailed statistical analysis of the gathered data is beyond the scope of the thesis the potential of the data set will be demonstrated by a descriptive analysis of the data acknowledging that a robust inferential analysis is appropriate to fully address the questions raised.

This chapter is divided into five sections to address the following research questions:

1. Determine how many amputations are conducted in Scotland, and at which levels. Determine at which facilities the amputation surgeries are performed, and the medical speciality in charge of the episode of care.
2. Investigate the profile of persons undergoing amputation, including sex, age, geographic location, and comorbidities

3. Investigate outcomes for people undergoing amputation
4. Determine the number of children born in Scotland with CLDs and identify the specific levels of limb difference
5. Calculate the incidence of amputation and birth prevalence of CLD in Scotland.

6.1 Amputation procedures

6.1.1 Number of amputations

During the ten-year period under review, 21,421 amputation procedures were conducted on 15,974 patients. The total number of amputation procedures conducted each year can be viewed in Figure 6.1.

There was a general increase in the number of amputation surgeries from 2012 to 2019. A decrease in the number of amputations is observed in 2020, which was the first year of Covid-19 restrictions. The trendline on Figure 6.1 illustrates the upward trend over the observation period.

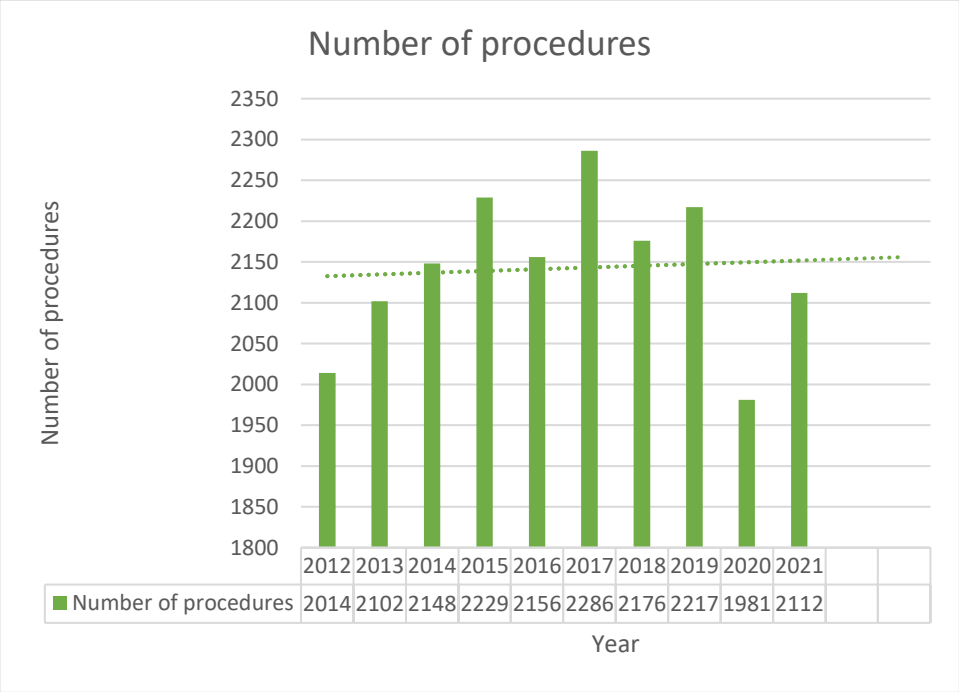


Figure 6.1 Number of amputation procedures per year

6.1.2 Site of amputation

During the ten-year review period, 17,255 LLA procedures and 4,166 ULA procedures were conducted. The numbers of lower and upper limb amputation surgeries per year

are shown in Figure 6.2. The mean number of LLA and ULA per year were 1,725.5 (SD 77.33) and 416.6 (SD 41.15), respectively. Of the amputation surgeries, 80.7 percent involved LLA procedures. The ratio of upper to lower limb amputations remained constant across the ten-year period (Figure 6.3).

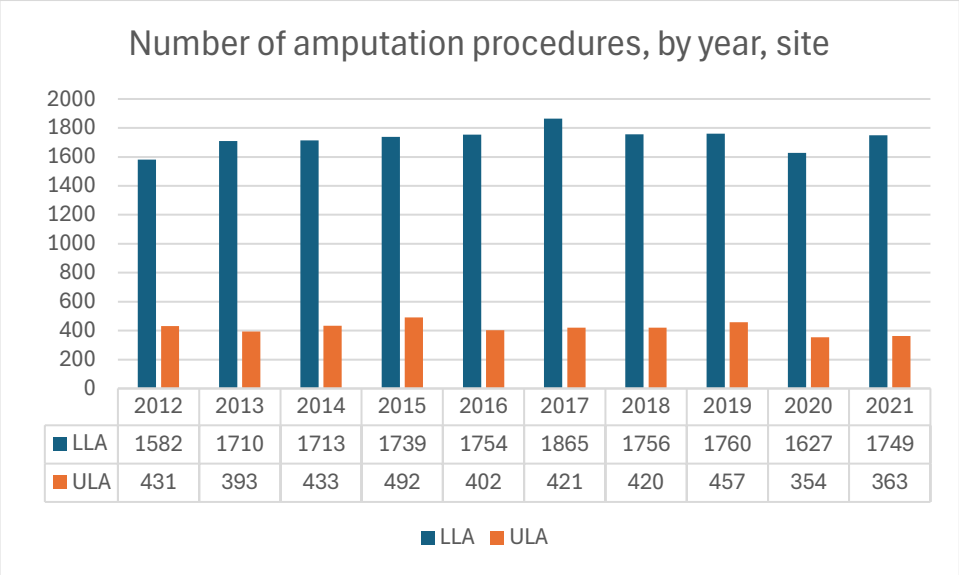


Figure 6.2 Number of LLAs and ULAs per year

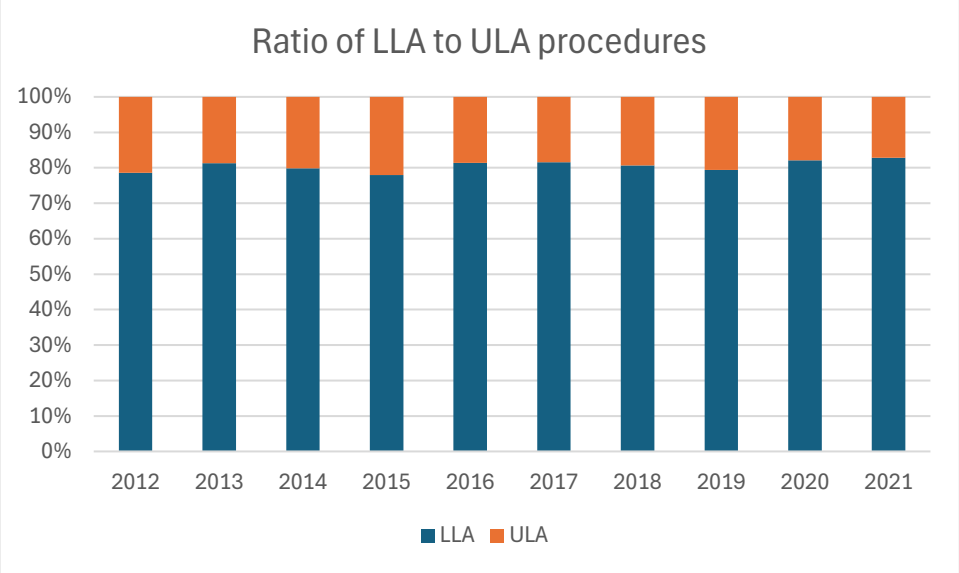


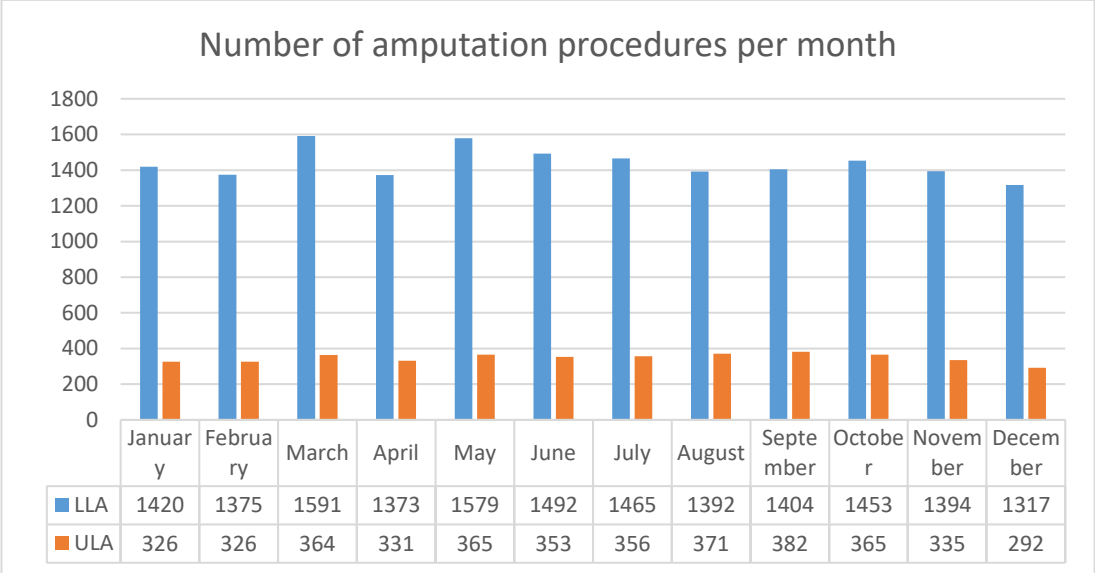
Figure 6.3 Ratio of LLA to ULA procedures per year

6.1.3 Distribution of procedures across the calendar

There was some seasonal variation in when amputation surgeries were conducted. Figures 6.4, and 6.5 show that the total number of amputation surgeries peaked in spring months and dipped in winter.

Over 120 amputation surgeries were performed during every month within the ten-year observation period (Figure 6.5). The mean number of amputation surgeries per month was 178.5 (SD 18.0). The highest number of surgeries occurred in May 2015 (n=222) and the lowest number of surgeries (n=122) occurred in April 2020.

Lower surgery numbers occurred during April 2020, which was the beginning of Covid-19 restrictions, with numbers remaining low until spring 2021. The change in amputation numbers from 2019 to 2021 is shown in Figure 6.6 to illustrate the change in surgery numbers over the course of the pandemic.



	January	February	March	April	May	June	July	August	September	October	November	December
LLA	1420	1375	1591	1373	1579	1492	1465	1392	1404	1453	1394	1317
ULA	326	326	364	331	365	353	356	371	382	365	335	292

Figure 6.4 Total number of LLA and ULA amputation procedures per month

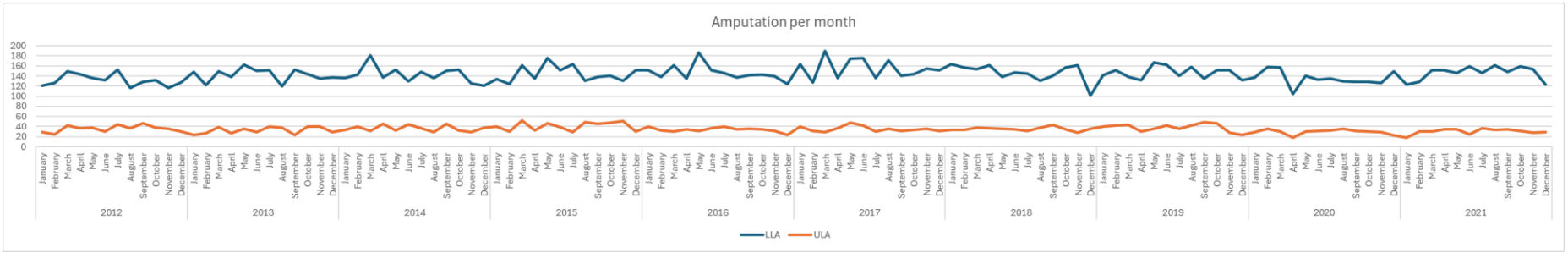


Figure 6.5 Number of LLA and ULA procedures per month throughout the study duration

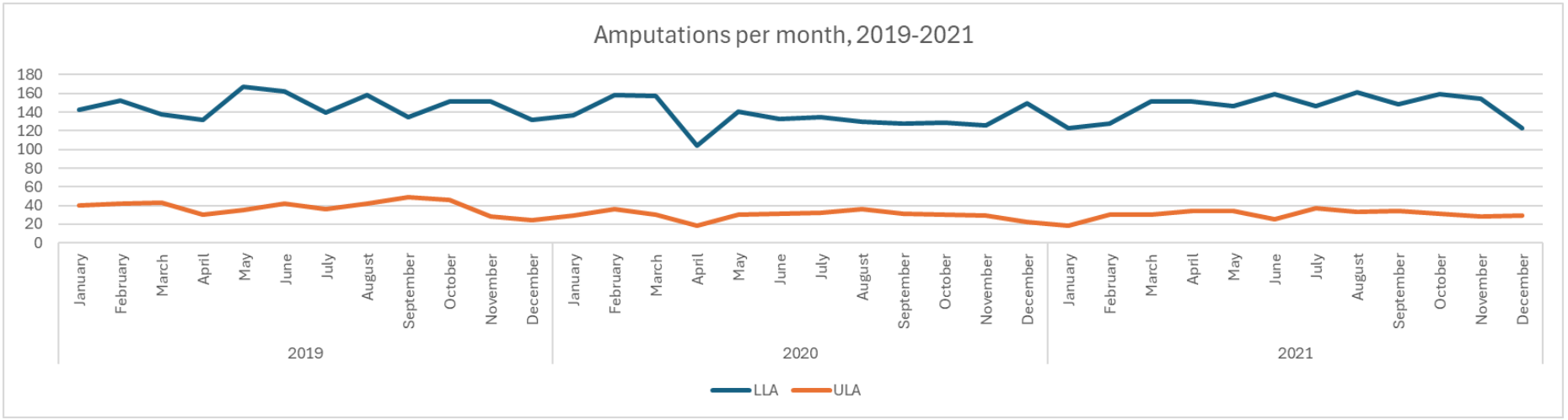


Figure 6.6 Number of amputations per month during the period 2019–2021

6.1.4 Type of amputation

Of the amputation procedures which were carried out, 61.4 percent were minor amputation procedures. However, this ratio differed according to the site of the amputation with 52.8 percent of LLA procedures classed as minor, compared with 96.9 percent of ULA procedures (Table 6.2).

The ratio of minor and major amputations was constant across the ten-year period in both the LLA and LLA groups (figures 6.7 and 6.8). The number of amputations of each type per year are also shown.

Table 6.2 Site and type of amputation procedures

	LLA		ULA		Total	
	n	%	n	%	n	%
Major	8141	47.2	129	3.1	8270	38.6
Minor	9114	52.8	4037	96.9	13151	61.4
Total	17255	100	4166	100	21421	100

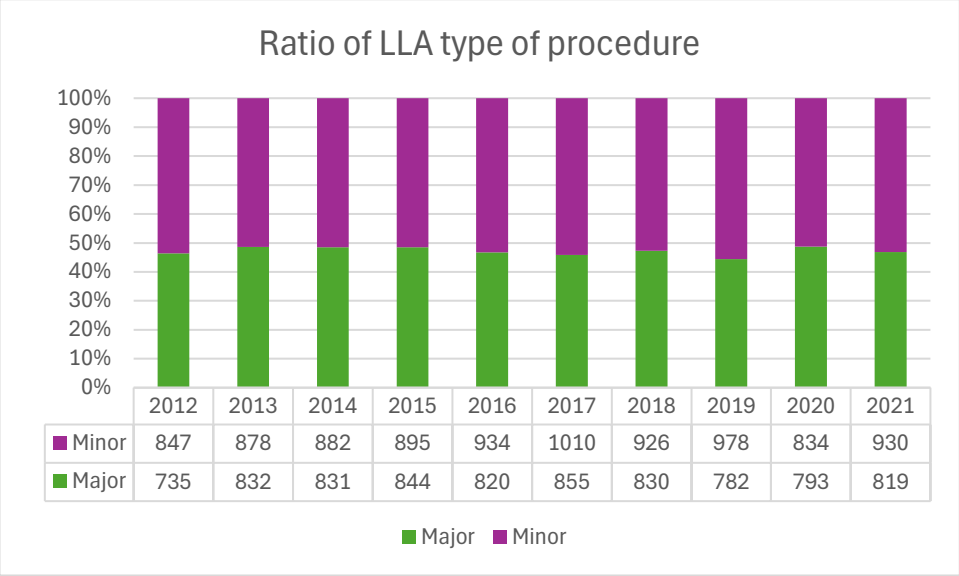


Figure 6.7 Ratio of LLA type of procedure

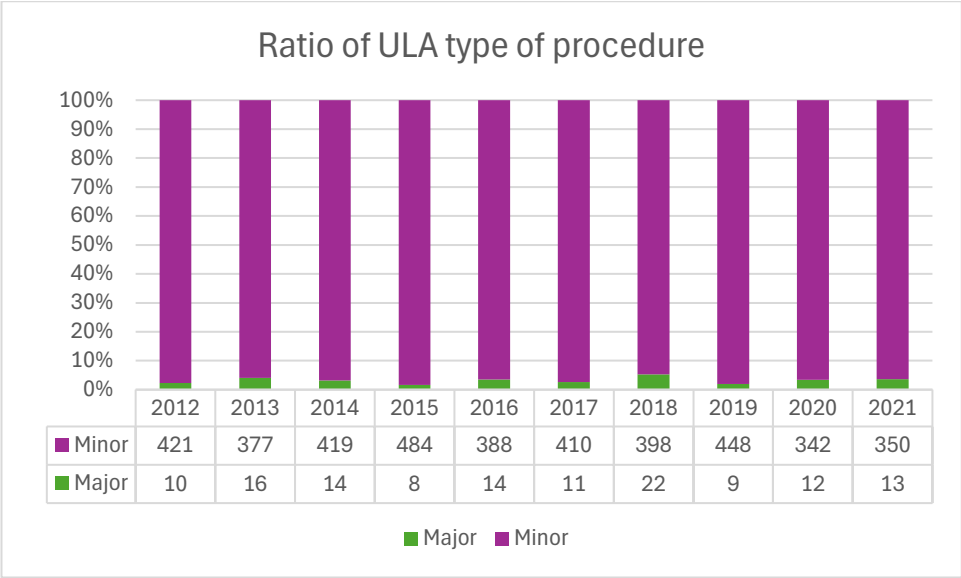


Figure 6.8 Ratio of ULA type of procedure

6.1.5 Level of amputation

6.1.5.1 Lower limb amputation

Due to low frequencies of tarsal amputation procedures, to minimise the risk of disclosure, tarsal and tarsometatarsal procedures were grouped together to form a 'midfoot' group.

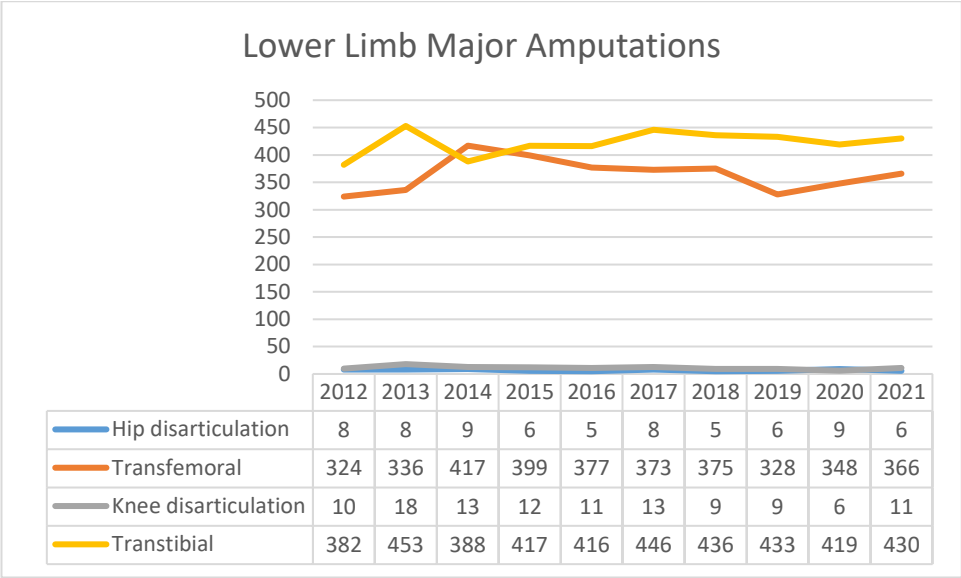
Table 6.3 shows the level of the 17,255 LLA procedures conducted during the ten-year observation period. The most common procedure was 'Other (toe)' (n=4,798), which accounted for 28 percent of the LLA procedures.

Table 6.3 Level of LLA procedures

Level of amputation			Number of procedures	% of LLA	% of Major LLA	% of Minor LLA
Major	Leg	Transpelvic	31	0.2	0.4	-
		Hip disarticulation	70	0.4	0.9	-
		Transfemoral	3643	21.1	44.7	-
		Knee disarticulation	112	0.6	1.4	-
		Transtibial	4220	24.5	51.8	-
		Ankle disarticulation	34	0.2	0.4	-
		Other (leg)	31	0.2	0.4	-
Minor	Foot	Midfoot	131	0.8	-	1.4
		Metatarsal	511	3.0	-	5.6
		Other (foot)	107	0.6	-	1.2
	Digit	Hallux	1890	11.0	-	20.7
		Phalanx (toe)	1677	9.7	-	18.4
		Other (toe)	4798	27.8	-	52.6

Major amputations

Of the 8,141 major lower limb amputations, 52 percent were classified as transtibial and 45 percent were transfemoral (Table 6.3). The distribution of levels remained constant across the ten-year observation period. To minimise risk of identification, frequency of amputation per year cannot be reported for transpelvic, ankle disarticulation, and other (leg). The distribution of hip disarticulation, transfemoral, knee disarticulation, and transtibial levels over the ten-year period are shown in Figure 6.9. In 2014, the number of transfemoral amputations exceeded the number of transtibial amputations before returning to a lower level. Since 2019, the number of transfemoral amputations has continued to rise.



	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Hip disarticulation	8	8	9	6	5	8	5	6	9	6
Transfemoral	324	336	417	399	377	373	375	328	348	366
Knee disarticulation	10	18	13	12	11	13	9	9	6	11
Transtibial	382	453	388	417	416	446	436	433	419	430

Figure 6.9 Number of hip disarticulation, transfemoral, knee disarticulation, and transtibial amputation procedures per year

Minor amputations

Of the 9,114 minor LLAs, 92 percent were amputations of the digits with the remaining 8 percent being foot amputations.

Foot amputations

Of the foot amputations, 68 percent were classified as an amputation through the metatarsal bones (metatarsal)(OPCS4 X104) (Figure 6.11). The total number of foot amputations remained constant across the ten-year period.

Digit amputations

Of the digit amputations, 57 percent were classified as ‘Other (toe)’ meaning that the procedure had been coded in SMR01 as OPCS4 X118 (other specified amputation of toe) or X109 (unspecified amputation of toe). The number of digit amputations peaked in 2017 (n=924) (Figure 6.10). The lowest number of digit amputation surgeries occurred in 2020 (n=738).

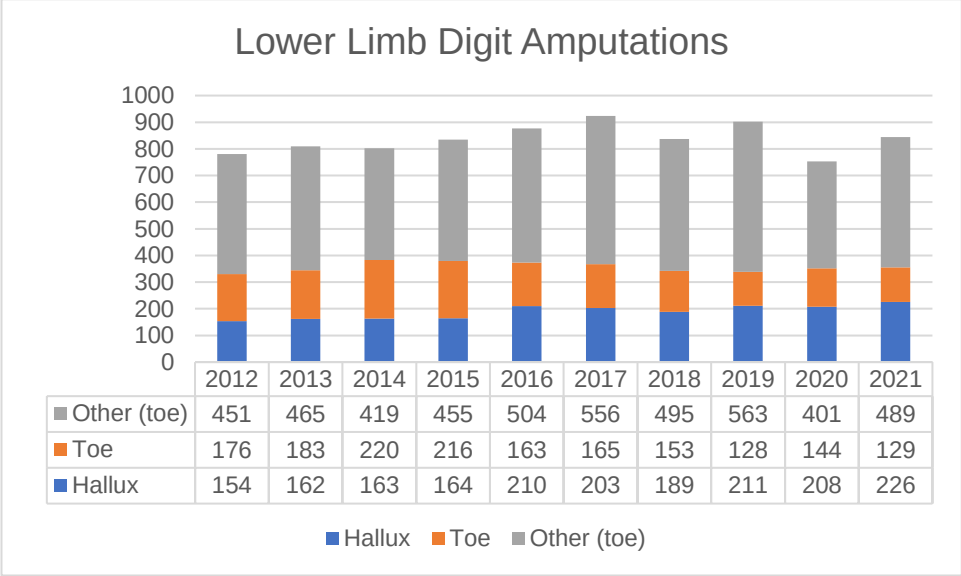


Figure 6.10 Lower limb digit amputations over ten-year period

6.1.5.2 Upper limb amputations

Table 6.4 shows the levels of the 4,166 ULA procedures conducted during the ten-year cohort. Amputations of the finger (X083, X084) accounted for 89 percent (n=3,702) of all ULAs, with amputations of the thumb accounting for an additional 7 percent (n=279).

Table 6.4 Level of ULA procedures

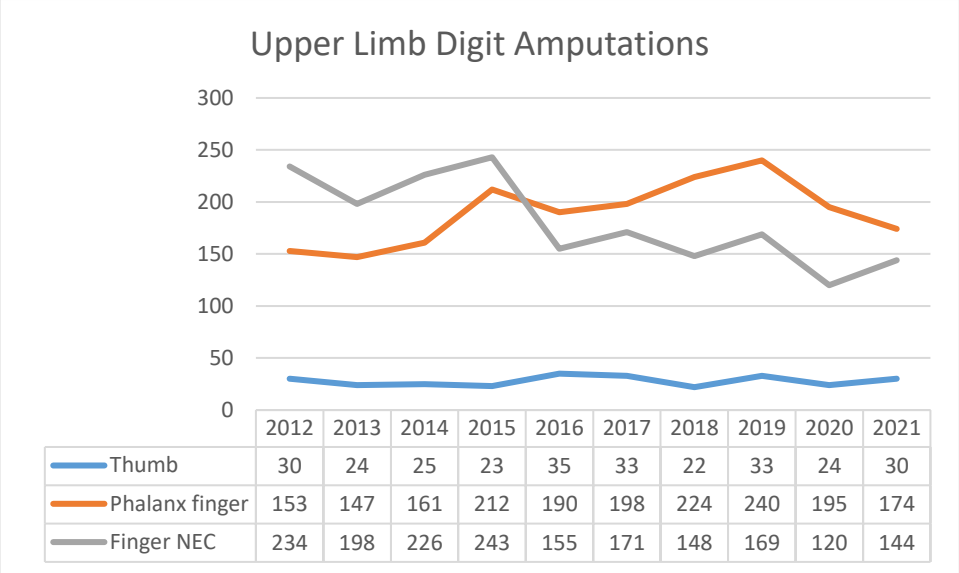
Level of amputation			Number of procedures	% of ULA	% of Major ULA	% of Minor ULA
Major	Arm	Scapulothoracic forequarter	10	0.2	7.8	-
		Shoulder disarticulation	9	0.2	7.0	-
		Transhumeral	49	1.2	38.0	-
		Elbow disarticulation	5	0.1	3.9	-
		Transradial	34	0.8	26.4	-
		Wrist disarticulation	11	0.3	8.5	-
		Other (arm)	11	0.3	8.5	-
Minor	Hand	Other (hand)	56	1.3	-	1.4
	Digit	Thumb	279	6.7	-	6.9
		Phalangeal (finger)	1894	45.5	-	46.9
		Other (finger)	1808	43.4	-	44.8

Major amputations

Of the 129 major ULAs, 38 percent of the were at transhumeral level, with a further 26 percent at transradial level (Table 6.4). Whilst the number of transradial amputations remained fairly constant across the ten-year period, the number of transhumeral amputations varied, peaking at ten. The exact number of amputations per year for levels of the arm cannot be presented due to low numbers increasing the risk of identification.

Minor amputations

Of the 4,037 minor ULAs, 91.7 percent were amputations of the fingers. A further 6.9 percent were amputations of a thumb (Table 6.4). There was some variance over the years between the codes used to identify finger amputation levels (Figure 6.11).



	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Thumb	30	24	25	23	35	33	22	33	24	30
Phalanx finger	153	147	161	212	190	198	224	240	195	174
Finger NEC	234	198	226	243	155	171	148	169	120	144

Figure 6.11 Number of finger amputations over ten-year period

6.1.6 Amputating hospitals

Amputation surgeries were conducted in 56 facilities over the ten-year period. The mean number of amputation surgeries conducted in each facility per year are shown in Table 6.5. The Queen Elizabeth University Hospital in Glasgow (n=2,767) and Ninewells Hospital in Dundee (n=2,485) performed the most procedures.

Table 6.5 Mean number of amputation surgeries conducted in each facility per year

Hospital	Mean	SD
University Hospital Crosshouse	31.7	5.66
University Hospital Ayr	122.7	19.64
Carrick Glen Hospital	0.2	0.63
Borders General Hospital	17.3	6.73
Lorn and Islands Hospital	1.1	1.37
Vale of Leven General Hospital	2	1.63
Inverclyde Royal Hospital	13.9	7.65
Royal Alexandra Hospital	20.8	8.23
Golden Jubilee National Hospital	9.4	8.30
Cameron Hospital	0.3	0.95
Victoria Hospital	62.4	20.62
Randolph Wemyss Memorial Hospital	0.1	0.32
Queen Margaret Hospital	10.3	4.14
Glasgow Royal Infirmary	124.7	27.31
Stobhill Hospital	2.3	1.16
New Victoria Hospital	13.4	11.53
Queen Elizabeth University Hospital	276.7	187.90
Ross Hall Hospital	0.4	0.70
Nuffield Health Glasgow Hospital	0.5	0.85
Royal Hospital for Children	8	5.16
West Glasgow	104.8	141.18
Caithness General Hospital	0.3	0.67
Lawson Memorial Hospital	0.2	0.63
Raigmore Hospital	132.8	16.85
Belford Hospital	0.9	1.45
Mackinnon Memorial Hospital	0.2	0.63
University Hospital Monklands	6.6	5.15
University Hospital Hairmyres	165.4	35.08
University Hospital Wishaw	17.3	8.39
Aberdeen Royal Infirmary	201.8	19.48
Albyn Hospital	0.2	0.63
Woodend General Hospital	26.2	6.84
Royal Aberdeen Children's Hospital	2.1	1.45
Glen O'Dee Hospital	0.1	0.32
Dr Gray's Hospital	7.1	2.77
Balfour Hospital	4.3	3.50
The Balfour	0.5	0.85
Western General Hospital	1.7	1.57
Murrayfield Hospital	1.1	1.60
Astley Ainslie Hospital	0.2	0.42
Royal Hospital for Sick Children (Edinburgh)	3.4	3.13
St John's Hospital	70.7	14.38

Royal Infirmary of Edinburgh at Little France	220.2	23.61
Royal Hospital for Children and Young People	0.1	0.32
The Edinburgh Clinic	0.3	0.48
Ninewells Hospital	248.5	26.26
Fernbrae Hospital	0.1	0.32
Perth Royal Infirmary	7.3	2.98
Stracathro Hospital	6.9	3.54
BMI King's Park Hospital	1.1	1.52
Forth Valley Royal Hospital	112.9	57.70
Western Isles Hospital	2.8	1.62
Dumfries and Galloway Royal Infirmary Old	43.9	39.03
Galloway Community Hospital	0.8	1.03
Dumfries and Galloway Royal Infirmary	26.3	33.55
Gilbert Bain Hospital	3.8	2.15

The number of surgeries conducted at facilities varied across the years. For example, at Queen Elizabeth University Hospital in Glasgow, amputations increased from 23 in 2014 to 519 in 2021, whilst the number of amputations at other facilities in Glasgow decreased (Table 6.6). Changing patterns in hospital use are also seen in Dumfries, where amputations moved from Dumfries and Galloway Royal Infirmary Old to the new Dumfries and Galloway Royal Infirmary in 2018 (Table 6.7).

Table 6.6 Number of surgeries at Glasgow amputating facilities by year

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Glasgow Royal Infirmary	99	111	121	135	128	129	144	186	102	92
Stobhill Hospital	*	*	*	*	*	5	*	*	*	*
New Victoria Hospital	25	15	33	28	6	12	7	6	0	*
Queen Elizabeth University Hospital	27	37	23	229	315	353	380	444	440	519
Ross Hall Hospital	0	*	*	*	0	0	0	0	0	0
Nuffield Health Glasgow Hospital	*	0	*	0	0	0	0	0	*	0
Royal Hospital for Children	13	8	11	5	0	9	16	*	12	*
West Glasgow	319	295	300	101	*	9	6	7	*	5

** Value suppressed to minimise risk of disclosure*

Table 6.7 Number of surgeries at Dumfries amputating facilities by year

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Dumfries & Galloway Royal Infirmary Old	52	70	88	86	69	74	0	0	0	0
Galloway Community Hospital	0	*	0	*	*	*	*	0	0	0
Dumfries & Galloway Royal Infirmary	0	0	0	0	0	6	78	68	47	64

** Value suppressed to minimise risk of disclosure*

6.1.6.1 Type of amputation at each location

The percentage of minor and major amputations conducted at each location can be viewed in Table 6.8. Surgeries involving major amputation were conducted at 39 out of 56 (70 percent) facilities. The number of major amputations per facility ranged from 1 to 1,381. The Queen Elizabeth University Hospital in Glasgow conducted the most major amputation surgeries (n=1,381, 16 percent), with the Royal Infirmary of Edinburgh at Little France conducting a similar number of procedures (n=1,363, 15.8 percent).

Surgeries involving minor amputation were conducted at 53 out of 56 (95 percent) facilities. The number of minor amputation surgeries per facility ranged from 1 to 1,514. The Queen Elizabeth University Hospital in Glasgow conducted the most minor amputation surgeries (n=1,514, 11 percent).

6.1.6.2 Site of amputation at each location

The percentage of upper limb and lower limb procedures at each location can be viewed in Table 6.8. Surgeries involving LLA were conducted at 54 out of 56 facilities. The number of LLA surgeries per facility ranged from 1 to 2,622.

Surgeries involving ULA were conducted at 48 out of 56 facilities. The number of ULA surgeries per facility ranged from 1 to 889. Glasgow Royal Infirmary conducted 21 percent of all ULA surgeries.

6.1.6.3 Surgeries by type and site

The number of each by type and site of amputation at each location is shown in Table 6.8. There was variability in the procedures that were carried out at each facility, with some performing only minor LLA (Caithness General Hospital, Lawson Memorial Hospital, Mackinnon Memorial Hospital, Fernbrae Hospital), major LLA (Randolph Wemyss Memorial Hospital, Glen O'Dee Hospital, Astley Ainslie Hospital), or minor ULA (Royal Hospital for Children and Young People, Edinburgh Clinic). The total number of amputations in each of these facilities was low. There were no facilities that only performed major ULA.

Table 6.8 Percentage type and site of surgery and each location

	Type of surgery				Site of surgery				Type and site of surgery							
									LLA		ULA					
	Major	Minor	% of amputations at facility		LLA	ULA	% of amputations at facility		Major	Minor	Major	Minor	% of amputations at facility			
FACILITY	% of all major amps	% of all minor amps	major	minor	% of all LLA	% of all ULA	LLA	ULA	%	%	%	%	Major LLA	Minor LLA	Major ULA	Minor ULA
University Hospital Crosshouse	0.34%	2.15%	9.09%	90.91%	0.88%	3.97%	47.65%	52.35%	0.33%	1.32%	0.74%	4.08%	8.78%	39.18%	0.31%	51.72%
University Hospital Ayr	6.60%	5.21%	44.78%	55.22%	6.44%	2.83%	90.35%	9.65%	6.66%	6.25%	2.96%	2.77%	44.47%	46.43%	0.31%	8.78%
Carrick Glen Hospital	0.00%	0.01%	0.00%	100.00%	0.01%	0.02%	50.00%	50.00%	0.00%	0.01%	0.00%	0.02%	0.00%	50.00%	0.00%	50.00%
Borders General Hospital	0.27%	1.11%	13.29%	86.71%	0.68%	1.31%	68.21%	31.79%	0.26%	1.01%	0.74%	1.34%	12.72%	55.49%	0.58%	31.21%
Lorn & Islands Hospital	0.00%	0.08%	0.00%	100.00%	0.06%	0.02%	90.91%	9.09%	0.00%	0.11%	0.00%	0.02%	0.00%	90.91%	0.00%	9.09%
Vale of Leven General Hospital	0.00%	0.15%	0.00%	100.00%	0.06%	0.21%	55.00%	45.00%	0.00%	0.12%	0.00%	0.22%	0.00%	55.00%	0.00%	45.00%
Inverclyde Royal Hospital	0.46%	0.75%	28.37%	71.63%	0.49%	1.31%	60.43%	39.57%	0.46%	0.50%	0.74%	1.34%	27.66%	33.33%	0.71%	38.30%
Royal Alexandra Hospital	0.62%	1.14%	25.96%	74.04%	0.67%	2.19%	55.77%	44.23%	0.58%	0.71%	3.70%	2.15%	23.56%	32.21%	2.40%	41.83%
Golden Jubilee National Hospital	0.29%	0.51%	26.60%	73.40%	0.46%	0.36%	84.04%	15.96%	0.23%	0.62%	3.70%	0.25%	21.28%	62.77%	5.32%	10.64%
Cameron Hospital	0.01%	0.01%	33.33%	66.67%	0.02%	0.05%	60.00%	40.00%	0.01%	0.01%	0.00%	0.02%	33.33%	33.33%	0.00%	33.33%
Victoria Hospital	2.23%	3.27%	30.39%	69.61%	2.71%	3.83%	74.44%	25.56%	2.19%	3.02%	5.19%	3.86%	29.29%	45.04%	1.10%	24.57%
Randolph Wemyss Memorial Hospital	0.01%	0.00%	100.00%	0.00%	0.01%	0.00%	100.00%	0.00%	0.01%	0.00%	0.00%	0.00%	100.00%	0.00%	0.00%	0.00%
Queen Margaret Hospital	0.02%	0.76%	1.90%	98.10%	0.29%	1.24%	49.51%	50.49%	0.02%	0.54%	0.00%	1.29%	1.90%	48.57%	0.00%	49.52%
Glasgow Royal Infirmary	2.47%	7.65%	17.16%	82.84%	2.11%	21.13%	29.11%	70.89%	2.16%	1.87%	22.22%	21.18%	14.76%	14.19%	2.41%	68.64%
Stobhill Hospital	0.00%	0.17%	0.00%	100.00%	0.10%	0.14%	73.91%	26.09%	0.00%	0.18%	0.00%	0.15%	0.00%	73.91%	0.00%	26.09%
New Victoria Hospital	0.16%	0.89%	10.45%	89.55%	0.61%	0.69%	78.36%	21.64%	0.13%	0.99%	2.22%	0.64%	8.21%	70.15%	2.24%	19.40%
Queen Elizabeth University Hospital	15.97%	11.21%	47.70%	52.30%	15.16%	3.64%	94.49%	5.51%	16.14%	14.49%	5.19%	3.51%	47.46%	47.39%	0.24%	4.91%
Ross Hall Hospital	0.00%	0.03%	0.00%	100.00%	0.02%	0.02%	75.00%	25.00%	0.00%	0.03%	0.00%	0.02%	0.00%	75.00%	0.00%	25.00%
Nuffield Health Glasgow Hospital	0.00%	0.04%	0.00%	100.00%	0.01%	0.10%	20.00%	80.00%	0.00%	0.01%	0.00%	0.10%	0.00%	20.00%	0.00%	80.00%
Royal Hospital for Children	0.34%	0.39%	35.37%	64.63%	0.25%	1.09%	48.31%	51.69%	0.26%	0.18%	5.19%	0.89%	26.83%	20.73%	8.54%	43.90%
West Glasgow	6.83%	3.82%	53.39%	46.61%	5.59%	2.02%	91.92%	8.08%	6.91%	4.61%	2.22%	1.98%	53.12%	39.39%	0.27%	7.23%
Caithness General Hospital	0.00%	0.02%	0.00%	100.00%	0.02%	0.00%	100.00%	0.00%	0.00%	0.03%	0.00%	0.00%	0.00%	100.00%	0.00%	0.00%
Lawson Memorial Hospital	0.00%	0.01%	0.00%	100.00%	0.01%	0.00%	100.00%	0.00%	0.00%	0.02%	0.00%	0.00%	0.00%	100.00%	0.00%	0.00%
Raigmore Hospital	4.96%	6.99%	31.25%	68.75%	6.37%	5.47%	82.73%	17.27%	4.99%	7.61%	2.96%	5.54%	30.95%	52.44%	0.29%	16.31%
Belford Hospital	0.03%	0.04%	33.33%	66.67%	0.05%	0.00%	100.00%	0.00%	0.04%	0.06%	0.00%	0.00%	33.33%	66.67%	0.00%	0.00%
Mackinnon Memorial Hospital	0.00%	0.01%	0.00%	100.00%	0.01%	0.00%	100.00%	0.00%	0.00%	0.02%	0.00%	0.00%	0.00%	100.00%	0.00%	0.00%
University Hospital Monklands	0.23%	0.34%	30.30%	69.70%	0.23%	0.64%	59.09%	40.91%	0.23%	0.20%	0.00%	0.67%	30.30%	28.79%	0.00%	40.91%
University Hospital Hairmyres	11.32%	5.43%	57.15%	42.85%	9.11%	1.85%	95.28%	4.72%	11.48%	6.95%	1.48%	1.88%	57.03%	38.41%	0.12%	4.44%
University Hospital Wishaw	0.28%	1.12%	13.71%	86.29%	0.36%	2.61%	36.42%	63.58%	0.25%	0.44%	2.22%	2.70%	12.00%	24.00%	1.71%	62.29%
Aberdeen Royal Infirmary	10.59%	8.65%	43.95%	56.05%	9.99%	7.20%	85.07%	14.93%	10.69%	9.21%	4.44%	7.32%	43.67%	41.84%	0.29%	14.20%
Albyn Hospital	0.00%	0.01%	0.00%	100.00%	0.01%	0.02%	50.00%	50.00%	0.00%	0.01%	0.00%	0.02%	0.00%	50.00%	0.00%	50.00%
Woodend General Hospital	0.65%	1.52%	21.37%	78.63%	0.99%	2.16%	65.27%	34.73%	0.59%	1.28%	4.44%	2.10%	19.08%	46.18%	2.29%	32.44%
Royal Aberdeen Children's Hospital	0.02%	0.14%	9.52%	90.48%	0.07%	0.26%	52.17%	47.83%	0.01%	0.11%	0.74%	0.22%	4.76%	47.62%	4.76%	42.86%
Glen O'Dee Hospital	0.01%	0.00%	100.00%	0.00%	0.01%	0.00%	100.00%	0.00%	0.01%	0.00%	0.00%	0.00%	100.00%	0.00%	0.00%	0.00%
Dr Gray's Hospital	0.01%	0.52%	1.41%	98.59%	0.16%	1.02%	39.44%	60.56%	0.01%	0.29%	0.00%	1.06%	1.41%	38.03%	0.00%	60.56%
Balfour Hospital	0.14%	0.23%	27.91%	72.09%	0.16%	0.36%	65.12%	34.88%	0.13%	0.18%	0.74%	0.35%	25.58%	39.53%	2.33%	32.56%
The Balfour	0.03%	0.01%	60.00%	40.00%	0.02%	0.02%	80.00%	20.00%	0.04%	0.01%	0.00%	0.02%	60.00%	20.00%	0.00%	20.00%
Western General Hospital	0.02%	0.11%	11.76%	88.24%	0.08%	0.10%	76.47%	23.53%	0.02%	0.12%	0.00%	0.10%	11.76%	64.71%	0.00%	23.53%
Murrayfield Hospital	0.00%	0.08%	0.00%	100.00%	0.06%	0.02%	90.91%	9.09%	0.00%	0.11%	0.00%	0.02%	0.00%	90.91%	0.00%	9.09%
Astley Ainslie Hospital	0.02%	0.00%	100.00%	0.00%	0.01%	0.00%	100.00%	0.00%	0.02%	0.00%	0.00%	0.00%	100.00%	0.00%	0.00%	0.00%
Royal Hospital for Sick Children (Edinburgh)	0.07%	0.22%	16.67%	83.33%	0.12%	0.45%	52.50%	47.50%	0.07%	0.16%	0.00%	0.37%	16.67%	41.67%	0.00%	41.67%
St John's Hospital	0.28%	5.09%	3.38%	96.62%	1.19%	12.02%	28.93%	71.07%	0.18%	2.01%	6.67%	12.30%	2.11%	26.72%	1.27%	69.90%
Royal Infirmary of Edinburgh at Little France	15.76%	7.24%	58.22%	41.78%	12.48%	1.16%	97.78%	2.22%	15.85%	9.99%	10.37%	0.79%	57.62%	40.41%	0.60%	1.37%
Royal Hospital for Children and Young People	0.00%	0.01%	0.00%	100.00%	0.00%	0.02%	0.00%	100.00%	0.00%	0.00%	0.00%	0.02%	0.00%	0.00%	0.00%	100.00%
The Edinburgh Clinic	0.00%	0.02%	0.00%	100.00%	0.00%	0.07%	0.00%	100.00%	0.00%	0.00%	0.00%	0.07%	0.00%	0.00%	0.00%	100.00%
Ninewells Hospital	12.96%	10.87%	43.30%	56.70%	12.13%	9.24%	84.36%	15.64%	13.05%	11.51%	7.41%	9.35%	42.91%	42.10%	0.39%	14.60%
Fernbrae Hospital	0.00%	0.01%	0.00%	100.00%	0.01%	0.00%	100.00%	0.00%	0.00%	0.01%	0.00%	0.00%	0.00%	100.00%	0.00%	0.00%
Perth Royal Infirmary	0.05%	0.51%	5.48%	94.52%	0.30%	0.50%	71.23%	28.77%	0.05%	0.51%	0.00%	0.52%	5.48%	65.75%	0.00%	28.77%
Stracathro Hospital	0.00%	0.51%	0.00%	100.00%	0.25%	0.59%	63.77%	36.23%	0.00%	0.46%	0.00%	0.62%	0.00%	63.77%	0.00%	36.23%
BMI King's Park Hospital	0.00%	0.08%	0.00%	100.00%	0.05%	0.07%	72.73%	27.27%	0.00%	0.08%	0.00%	0.07%	0.00%	72.73%	0.00%	27.27%
Forth Valley Royal Hospital	3.38%	6.64%	24.56%	75.44%	5.77%	3.37%	87.54%	12.46%	3.40%	8.07%	2.22%	3.29%	24.31%	64.26%	0.25%	11.19%
Western Isles Hospital	0.01%	0.20%	3.57%	96.43%	0.13%	0.12%	82.14%	17.86%	0.01%	0.23%	0.00%	0.12%	3.57%	78.57%	0.00%	17.86%
Dumfries & Galloway Royal Infirmary Old	1.56%	2.29%	30.34%	69.66%	1.91%	2.59%	75.17%	24.83%	1.59%	2.12%	0.00%	2.70%	30.34%	45.17%	0.00%	24.49%
Galloway Community Hospital	0.00%	0.06%	0.00%	100.00%	0.01%	0.14%	25.00%	75.00%	0.00%	0.02%	0.00%	0.15%	0.00%	25.00%	0.00%	75.00%
Dumfries & Galloway Royal Infirmary	0.87%	1.42%	28.09%	71.91%	1.13%	1.62%	74.14%	25.86%	0.87%	1.32%	0.74%	1.66%	27.72%	46.82%	0.37%	25.09%
Gilbert Bain Hospital	0.09%	0.22%	21.05%	78.95%	0.19%	0.12%	86.84%	13.16%	0.08%	0.27%	0.74%	0.10%	18.42%	68.42%	2.63%	10.53%

6.1.7 Medical specialty

Over the ten-year period, amputations were conducted on patients under the care of 35 different specialties. The percentage of procedures conducted on patients under each specialty is shown in Table 6.9.

Of all amputations, 56 percent were conducted on patients under the vascular surgery specialty. The next largest group (22 percent) was trauma and orthopaedic surgery. Plastic surgery accounted for 10 percent of amputation procedures (Table 6.9).

Table 6.9 Percentage of procedures conducted under medical specialties

Specialty	Total procedures %	LLA %	ULA %
General medicine	2.57	3.11	0.40
Acute medicine	0.14	0.16	0.02
Cardiology	0.09	0.10	0.07
Infectious diseases	0.22	0.28	0.12
Dermatology	0.01	0.01	0.00
Endocrinology & diabetes	0.05	0.06	NA
Endocrine	0.05	0.06	NA
Diabetes	0.19	0.24	NA
Gastroenterology	0.03	0.04	NA
Geriatric medicine	0.34	0.42	0.07
Medical oncology	0.00	NA	0.02
Paediatrics	0.07	0.05	0.29
Renal medicine	1.20	1.34	0.64
Neurology	0.00	0.00	0.02
Rehabilitation medicine	0.04	0.04	0.02
Respiratory medicine	0.06	0.07	0.02
Rheumatology	0.01	0.01	0.05
General surgery	3.79	4.43	1.14
General surgery (excluding vascular)	1.09	1.27	0.36
Vascular surgery	56.23	69.01	3.26
Major trauma	0.01	0.01	0.02
Accident & emergency	0.00	NA	0.02
Anaesthetics	0.78	0.83	0.71
Cardiac surgery	0.07	0.07	0.05
Thoracic surgery	0.00	0.01	NA
Ear, nose & throat	0.01	0.01	NA
Neurosurgery	0.01	0.01	0.02
Ophthalmology	0.00	NA	0.02
Trauma & orthopaedic surgery	22.27	16.65	44.99
Plastic surgery	10.44	1.50	47.36
Paediatric surgery	0.01	0.01	0.02
Urology	0.02	0.02	0.02
Intensive care medicine	0.14	0.17	0.19
GP other than obstetrics	0.01	0.02	NA
Haematology	0.02	0.01	0.05

6.1.7.1 Medical specialty by site of amputation

The medical specialty varied depending on the site of the amputation. Of LLA surgeries, 69 percent were under the care of vascular surgery, compared to only 3 percent ULA.

Of ULAs, 48 percent were carried out under plastic surgery, compared with 1 percent LLA. The second largest group in ULA was trauma and orthopaedic surgery, which accounted for 46 percent ULA, compared with 17 percent LLA (Table 6.9).

6.2 Persons undergoing amputation procedures

During the ten-year period, 15,974 individuals underwent an amputation procedure. Demographic profiles were analysed only for patients who had their first amputation during the period 2012–2021 (n=15,291). The data in this section relates to the patient's status at the time of their first amputation.

To reduce the risk of disclosure, where the effect of sex is considered, the analysis includes only people who have been identified as male or female.

6.2.1 Sex

During the observation period, 4,818 (31 percent) females and 10,472 (69 percent) males underwent amputation. The ratio of male to female patients was higher when the first amputation was an upper limb procedure (Figure 6.12). There was a slight increase in the of ratio of males to females undergoing LLA across the ten-year period (Figure 6.13), whilst the ratio of males to females remained constant for ULA (Figure 6.14).

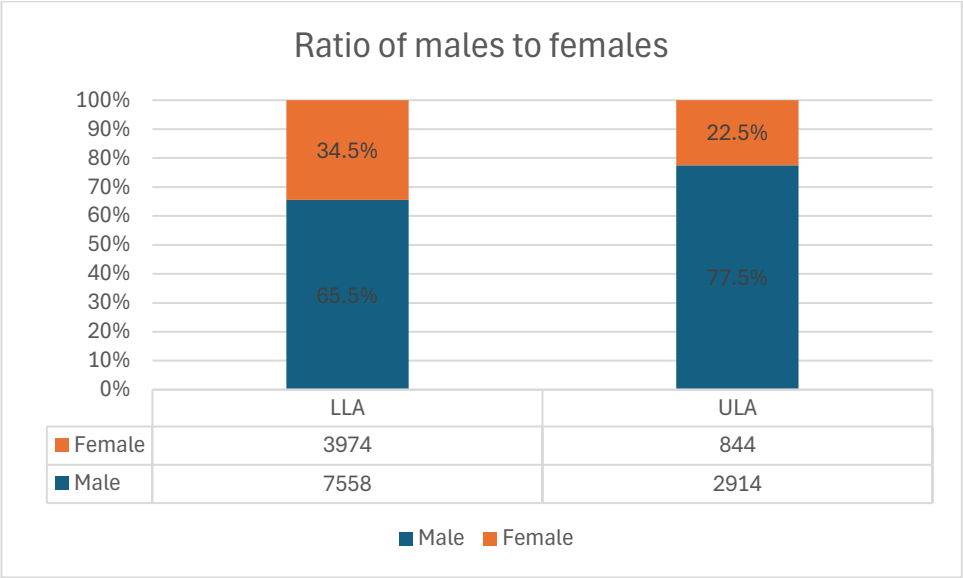


Figure 6.12 Sex of patients

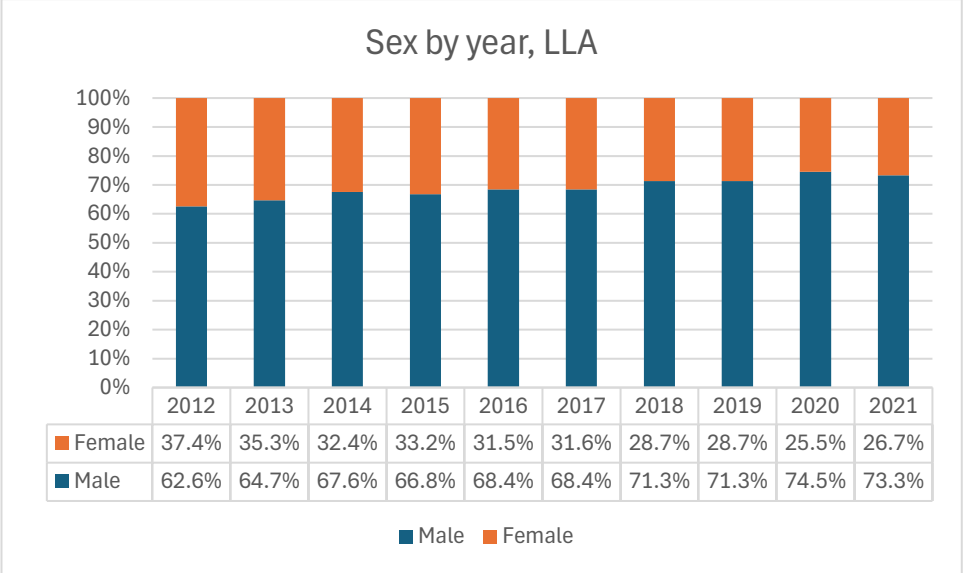


Figure 6.13 Sex by year, LLA

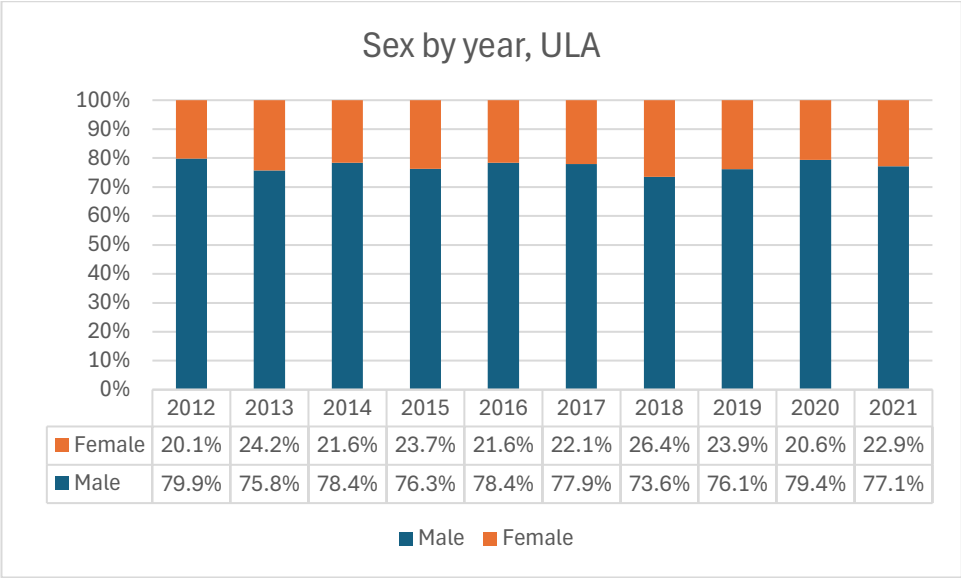


Figure 6.14 Sex by year, ULA

6.2.2 Ethnicity of patient

Ethnicity was missing in 661 (4 percent) cases and recorded as unknown (refused or not known) in a further 2,337 (14 percent) cases.

Of persons undergoing amputation, 78 percent reported that their ethnicity was 'Group A: White' (Table 6.10).

Table 6.10 Percentage of cohort by ethnic group

Ethnic group		% of cohort
Group A	White	78.16
Group B	Mixed or multiple ethnic groups	0.11
Group C	Asian, Scottish Asian, or British Asian	0.63
Group D	African, Scottish African, or British African	0.08
Group E	Caribbean or Black	0.02
Group F	Other ethnic group	2.95
Unknown		14.07
N/A		3.98

6.2.3 Scottish Index of Multiple Deprivation

A higher percentage of people living in lower SIMD areas underwent LLA, compared with those living in higher SIMD areas. For those undergoing ULA, the percentage of people decreased from SIMD group 8 onwards (Figure 6.15, Table 6.11).

A higher percentage of people living in lower SIMD areas underwent major amputation procedures, compared with those living in higher SIMD areas. The effect was less but still present for those undergoing minor procedures (Figure 6.16, Table 6.11).

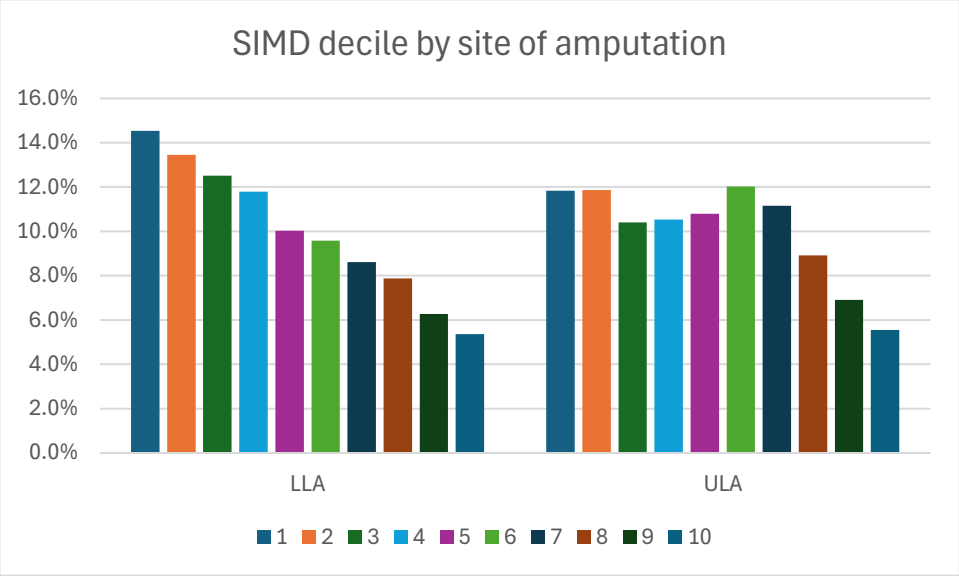


Figure 6.15 SIMD decile by site of amputation

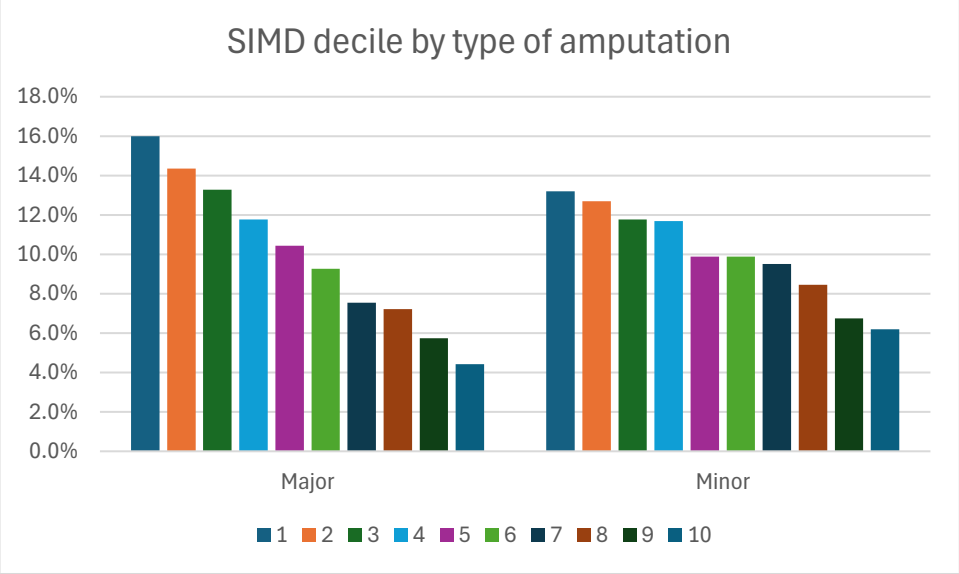


Figure 6.16 SIMD decile by type of amputation

Table 6.11 Percentage of people living in each SIMD datazone

SIMD decile	All %	LLA %	ULA %	Major %	Minor %
1	13.9	14.5	11.8	16.0	13.2
2	13.1	13.4	11.9	14.3	12.7
3	12.0	12.5	10.4	13.3	11.8
4	11.5	11.8	10.5	11.8	11.7
5	10.2	10.0	10.8	10.4	9.9
6	10.2	9.6	12.0	9.3	9.9
7	9.2	8.6	11.2	7.5	9.5
8	8.1	7.9	8.9	7.2	8.5
9	6.4	6.3	6.9	5.7	6.7
10	5.4	5.4	5.6	4.4	6.2

6.2.4 Age at first amputation

The mean age of people at the time of their first amputation was higher for people undergoing an LLA procedure (66.2, SD 14.7) than those undergoing a ULA procedure (51.9, SD 19.4). The mean age was higher for females than males (Table 6.12).

Males undergoing minor amputations had a lower mean age than those undergoing major amputations; however, this was not the case for females, where the mean age was similar (Table 6.12).

Table 6.12 Mean age at first amputation

		All		Male		Female	
Site and type		Mean age	SD	Mean age	SD	Mean age	SD
Lower	All	66.2	14.7	65.5	14.3	67.5	15.3
	Major	66.2	14.8	65.9	14.5	67	15.4
	Minor	66.1	14.6	65.2	14.1	67.9	15.3
Upper	All	51.9	19.4	50.6	18.5	56.5	21.5
	Major	54.2	22.2	52.6	21.9	56.8	22.7
	Minor	51.8	19.3	50.5	18.4	56.5	21.5

6.2.4.1 Age at amputation by level

Mean age at the time of first amputation, by level of amputation, can be viewed in Table 6.13.

Of the people who underwent a lower limb procedure, the mean age was similar across many of the levels; however, the mean age was lower for those undergoing hip disarticulation and ankle disarticulation procedures, and males undergoing a transpelvic amputation (Table 6.13).

Of the people who underwent an upper limb procedure, the mean age was highest in females undergoing shoulder disarticulation and other (arm) procedures. Age at amputation was higher in people undergoing transhumeral amputation than transradial (Table 6.13).

Table 6.13 Mean age at the time of first amputation, by level of amputation

Site, type, and level				Male		Female	
				Mean age	SD	Mean age	SD
LLA	Major	Leg	Transpelvic	48.1	14.8	63.5	13.6
			Hip disarticulation	55.8	16.9	60.3	20.8
			Transfemoral	68.1	13.3	69.7	14.2
			Knee disarticulation	59.2	19.8	63.7	20.5
			Transtibial	64.7	14.6	64.3	15.7
			Ankle disarticulation	52.8	24.6	34.7	27.6
			Other (leg)	53.2	19	67.2	16.6
	Minor	Foot	Midfoot	64.9	16.3	76.1	8.77
			Metatarsal	65	11.9	64.5	17.3
			Other (foot)	63.7	14.3	68.4	10.9
		Digit	Hallux	66	13.1	67.4	15.5
			Phalangeal (toe)	65	15.2	67.8	14.7
			Other (toe)	64.8	14.4	68.2	15.4
ULA	Major	Arm	Scapulothoracic forequarter	66.3	12.7	47.2	27.6
			Shoulder disarticulation	38.4	*	72	12.7
			Transhumeral	58.5	21.6	64.2	16.6
			Elbow disarticulation	42.8	28.6	36.3	*
			Transradial	47.9	19.9	51.3	22.3
			Wrist disarticulation	44.3	19.3	35.1	33.5
			Other (arm)	45.4	24.4	71.5	*
	Minor	Hand	Other(hand)	45	22.5	59.8	16.4
		Digit	Thumb	55.5	18.2	59.8	25.7
			Phalangeal (finger)	50.2	17.2	56.2	20.7
			Other (finger)	50.2	18.9	56.3	21.6

* Value suppressed to minimise risk of disclosure

6.2.4.2 Age at amputation by ethnicity

The mean ages at first amputation for each ethnic group can be viewed in Table 6.14. People identifying as White and those whose ethnicity was unknown had the highest mean age at first amputation. Males identifying as mixed or multiple ethnic groups had the lowest mean age (42.4, SD 23.8) (Table 6.14).

The mean age at first amputation was more variable across ethnic groups in males than females (Table 6.14).

Table 6.14 Mean age at first amputation by ethnic group

Ethnic group		All		Male		Female	
		Mean age	SD	Mean age	SD	Mean age	SD
Group A	White	63.24	16.7	61.9	16.6	66	16.7
Group B	Mixed or multiple ethnic groups	41.02	18.44	36.5	20	48.8	13.1
Group C	Asian, Scottish Asian, or British Asian	55.94	17.31	55	16.6	58.6	19.1
Group D	African, Scottish African, or British African	42.9	22.89	42.4	23.8	49.4	*
Group E	Caribbean or Black	55.73	6.39	57.7	6.23	49.9	*
Group F	Other ethnic group	50.14	21.32	46.4	20.2	63.1	21.9
Unknown		62.45	17.4	61.4	16.9	64.9	18.2

** Value suppressed to minimise risk of disclosure*

6.2.4.3 Age at amputation by SIMD

Mean age at amputation according to the SIMD decile which the person lived in can be viewed in Table 6.15. The mean age at amputation was higher for people living in higher SIMD data zones. This was true across all categories of LLA (Table 6.15, Figures 6.17, 6.18). This was also the case for ULAs, but the trend was not as strong (Table 6.15, Figures 6.19, 6.20).

Table 6.15 Age at amputation by SIMD decile

Site	Type	Sex	Mean age	SIMD decile 1	2	3	4	5	6	7	8	9	10
LLA	Major	Male	Mean age	62.3	63.6	65	65.8	67.5	66.1	69.2	68.8	68	72.7
			SD	14.1	14.2	14.2	14.2	13.8	15.1	14.7	15.2	13.8	12.3
		Female	Mean age	60.3	65.9	67.4	66.8	66.9	70.2	71	70.1	70.6	71.2
			SD	15.6	14.2	13.8	16.3	16.1	15.1	15	13.8	15.5	14.7
	Minor	Male	Mean age	61.3	62.6	64.4	65.5	65.9	65.5	68.2	66.5	67.2	70.5
			SD	14.1	14.4	14.1	12.8	13.9	14.2	12.3	15.2	14	13
		Female	Mean age	62.5	66.3	66.2	67.8	68.1	68.6	68.7	71.1	72.5	72
			SD	15.2	14.7	15.8	15	15.3	15.3	14.7	14.5	13.8	15.6
ULA	Major	Male	Mean age	55.8	46.5	54.2	41	48.3	48.1	71.7	43.5	61	64.4
			SD	21.8	22.8	25.1	22	22.2	25.4	12.3	12	32	20.3
		Female	Mean age	60.1	52.2	42.1	37.6	71.5	71	66	47.9	65.1	70.2
			SD	43.7	12	27.1	38.8	12.4	19.9	18	26.7	10.8	18.7
	Minor	Male	Mean age	61.3	62.6	64.4	65.5	65.9	65.5	68.2	66.5	67.2	70.5
			SD	14.1	14.4	14.1	12.8	13.9	14.2	12.3	15.2	14	13
		Female	Mean age	54.4	54.3	54.9	56.9	57.9	54.8	59.4	58.8	57.8	58.4
			SD	15.2	14.7	15.8	15	15.3	15.3	14.7	14.5	13.8	15.6

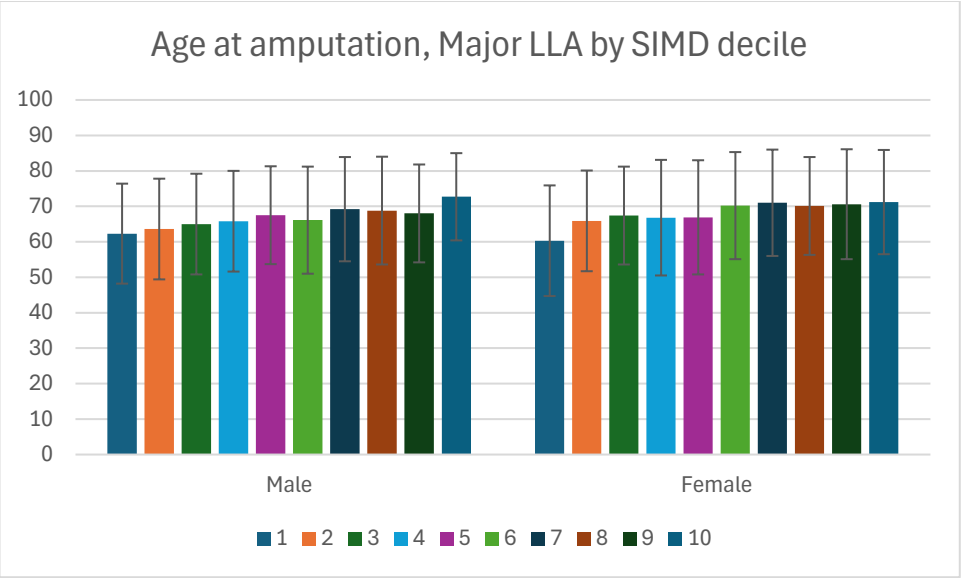


Figure 6.17 Mean age at amputation, major LLA, by SIMD decile and sex

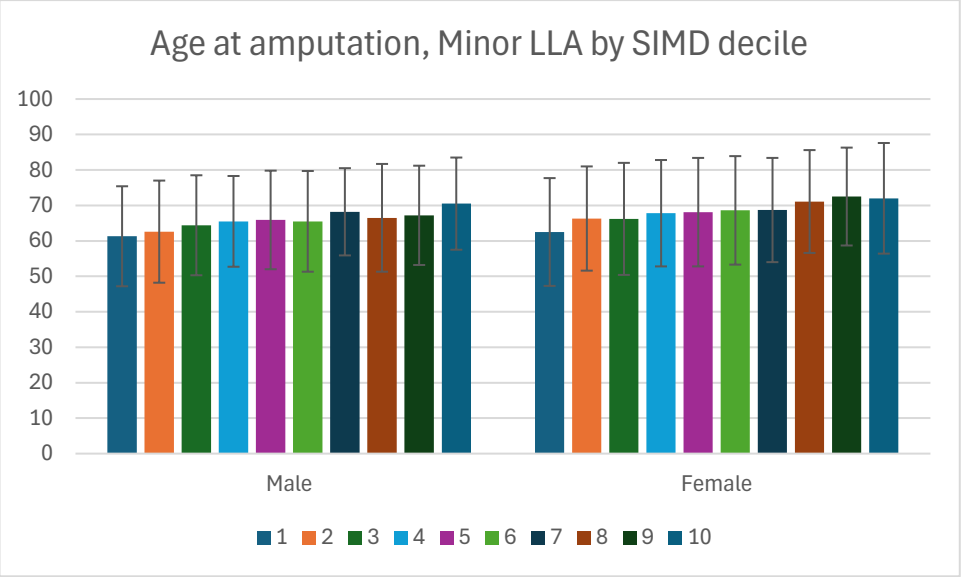


Figure 6.18 Mean age at amputation, minor LLA, by SIMD decile and sex

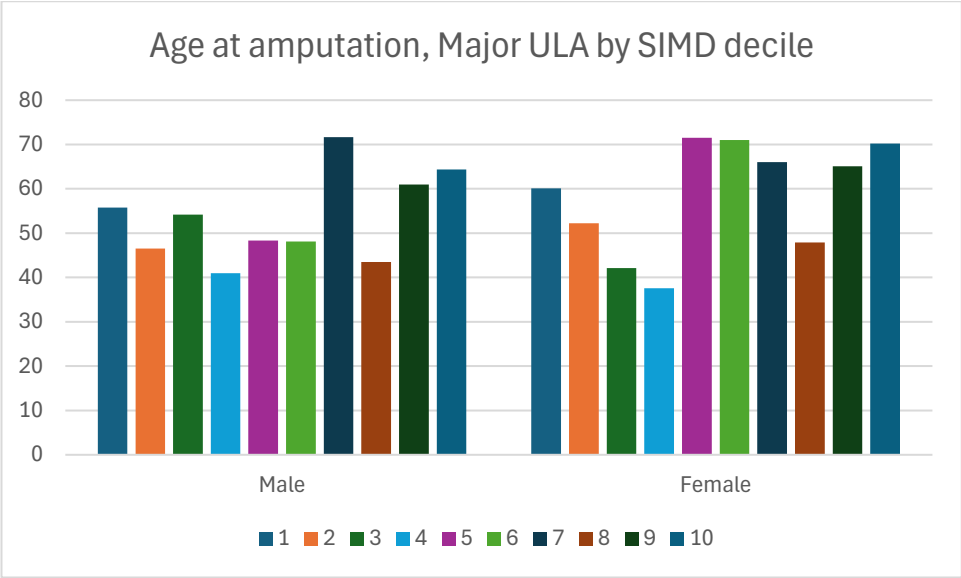


Figure 6.19 Mean age at amputation, major ULA, by SIMD decile and sex

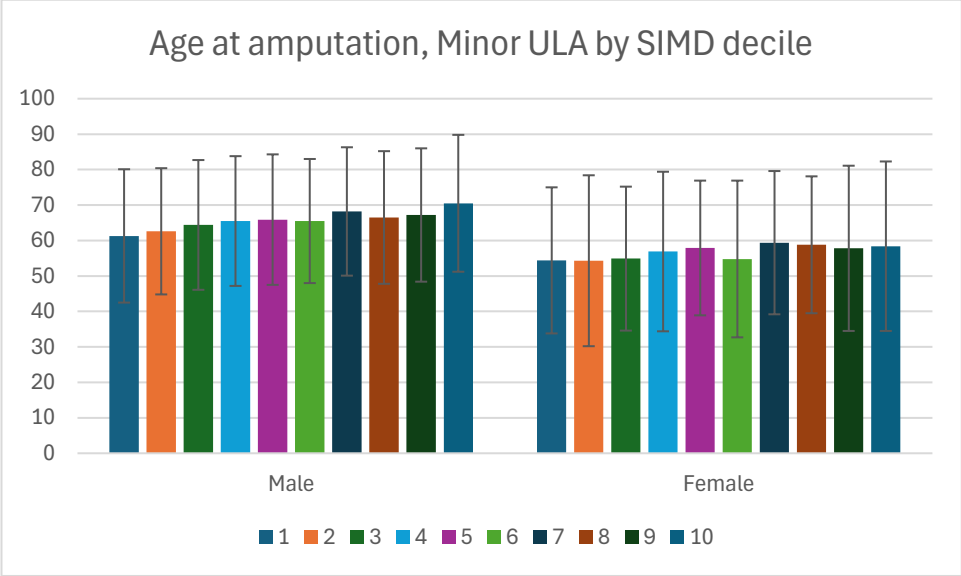


Figure 6.20 Mean age at amputation, minor ULA, by SIMD decile and sex

6.2.5 Comorbidities

Diabetes was recorded as a comorbidity for 41.5 percent of people undergoing an LLA procedure, compared with only 4.8 percent of those undergoing ULA (92.5 percent) (Figure 6.21). In the CCI datafile, which reports the presence of comorbidities

during the five-year timeframe prior to the amputation procedure, PVD was identified in 26.2 percent of people undergoing amputation.

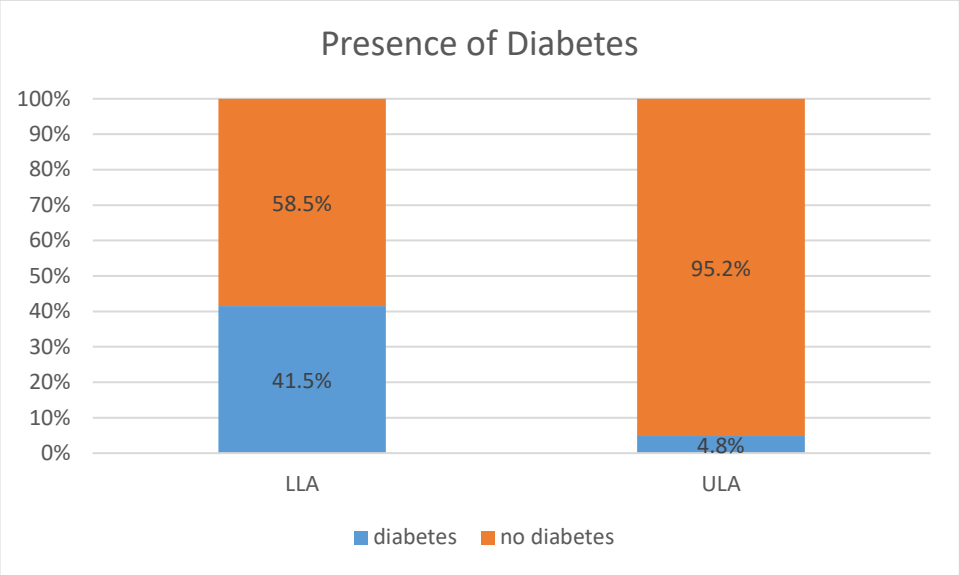


Figure 6.21 Presence of diabetes

6.2.5.1 Charlson Comorbidity Index

A CCI score was provided for 11,007 people who had undergone their first amputation during the ten-year period. Of these, 53 percent had a score of zero and 90 percent had a score of 2 or less.

Of the people who had a CCI score recorded for their first amputation, 83 percent had undergone LLA. Lower scores were found in people undergoing an upper amputation compared with those undergoing a lower amputation, with 89 percent and 96 percent respectively scoring 2 or less. Lower scores were also found in people undergoing a minor amputation than in those undergoing a major amputation. This was the case in both ULA and LLA.

6.3 Patient outcomes following amputation

6.3.1 Outpatient appointments following amputation

The numbers of outpatient physiotherapy, occupational therapy, podiatry, prosthetics, and clinical psychology appointments were analysed. The number of patients with outpatient appointments appears low (Table 6.16) suggesting that this may be an incomplete dataset.

Table 6.16 Number of outpatient appointments following amputation

Type of appointment	Total number of appointments	Number of patients having appointments	Mean number per patient	SD	Range	Mode
Physiotherapy	713	214	3.33	4.71	1, 48	1
Occupational therapy	130	29	4.48	3.71	1, 18	2,3
Podiatry	13201	519	25.44	40.00	1, 230	1
Prosthetics	535	101	5.30	3.95	1, 20	1
Clinical psychology	215	37	5.81	6.70	1, 29	1

6.3.2 Subsequent amputations

Of the 15,291 people who had their first amputation during the period 1st January 2012 to 31st December 2021, 3,525 (23.0 percent) underwent more than one amputation surgery before the end of the observation period on 31st August 2022. A total of 5,376 subsequent amputation surgeries were conducted. Most of the patients, 76 percent, who had multiple amputation surgeries had a total of two procedures. The highest number of amputation surgeries conducted on one patient was 11.

Of the patients whose first amputation was an LLA, 57.2 percent of subsequent amputation surgeries were performed on the same limb. Of the patients whose first amputation was upper limb, 48.2 percent of subsequent amputation surgeries were performed on the same limb.

6.3.3 Survival following amputation

Kaplan–Meier curves for different risk-factor groups, where a horizontal line (not marked on figures) from probability 0.5 indicates the median survival times are shown in Appendix B. Survival probability derived at 30 days, one year, two years, five years, and ten years after amputation, and median survival time, are shown in Table 6.17. Significant differences were found based on sex, site of amputation, type of amputation, level of amputation (excluding ULA major), and ULA SIMD decile. Non-significant differences in survival probability were found between ULA major amputation levels, and between LLA SIMD decile data zones (Table 6.17). Survival analysis revealed that male patients and those undergoing minor amputation

procedures have a longer post-operative survival time than female patients and those who undergo a major amputation procedure.

Median survival time after amputation varied between 574 days and 3,620 days depending on the level of amputation procedure (Table 6.17). Note that median survival times could not be calculated for some levels of amputation due to high numbers of censored events.

It was noticed in Section 6.2.4 that the mean age at amputation differs between groups. To determine the combined effect of sex and type of amputation on a person's chance of survival after amputation, a multivariable Cox proportional hazards regression model was applied. Table 6.18 demonstrates the results based on Cox proportional hazards models adjusted by mean age at amputation. The hazard ratio (HR) being below 1 indicates that female patients have a lower risk of event occurrence in all groups except LLA major and ULA minor once age at amputation is accounted for.

Table 6.17 Survival probability

			Number	*Number of events*	*Survival Probability*					*Median survival time, days*	*Log-rank test (* signifies significant, p<0.05)*
					30 days	1 year	2 years	5 years	10 years		
All patients			15291	-	0.97	0.85	0.77	0.59	0.41	2552	-
Sex		Female	4818	2214	0.96	0.84	0.75	0.56	0.38	2321	Chisq= 20.7 p= 0.0000058*
		Male	10472	4274	0.97	0.86	0.78	0.60	0.42	2689	
Site of first amputation		LLA	11532	5900	0.96	0.82	0.72	0.50	0.29	1833	Chisq= 1406 p= <2e-16*
		ULA	3728	579	0.99	0.96	0.93	0.86	0.76	NA	
Type of first amputation	LLA	Major	5292	3191	0.93	0.75	0.64	0.40	0.21	1271	Chisq= 509 p= <2e-16*
		Minor	6010	2571	0.98	0.88	0.80	0.59	0.37	2461	
		Both	230	138	0.95	0.81	0.70	0.43	0.16	1572	
	ULA	Major	102	44	0.93	0.78	0.69	0.52	0.50	2057	Chisq= 94.8 p= <2e-16*
		Minor	3623	535	1.00	0.96	0.93	0.87	0.77	NA	
Level of first amputation	LLA major	Hemipelvectomy	26	15	0.88	0.73	0.56	0.35	NA	1374	Chisq= 141 p= <2e-16*
		Hip disarticulation	51	32	0.90	0.71	0.61	0.42	NA	1230	
		Transfemoral	2496	1665	0.90	0.68	0.57	0.33	NA	967	
		Knee disarticulation	73	46	0.92	0.73	0.61	0.37	NA	1185	
		Transtibial	2603	1413	0.96	0.81	0.70	0.46	NA	1597	
		Ankle disarticulation	25	9	1.00	0.92	0.92	0.70	NA	3620	
		Other	18	11	0.94	0.78	0.67	0.46	NA	1138	
	LLA minor	Midfoot	36	15	0.94	0.86	0.81	0.73	0.42	2607	Chisq= 65.5 p= 9e-13*
		Metatarsal	282	125	0.98	0.86	0.76	0.55	0.26	2042	
		Other (foot)	53	24	0.92	0.77	0.73	0.57	0.33	2290	
		Hallux	1395	660	0.97	0.85	0.75	0.51	0.31	1896	
		Phalanx	1157	460	0.99	0.91	0.84	0.67	0.41	3069	
		Other (toe)	3087	1287	0.98	0.89	0.81	0.60	0.39	2537	
	ULA major	Scapulothoracic forequarter	10	4	1.00	1.00	0.90	0.51	NA	NA	Chisq= 4.3

Table 6.18 Cox proportional hazards regression model

			Wald Statistic		*Regression coef (β)*	*Hazard Ratio*		*Global statistical significance*
			z	*significance*		exp (coef)	95% CI	
All		Male			Ref.			Likelihood ratio test= 20.76 on 1 df, p=5e-06
	Unadjusted	Female	4.586	0.00000451	0.1202	1.128	1.071, 1.187	Wald test = 21.03 on 1 df, p=5e-06
								Score (logrank) test = 21.06 on 1 df, p=4e-06
	Adjusted for age	Male			Ref.			Likelihood ratio test= 3436 on 2 df, p=<2e-16
		Female	-5.681		-0.1514173	0.8595	0.8157, 0.9056	Wald test = 2780 on 2 df, p=<2e-16
								Score (logrank) test = 2831 on 2 df, p=<2e-16
LLA		Male	Ref.					Likelihood ratio test= 7.79 on 1 df, p=0.005
	Unadjusted	Female	-0.2781	0.00542	-0.07633	0.9265	0.878, 0.9777	Wald test = 7.73 on 1 df, p=0.005
								Score (logrank) test = 7.74 on 1 df, p=0.005
	Adjusted for age	Male	Ref.					Likelihood ratio test= 1777 on 2 df, p=<2e-16
		Female	-7.933	2.13E-15	-0.22032	0.80227	0.7598, 0.8471	Wald test = 1532 on 2 df, p=<2e-16
								Score (logrank) test = 1516 on 2 df, p=<2e-16
LLA major	Unadjusted	Male	Ref.					Likelihood ratio test= 10.55 on 1 df, p=0.001
		Female	3.269	0.00108	0.12118	1.12882	1.05, 1.214	Wald test = 10.69 on 1 df, p=0.001
								Score (logrank) test = 10.7 on 1 df, p=0.001
	Adjusted for age	Male	Ref.					Likelihood ratio test= 842.7 on 2 df, p=<2e-16
		Female	1.26	0.208	0.046911	1.048029	0.9743, 1.127	Wald test = 740.3 on 2 df, p=<2e-16
								Score (logrank) test = 746 on 2 df, p=<2e-16
LLA minor	Unadjusted	Male	Ref.					Likelihood ratio test= 33.76 on 1 df, p=6e-09
		Female	-5.742	9.34E-09	-0.23998	0.78664	0.7248, 0.8538	Wald test = 32.97 on 1 df, p=9e-09
								Score (logrank) test = 33.13 on 1 df, p=9e-09
	Adjusted for age	Male	Ref.					Likelihood ratio test= 1018 on 2 df, p=<2e-16
		Female	29	<2e-16	-0.458595	0.632171	0.5816, 0.6872	Wald test = 872.9 on 2 df, p=<2e-16
								Score (logrank) test = 842.5 on 2 df, p=<2e-16
ULA		Male	Ref.					Likelihood ratio test= 36.34 on 1 df, p=2e-09
	Unadjusted	Female	6.265	3.74E-10	0.5593	1.749	1.469, 2.084	Wald test = 39.25 on 1 df, p=4e-10
								Score (logrank) test = 40.28 on 1 df, p=2e-10
	Adjusted for age	Male	Ref.					Likelihood ratio test= 732.5 on 2 df, p=<2e-16
		Female	0.615	0.539	0.056676	1.058313	0.8834, 1.268	Wald test = 581.9 on 2 df, p=<2e-16
								Score (logrank) test = 650.9 on 2 df, p=<2e-16
ULA major	Unadjusted	Male	Ref.					Likelihood ratio test= 0.14 on 1 df, p=0.7
		Female	0.377	0.707	0.1183	1.1255	0.6081, 2.083	Wald test = 0.14 on 1 df, p=0.7
								Score (logrank) test = 0.14 on 1 df, p=0.7

6.4 Congenital limb difference births

Forty-one babies were born with CLD during the study duration, displaying 43 limb differences. Seventy percent of the limb differences affected the upper limbs and 30 percent affected the lower limbs (Table 6.19). The highest number of affected babies born in a calendar year was seven. Due to the risk of identification, only limited findings can be released about the numbers and presentation of cases. A summary of the findings is displayed in Table 6.19.

Of the babies born with a CLD, 57 percent were male (Table 6.19). Ethnic group was not well reported; of the cases where it was reported, 78 percent of babies were identified as White (Table 6.19).

The three most common conditions identified in babies with CLD are shown in Table 6.20.

Table 6.19 Summary of CLD findings

		n	%
Babies born with CLD	-	41	-
Site of limb difference	Upper limb	30	69.8
	Lower limb	13	30.2
Sex	Male	-	57.1
	Female	-	42.9
Ethnic group	Not reported	-	53
	Group A White	-	37
Of cases where ethnic group was reported	Group A White	-	78

Table 6.20 Level of CLD reported

Level	n
Congenital absence of the forearm and wrist (Q712)	6
Congenital absence of hand and fingers (Q713)	21
Congenital absence of foot and toes (Q723)	10

6.5 Incidence of amputation and birth prevalence of congenital limb difference

Table 6.21 shows the incidence of amputation per 100,000 population that was calculated for different procedures and groups. Over the ten-year period, there were 31.93 LLA procedures per 100,000 population and 7.71 ULA procedures per 100,000 population. Also shown is that 19.4 males per 100,000 population and 8.9 females per 100,000 population underwent their first amputation during the ten-year period. The birth prevalence of CLD was calculated to be 0.78 per 10,000 live births.

Table 6.21 Incidence of amputation per 100,000 population

			n	%	Incidence per 100,000 population
All			21,421		39.64
LLA	All		17255	80.55	31.93
	Major		8141	47.18	15.07
		Transpelvic	31	0.18	0.06
		Hip disarticulation	70	0.41	0.13
		Transfemoral	3643	21.11	6.74
		Knee disarticulation	112	0.65	0.21
		Transtibial	4220	24.46	7.81
		Ankle disarticulation	34	0.20	0.06
		Other (leg)	31	0.18	0.06
	Minor		9114	52.82	16.87
		Midfoot	58	0.34	0.11
		Metatarsal	574	3.33	1.06
		Other (foot)	117	0.68	0.22
		Hallux	1890	10.95	3.50
		Phalangeal (toe)	1677	9.72	3.10
		Other (Toe)	4798	27.81	8.88
ULA	All		4166	19.45	7.71
	Major		129	3.10	0.24
		Scapulothoracic forequarter	10	0.24	0.02
		Shoulder disarticulation	9	0.22	0.02
		Transhumeral	49	1.18	0.09
		Elbow disarticulation	5	0.12	0.01
		Transradial	34	0.82	0.06
		Wrist disarticulation	11	0.26	0.02
		Other(arm)	11	0.26	0.02
	Minor		4037	96.90	7.47

		Other (hand)	56	1.34	0.10
		Thumb	279	6.70	0.52
		Phalangeal (finger)	1894	45.46	3.50
		Other (finger)	1808	43.40	3.35
All patients			15974		29.56
First amputation	All		15291		28.30
	Males		10475	68.50	39.85
	Females		4818	31.51	17.36
	SIMD decile	1	2193	13.88	42.29
		2	2064	13.06	38.40
		3	1896	12.00	36.19
		4	1814	11.48	34.07
		5	1614	10.22	30.27
		6	1608	10.18	29.90
		7	1458	9.23	26.66
		8	1284	8.13	23.01
		9	1015	6.42	18.19
		10	854	5.41	15.32

6.6 Discussion

The results of Study 3 have provided us with new knowledge about the number of amputation procedures conducted at different levels, and details about where these surgeries take place. Prior to this study, only the number of amputations conducted annually was known until 2013, as this was derived in Study 2, and very little was known about the amputation procedures that are conducted in Scotland.

Studies to date have considered only certain groups of patients, usually diabetic or vascular patients undergoing LLA. Whilst this group may make up a large proportion of the total cohort, their characteristics do not represent the entire cohort. To effectively plan rehabilitation services, it is essential that all groups are considered and catered for. A strength of Study 3 is that all amputation procedures and the entire population of persons undergoing amputation are considered, which provides accurate information that can be used when planning services.

As discussed in Chapter 3, it has been reported in the literature that the annual rate of LLA decreased in the early to mid-2000s with the introduction of better foot care services, and Kennon et al. (2012) reported a 40.7 percent reduction of major LLA in

patients with diabetes in Scotland between 2004 and 2008. Whilst Study 3 did not consider the diabetic cohort separately, there was no evidence of the reduction in major LLA during the timeframe 2012–2021. In fact, the total number of amputation procedures performed in Scotland rose gradually from the beginning of the observation period, peaking in 2017. Within this, the ratio of minor to major procedures remained constant across the ten-year period. This may indicate that the ratio of major to minor LLA procedures has stabilised following the implementation of the Scottish Diabetic Framework; however, an in-depth comparison with amputation procedures in the mid-2000s would be required to substantiate this hypothesis.

6.6.1 Type and level of amputation

Minor amputations accounted for 53 percent of all lower limb procedures and 97 percent of all upper limb procedures. Despite this, the incidence of minor amputations is poorly described in the literature with little detail provided about the level of procedures conducted. People who have undergone minor amputation procedures may experience limitations to their function or wellbeing following amputation, and therefore should be considered within the rehabilitation services model. By not reporting minor amputations within amputation statistics, a partial picture is given about the population of people who may require rehabilitation services.

In Study 3, 28 percent of all LLAs and 43 percent of ULAs were classed as ‘Other (toes)’ or ‘Other (finger)’. ‘Other’ descriptors are used in medical coding when the procedure does not fit the description of any other listed procedures. The high use of ‘other’ when describing minor amputations may be due to the complex nature of a surgery that could involve different combinations of removal.

As described in Chapter 2, there is limited data available about ULAs, and in particular minor ULA procedures. Study 3 presents data about all ULA procedures, providing a unique insight into amputation practice. The high ratio of minor procedures reported in Study 3 is comparable with the estimates published by Ziegler-Graham et al. (2008) for the USA, where it was estimated that 92 percent of ULAs were minor procedures, and with Vakhshori et al.’s (2019) finding that 93 percent of traumatic paediatric ULAs were finger amputations. As Study 3 reports data about the entire cohort rather than estimates and includes amputations due to all causes, it is now possible to confirm that over 90 percent of ULAs involve procedures distal to the wrist.

Transtibial amputation procedures were the most common major LLA procedures conducted in Scotland, accounting for 52 percent of major LLAs across the ten-year period. Transfemoral amputation accounted for a further 45 percent of all major LLAs. These results are comparable to findings published by SPARG, who report annual rates of ~57 percent for transtibial and ~41 percent for transfemoral (Carr et al., 2023). The lower percentage of transfemoral amputation procedures seen in SPARG reports may be due to their exclusion of patients receiving palliative care at the time of amputation and the omission of data from NHS Grampian.

Knee disarticulation is performed infrequently, accounting for 1.4 percent of all major LLAs in Scotland over the ten-year period. This finding is comparable to data published by SPARG, who report that knee disarticulation accounts for ~1 percent of major LLAs each year (Carr et al., 2023), but is lower than reported rates in England of 4.6 percent (Panhelleux et al., 2022). Knee disarticulation has historically been used primarily for amputations due to trauma or malignancy due to concerns about post-operative healing, or reserved for patients who are not expected to ambulate (Newcombe and Marcuson, 1972; Ten Duis et al., 2009; Bergman and Metcalfe, 2020). It was found in Study 3 that the mean age at amputation of patients undergoing knee disarticulation was lower than for transfemoral amputation, suggesting that there is still reluctance to perform knee disarticulation procedures on older patients.

In recent years there has been increased interest in the use of knee disarticulation surgery when treating vascular patients with reports of similar or improved rehabilitation outcomes when compared with patients undergoing transfemoral amputation (Lim et al., 2018; Gordon et al., 2023). However, insufficient evidence was found in a Cochrane Review published in 2021, with recommendations made for future high-quality research studies (Crane et al., 2021). Study 3 showed similar or improved survival probability for patients undergoing knee disarticulation amputations compared with those undergoing transfemoral amputation, which may indicate improved outcomes; however, a more in-depth analysis of this cohort is required. Study 3 provides baseline data for the incidence of knee disarticulation amputation procedures, which may be used in future research studies, and potential for further exploration of the dataset.

6.6.2 Age at amputation and survival

When considering quality years and survival after amputation it is important to consider the age of the patient at the time of the amputation and the life expectancy

for individuals living in the country. The mean age for people undergoing LLA was 66.2 years with a median survival time of 1,833 days (5.2 years). This is considerably lower than national estimates that in 2020–2022 life expectancy at age 65 was 17.3 for males and 19.6 years for females (National Records of Scotland, 2023a).

Published mortality rates vary considerably depending on the cohort being examined. The results found in Study 3 are comparable with survival probability scores reported by Lavery et al. (2010) in a study that included people who had undergone either major or minor LLA (Lavery et al., 2010). Thirty-day survival probability after major LLA in Study 3 was similar to findings by Davenport et al. (2012), with similar age at amputation and sex distribution reported (Davenport, Ritchie and Xenos, 2012). However, one-year, two-year, and five-year survival probabilities were higher than has been reported in other studies (Stern et al., 2017). This may be due to inclusion and exclusion criteria applied to other studies, where the focus was on vascular and diabetic patients. Further multivariate analyses of the Study 3 cohort could be conducted to investigate this topic further.

6.6.3 Inequalities

Inequalities in society can impact health outcomes, as marginalised and disadvantaged populations may face barriers to accessing healthcare services, preventative measures, and socioeconomic opportunities. Differences in incidence of amputation have previously been found in relation to race and ethnicity, geographic location, and social deprivation. Addressing inequalities in healthcare access and socioeconomic determinants is essential for achieving equitable health outcomes across all segments of society.

Study 3 used the SIMD to analyse inequalities due to social deprivation. It was clear that patients living in more deprived areas were more likely to undergo LLA than people living in less deprived areas, and that they were likely to be younger at the time of their amputation. In Study 3 it was found that 52 percent of people undergoing an LLA lived in the 40 percent most deprived areas at the time of their amputation. This figure is lower than the 67 percent reported by Davie-Smith et al. (2019), who only considered LLA major amputations in the West of Scotland. Similarly, people living in more deprived areas were more likely to undergo an ULA than those living in the least deprived areas and were likely to be younger at the time of amputation; however, the link is not as strong as with LLA.

It was found in Study 3 that 78 percent of people undergoing their first amputation identified as White, which is lower than the 96 percent who identified as White in 2011 (National Records of Scotland, 2014). However, as there was a high percentage of unknown or missing data, it is not possible to know if the findings from Study 3 accurately represent the population, and therefore further reasoning cannot be made.

6.6.4 Effect of the Covid-19 pandemic

The Covid-19 pandemic, caused by the novel coronavirus SARS-CoV-2, emerged in late 2019 and rapidly spread globally, leading to significant public health, social, and economic impacts. In response to the Covid-19 pandemic, Scotland implemented a series of stringent restrictions aimed at curtailing viral transmission and safeguarding public health. These measures encompassed a range of interventions, including social distancing mandates, limitations on public gatherings, closure of non-essential businesses, travel restrictions, and mandatory mask-wearing in indoor settings. In addition Scotland implemented measures to manage healthcare resources effectively, including adjustments to planned surgical procedures. These measures aimed to prioritise urgent and life-saving surgeries while mitigating risks associated with viral transmission and conserving hospital capacity. Consequently, non-urgent elective surgeries were deferred to allocate resources, such as hospital beds, staff, and personal protective equipment, towards the pandemic response.

It can be seen from the figures in Section 6.1.3 that the number of amputation procedures decreased from April 2020, coinciding with periods of national restrictions, but later returned to pre-pandemic frequencies. These findings show that the pandemic had little effect on overall LLA or ULA numbers. Whilst no other studies reporting the frequency of ULAs during the pandemic could be found, similar findings were found in the USA when national inpatient records reviewed LLA cases over the duration of the pandemic (Tedesco et al., 2023).

Whilst the ratio of major LLA to minor LLA procedures rose slightly in 2020 (Figure 6.7), there is inconclusive evidence that the pandemic influenced the type of amputation procedure that was conducted. There is, however, evidence in other studies that circumstances surrounding a person’s amputation changed, with more amputations being conducted as urgent cases, or at higher levels. Jain et al. (2024) recently reported findings from a single-centre review of surgical records of patients with critical limb ischemia and diabetic foot complications at Aberdeen Royal Infirmary. They identified an increase in the percentage of urgent referrals and an increase in

the number of above and below knee amputation procedures (Jain et al., 2024). This may indicate that disruption to routine health services could have influenced the nature of the amputation procedure that was necessary. Similar findings were found in a vascular emergency clinic in Leicestershire, England. Messeder et al. (2023) reported that whilst pre-pandemic rates of major LLA were comparable with rates during the pandemic, patients presented with more severe disease progression prior to amputation (Messeder et al., 2023).

Globally there are different trends in amputation figures emerging, which may be influenced by local decisions during the pandemic to delay medical procedures or amputate at higher levels. Reductions in amputation procedures were observed in diabetic populations in England (Valabhji et al., 2021) and Canada (de Mestral et al., 2022). There were, however, indications in studies from Italy, South India, Australia, and the USA that the rate of major LLAs rose in patients with diabetes, which may have been influenced by the detrimental impact of delayed foot services during the pandemic (Caruso et al., 2020; Viswanathan and Nachimuthu, 2023; Anthony et al., 2023; Casciato et al., 2023).

The long-term effect of disruption to medical services during the Covid-19 pandemic may not be visible for some years. Long-term follow-up of patients attending foot care services during this period will provide more information about the effect of Covid-19 on this population.

6.6.5 Congenital births

During the ten-year period 2012–2021, 528,979 live births were recorded in Scotland. Out of these, Study 3 found that there were 41 births with a CLD, which relates to a birth prevalence of 0.78 per 10,000 live births. The level of detail that could be disclosed in Study 3 was restricted due to the risk of disclosure.

Prior to the start of this study there was no national data available about congenital births in Scotland. In 2018 the Congenital Conditions and Rare Diseases Registration and Information Service for Scotland (CARDRISS) was established, which will report Scotland's data to EUROCAT. Whilst the register is being established, an interim dataset has been created, called the Scottish Linked Congenital Condition Dataset (SLiCCD). In December 2023, Public Health Scotland published their first report from SLiCCD, which included data about babies born with CLD. Public Health Scotland are permitted to disclose lower frequencies than is permitted by researchers using the

eDRIS service. They reported that congenital conditions were present in 231.7 per 10,000 live births. The report included data from all pregnancies which ended in Scotland in 2021. During this timeframe there were ten births identified as having limb reduction defects (2.1 per 10,000 live births), of which two had transverse limb reduction defects (0.4 per 10,000 live births) and two had longitudinal limb reduction defects (0.4 per 10,000 live births). There were no reported cases of spontaneous stillbirth, late foetal loss, or termination of pregnancy (Public Health Scotland, 2023a). It was found in Study 3 that the number of congenital births varied each year. Considering this, a longer review period will give a more accurate account of the number of births with congenital limb reduction defects in Scotland, and therefore it is encouraging that Scotland will continue to analyse congenital limb births through CARDRISS.

6.7 Summary of Chapter 6

Chapter 6 presented the results from a ten-year review of all amputation procedures and congenital limb births in Scotland. In total 17,255 LLA procedures and 4,166 ULA procedures were conducted on 15,974 patients, and 41 babies were born with 30 upper limb and 13 lower limb differences. An analysis of demographic characteristics showed that the majority of people undergoing their first amputation were male, and a higher percentage lived in the most deprived areas of Scotland. Age of amputation and mean survival time varied according to the site, type, and level of amputation procedure. Findings were compared with existing literature and discussed in this chapter. The methods used to obtain the data will be discussed in Chapter 7.

7. Reflections and opportunities for future investigations

This chapter will reflect on the information learned in the scoping review (Study 1) and the experiences of Study 2 and Study 3 with a view to determining a suitable method for investigating the epidemiology of people with limb difference living in Scotland.

An aim of this thesis was to find out epidemiological information about the people who undergo limb amputation or are born with a CLD. Through a scoping review of published literature, it was possible to observe trends within the patient population. The review exposed a lack of large-scale studies and challenges in generalising findings due to differences in the ways that individual studies collect and process data. Whilst information about LLAs was plentiful, it was difficult to draw meaningful conclusions about the population as studies were often designed to measure the effect of procedures on specific populations. In addition to this, information about the upper limb population was scarce. A need for information about the limb difference population living in Scotland was identified, and this was explored through two retrospective studies.

In Study 2, historical data about the number of people undergoing amputation or being born with a limb difference was obtained via an FOI request to NHS Scotland. This data was used to estimate the incidence of amputation in Scotland, and then combined with published data from prosthetic clinics to calculate the referral rate to prosthetic services following amputation. The limitations of this study included a lack of detail about the procedures which were being investigated and no demographic information about the people within the population.

To address this issue a further study was conducted which examined all individual cases of amputation that had taken place between 1st January 2012 and 31st August 2022. Through the use of data linkage techniques, it was possible to identify the cohort population and then combine EHRs to obtain detailed information about the surgical procedures, individual patient demographics, and outcomes following amputation.

Conducting this research provided opportunities for experiential learning, which should influence the collection and management of data in future studies. This chapter

will reflect on the successes and challenges encountered when conducting the studies and will provide recommendations that should be considered when devising future limb difference epidemiological studies.

7.1 A reflection on successes and lessons learned

7.1.1 Identifying the cohort

Epidemiology helps us to understand the patterns, causes, and effects of health and disease conditions within populations. It plays a vital role in advancing our understanding of health and disease, guiding public health interventions, and improving population health outcomes. To do so, it is essential that the population being examined is accurately identified and studied. It is often impractical to study entire populations. Commonly, data will be obtained from a study sample of the target population and findings extrapolated to the entire population. This, however, can introduce errors as findings from a small sample may not accurately represent the larger population. For this reason, to minimise errors introduced through extrapolation of data, an aim of this thesis was to study a large sample that would represent the target population. This would then enable future inferences to be made about similar populations outside Scotland.

When a surgery is conducted in Scotland, surgeons document information about the procedure within EHR. Through accessing information in EHR, it was possible to identify all cases of amputation surgery during the selected timeframe. In both studies, amputation surgeries were identified using procedure codes. Most hospital-based procedures that are conducted in Scotland are performed in NHS facilities. As discovered in Study 3, details about amputation procedures conducted at private centres may also be reported in SMR. This meant that the risk of missing cases of amputation surgery was low. It can therefore be concluded that the method used within the studies was appropriate for identifying people undergoing amputation surgery, and a similar method could be used in future studies or within a registry.

This method, however, only identified people undergoing a new amputation procedure. It can be assumed that the Scottish amputee population will also contain people with existing amputations which pre-date electronic medical records or were conducted outside Scotland. Additional methods would need to be used if the cohort was to include all people with limb difference. This may be possible through linking in

GP datasets or datasets which report new referrals to rehabilitation services, including prosthetic services.

Congenital cases were identified using data recorded in the SBR. The frequencies identified for 2021 matched frequencies reported by Public Health Scotland, suggesting that the method for identifying new cases of CLD was accurate. However, to identify older people with existing CLD, other methods would need to be employed such as linking in GP datasets.

7.1.2 General demographic data

Investigating demographic information in healthcare research is important for improving our understanding of health disparities, tailoring interventions, and improving healthcare delivery. Demographic factors such as age, gender, race, ethnicity, socioeconomic status, and geographic location are critical determinants of health outcomes and healthcare access. By analysing demographic data, researchers can identify patterns of health disparities and inequities across different population groups. Describing a population using demographic data helps researchers and decision-makers uncover areas of inequality and can provide insight into the issues that the population may experience. Demographic data may provide information that can be useful when planning health services, budgeting, producing patient education materials, assessing inequalities, and investigating methods for reducing barriers.

Epidemiological studies examine the structure and dynamics of a population using demographic indicators such as age, ethnicity, and behaviour. Demographic data is commonly collected in experimental studies and surveys, but there is little consistency about the types of data being collected or the language used. Attempts have been made in some areas of medicine to standardise the collection and presentation of demographic data; however, no guidelines for the collection and processing of demographic data in rehabilitation medicine could be found.

While demographic data undoubtedly holds significant value in research and decision-making processes, ethical considerations must guide its collection and utilisation. It is imperative to recognise that gathering data without a clear purpose raises ethical concerns regarding privacy invasion and potential misuse. When collecting and processing demographic information, careful attention must be paid to safeguarding individuals' privacy and ensuring compliance with relevant regulations, such as the GDPR. Notably, certain categories of demographic data, including ethnicity, sexual

orientation, and physical or mental health conditions, are classified as 'special category data' under the GDPR. Therefore, any collection or processing of such sensitive information must be justified by a lawful basis and conducted with utmost care to uphold individuals' rights and confidentiality.

No demographic data was obtained from the FOI requests made in Study 2, and this is identified as a limitation of the study. In Study 3 general demographic data for the cohort was obtained using data routinely collected by NHS Scotland. The ethical issues concerning the processing of NHS data for this study were examined and approval was given by the PBPP. Precautions were taken to protect the identity of individuals being studied, including retracting frequencies below five in any outputs, and retrieving date of birth as month/year and postcode at sector level. These measures restricted some of the results that could be released. In retrospect, these measures may be viewed as conservative, as similar frequencies to those which were retracted in Study 3 have been released within Public Health Scotland's *Congenital Conditionals in Scotland* report. Low frequencies have also been reported in Limbless Statistics and SPARG reports. When studying rare conditions, a balance needs to be found between protecting an individual from the risk of identification and permitting responsible research for the benefit of the population. When devising methods for future work, alternative methods to protect individuals' identities should be investigated.

Study 3 provided a good insight into the demographic profile of the population of people in Scotland undergoing amputation surgery. Sex, age at amputation, and geographic location were obtained for most of the cohort, and this information can be useful for future planning of services.

Investigations into the ethnicity of people with amputation were, however, not as insightful. This was due to ethnicity being missing or unknown in 18 percent of SMR01 records. It is not uncommon to encounter issues collecting ethnicity data in healthcare or research. *JAMA* investigated this issue and produced guidance in 2021 on reporting race and ethnicity which may reduce barriers and improve reporting (Flanagin et al., 2021). They discussed the sensitivities of language and changes in nomenclature that occur over time and between regions. Through the use of better language and education about why data is being collected, it may be possible to improve collection rates. In future studies, it may be appropriate to seek alternative sources of data for recording ethnicity, such as census data. Another possible source

could be at specialist service level, where individuals would be able to ask questions about the need to obtain data and what it will be used for.

7.1.2.1 Geospatial and socioeconomic factors

Understanding geographic and socioeconomic factors provides valuable insights into the complex relationships between environmental, social, and individual factors that influence health outcomes, helping to inform evidence-based decision-making in public health policy and practice. By mapping health data geographically, researchers can identify 'hotspots' of prevalence. This information is crucial for targeting interventions and resources effectively to areas most in need. Geographic data also enables researchers to study how environmental factors, such as access to green spaces or proximity to healthcare facilities, impact health outcomes. This understanding can inform public health policies and urban planning decisions.

Geographic information, including the person's home address and the location of the amputating hospital, was gathered in Study 3. The researcher aimed to utilise this data to generate geospatial maps and compute travel distances to rehabilitation centres. However, due to constraints within the Safe Haven, this analysis could not be conducted presently. Nonetheless, there exists the potential to undertake this analysis in the future.

We learned from the literature that there are strong links between amputation and deprivation. Individuals with lower socioeconomic status may face barriers such as limited transportation options. Socioeconomic factors also influence health behaviours such as diet, exercise, smoking, and preventative care utilisation. Understanding these barriers is essential for designing interventions to improve access to healthcare for vulnerable populations. SIMD data used in Study 3 provided an insight into the socioeconomic profile of the Scottish limb difference population. There is potential for deeper analysis using this dataset to further investigate the barriers which may influence patient outcome.

Data linkage has proved to be a suitable method for obtaining demographic data about the population of people undergoing amputation. Future studies could be extended to include other characteristics, such as employment and education, which are available in census data. This would enable future investigations into inequalities that may help remove barriers to inclusion.

7.1.3 Procedures

It is clear from the literature that people with limb difference have very different outcomes depending on the level of amputation they have undergone. Having knowledge about the procedures which are carried out within the region can inform policy makers on where to focus resources, and which rehabilitation services may be required. This data can also be used to monitor trends in amputation surgery. There is currently an interest in knee disarticulation surgery in the UK, with research being conducted into the longer-term benefits over other levels. Retrospective data could be used to identify cohorts of people who have undergone procedures such as knee disarticulation amputation and then monitor their progress over time, without adding an additional burden of collecting large amounts of new data.

Patient outcomes may also be influenced by the procedures performed before amputation, such as revascularisation procedures, the specific techniques used during surgery, and the methods used following surgery, such as wound management. There is a plethora of published literature comparing patient outcomes after revascularisation procedures. Avoidance of amputation is commonly used as a measure of success following such procedures; however, the follow-up period is often short. Using data linkage techniques, amputation data could be combined with study data to enable longer observation periods, providing additional information about a cohort's life events. Other areas where further investigation could be conducted include re-amputations, bilateral cases, revision surgery, and rare sites. These cohorts could be identified using procedure codes, enabling information to be gained about the population that may be difficult to obtain otherwise.

In studies 2 and 3, the cohort was identified using procedure codes. In Study 2 the procedures codes used were defined by NSS when the FOI request was made. In Study 3, the procedure codes were predefined based on the information gained in Study 2, the investigator's knowledge of amputation surgery, and advice from eDRIS. In retrospect, the inclusion of procedure codes for revision, re-amputation, and bilateral amputation would have made it easier to identify people in these categories. Future studies should construct their cohort based on an in-depth knowledge of the conditions being investigated and the research question.

When treating patients, clinicians usually determine the level of amputation from either reading the clinical notes, viewing x-rays, or conducting a physical examination of the residual limb. Errors in classification can occur, particularly at partial hand and

partial foot levels, where amputation levels can be complex and the presentation variable. Retrieving information about an amputation procedure from the surgical team via the OPCS code can be more accurate than using palpation to determine what structures remain in a residual limb. However, the use of OPCS-4 procedure codes has some drawbacks as the language used to describe procedures does not always match the procedure that has been carried out. An example of this could be where, in a single surgery, a thumb and several fingers are amputated from a hand at different levels. Guidance is lacking on how to code such a procedure and therefore surgeons may record it as individual procedures or under the 'Other' codes. It is assumed that these are the reasons for a high proportion of minor ULAs in Study 3 being recorded using 'Other' codes.

7.1.4 Aetiology and comorbidities

7.1.4.1 Issues classifying aetiology

Understanding the aetiology, or the causative factors and mechanisms underlying a condition, helps us to understand the complex interplay of genetic, environmental, lifestyle, and socioeconomic factors that contribute to disease onset and progression. It is commonly accepted that the main reason for LLA in developed countries is dysvascularity. PAD, PVD, and diabetes are frequently reported as causes of LLA, and patients may have a combination of these conditions (Beckman, Creager and Libby, 2002; British Society of Rehabilitation Medicine, 2018). Trauma is believed to be the main cause of LLA in developing countries, and the main cause of ULA globally.

As discovered in the review of literature, presented in Chapter 2, many published papers which describe aetiology do so for a specific group of patients, for example those attending a foot clinic or a prosthetic service. As not all people who undergo amputation will access such services, these figures may not represent the entire population of people undergoing amputation. An aim of this thesis was to determine the main causes of amputation in the Scottish population. This was investigated in the literature review, which told us that ~85 percent of people having major LLA in Scotland had PAD (Smith, Scott and Hebenton, 2019), but people undergoing palliative amputation were not included in this study. Cause of amputation for people attending prosthetic centres in Scotland was reported by Limbless Statistics, with the main causes identified as PVD with diabetes for LLA and mechanical trauma for ULA, although cause was unknown in a large percentage of cases (Limbless Statistics,

2013d). As these reports only capture data about people who are referred to prosthetic services, they may not provide an accurate picture of the population. It is also not clear in these two studies how aetiology was determined for each patient.

An attempt to determine the main causes of amputation in the entire population of people undergoing amputation in Scotland was made in Study 3. In this study aetiology was determined using information supplied in SMR01 as either 'main condition' or 'other condition'. According to the iSD Data Dictionary, 'main condition', a mandatory input, is determined at the end of the episode, and describes 'the main medical (or social) condition managed/investigated during the patient's stay' (Public Health Scotland, g). Up to five other conditions or problems dealt with during the episode should be listed as 'other condition'. Advice within the Data Dictionary states that conditions that have no bearing on the current episode should not be recorded. This means that pre-existing conditions, such as PVD, diabetes, and trauma, may not have been listed if they were not considered relevant to the hospital episode being reported. Considering the average age of amputation, it can be assumed that many people undergoing amputation have pre-existing conditions. If these pre-existing conditions were not considered relevant to the hospital episode, they would not have been listed. This may have resulted in under-reporting of conditions such as diabetes in Study 3.

Another limitation when using SMR01 diagnosis data was the volume of different codes used to describe 'main condition' and 'other condition'. Over 4300 unique ICD-10 codes were identified, some of which would appear to have no relevance to limb amputation. It was not possible to know which of the listed codes in a hospital episode were relevant to the amputation, and which were relevant to other procedures investigated during the same episode of care.

7.1.4.2 Reporting aetiology

When reporting the cause of amputation, it is common to use groupings of different conditions. There is, however, no consistency within the published literature in the groups that are used: Limbless Statistics uses seven groups containing a total of 27 descriptors, SPARG uses 16 groups, Ziegler-Graham et al. (2008) used four groups, and George et al. (2018) used five groups (Carr et al., 2023; Ziegler-Graham et al., 2008; George et al., 2018; Limbless Statistics, 2013d).

Details about how diagnostic information was obtained and handled was not reported in many publications. Aetiology reported in studies is often obtained directly from clinical documentation; however, information is rarely provided about how aetiology was determined. Aetiology is sometimes documented in clinical notes based on information which has been self-reported by the patient or from the patient history. Ziegler-Graham et al. (2008) and George et al. (2018) both used diagnostic codes to determine aetiology and published lists of the ICD-9 codes used within their studies. Direct conversion from ICD-9 to ICD-10 is not possible and so the equivalent ICD-10 codes could not be determined.

Considering the high volume of ICD-10 codes reported in SMR01, and the difficulties in creating lists of diagnostic codes for aetiology groupings, it was not possible to accurately determine the cause of amputation for each patient in Study 3. An analysis of aetiology data was performed for diabetes conditions as proof of concept only. It is recommended that a consensus is agreed on how to determine aetiology and how this is reported in clinical notes and publications.

7.1.4.3 Comorbidities

Comorbidities, often referred to as coexisting or concurrent medical conditions, represent the simultaneous occurrence of multiple health conditions within an individual. The presence of comorbidities can significantly impact disease management and treatment outcomes. Understanding common patterns of comorbidity occurrence can inform strategies for disease prevention and intervention, and contribute to the development of clinical guidelines, healthcare policies, and public health interventions aimed at addressing complex healthcare needs.

Comorbidities data, sourced from the CCI calculation, was used in Study 3 as an additional method of determining the presence of key conditions such as diabetes. When calculating the CCI score, SMRs for the previous five years were screened for the presence of identified diagnostic codes. As this data goes further back, it may include conditions that could be relevant to the person's future health and quality of life that did not have a bearing on the episode of care when the amputation was performed. This analysis was incomplete due to errors which occurred when data was refreshed by eDRIS in 2022. This error was identified by the investigator and acknowledged by eDRIS, but a replacement datafile was not supplied in sufficient time to allow a full analysis. Despite this, it is the investigator's opinion that this datafile could provide a more accurate indication of comorbidities and should be considered

for further studies. An alternative method would be to predefine diagnostic codes of interest and request these when the study is designed.

Determining aetiology of amputation and identifying comorbidities has been highlighted as problematic in many publications. The Limb Loss and Preservation Registry recently reported summary data suggesting that diabetes is under-reported in clinical notes. Their report shows that less than 50 percent of patients were documented as having diabetes, and that zero complications were most frequently documented (Limb Loss and Preservation Registry, 2023). A review of ICD-10 codes used to classify revascularisation procedures showed variability when reporting comorbidities and it was noted that misclassification bias is likely. Suggested solutions include using an extended ICD-10 or ICD-11 (Birmpili et al., 2023). It is a recommendation of this thesis that methods for determining, and reporting, aetiology and comorbidities are investigated further, and a standardised format agreed internationally.

7.1.5 Measuring outcomes

A limb amputation is often performed as a life-saving procedure, but it can also be performed with the goal of improving quality of life of an individual (Wurdeman, Stevens and Campbell, 2018), for example, by reducing the source of chronic pain or improving mobility. Understanding what happens to a person after they have undergone a life-changing event such as an amputation is important as it helps us understand the effectiveness and consequences of medical procedures and treatments.

Outcomes which are often investigated after amputation include death, health status, and quality of life. Survival time after amputation, or any procedure, can be a useful measure for comparing the impact of procedures on longevity. In Study 3, it was found that mean survival time after amputation varied depending on factors such as sex, deprivation, and level of amputation procedure.

Whilst survival time is a useful indicator, the amount of time someone lives in good health can give a better indication of the quality of a person’s life. Healthy life expectancy was introduced in Chapter 3 and is a measure used by governments to monitor and compare health in the aging population. In a similar way, health status and quality of life are often used as indicators of healthy life after procedures such as amputation.

Health status and quality of life after amputation are commonly reported in the literature. Subgroups often reported when investigating health status include comorbidities such as PVD, diabetes, mental health conditions, and cardiovascular impairment. Presence of these conditions could be identified in future studies by identifying the relevant ICD-10 codes or examining EHRs for outpatient clinic appointments or prescriptions. Other events which may be of interest include further amputations and revascularisation procedures. In Study 3, it was possible to identify patients who underwent further amputations and determine if these were conducted on the same limb or a different limb. There is potential for a deeper analysis of this data to be conducted, which could include survival analysis to time of re-amputation.

Quality of life after amputation may consider the richness of a person's life, and examine participation in activities such as employment, friendship, hobbies, and sports. It is often measured using outcome measurement tools, and there are many such tools which have been validated for measuring quality of life after amputation. ISPO conducted a review of outcome measurement tools for use after LLA within their LEAD and COMPASS project and published a user guide to help improve the quality of administration of the tools (International Society for Prosthetics and Orthotics, 2021).

Study 3 analysed the number of outpatient appointments following a patient's amputation. The resulting numbers were lower than expected and indicate that not all appointments may have been recorded within SMR. After talking to clinicians working in NHS Scotland, it became evident that this may be the case, and it is possible that not all appointments are recorded in this way. Standardisation of the appointment system would increase quality of data and facilitate better audit and research about outcomes following amputation.

7.1.5.1 Rehabilitation services

The services which a person receives after amputation, and whether they use a prosthesis or not, will have an influence on their future health status and quality of life. The recommended rehabilitation pathway for people undergoing major LLA is well documented. Bodies including the BSRM, NCEPOD, and Vascular Society have published recommendations which emphasise the importance of multidisciplinary teamwork in both the pre-operative and post-operative phases of patient care (Gough et al., 2014; Vascular Society, 2016; British Society of Rehabilitation Medicine, 2018; British Society of Rehabilitation Medicine, 2021). In 2018, BSRM stated that services

for limbless people in the UK should continue to be delivered by specialised services, but through different models of delivery depending on the presentation of the patient. The proposed models each involve assessment by the multidisciplinary team, including pre-amputation consultation where possible, and access to a consultant in rehabilitation medicine. Access to these services should be through a referral to the service from a consultant surgeon or their team. Auditing of this could be performed using linked datasets.

Who should be fitted with a prosthesis is not clearly defined; however, guidelines have been published describing factors that should be considered during the decision-making processes. LLA clinical guidelines state that a person's potential ability to transfer or ambulate should be assessed, and a decision made as to whether a prosthesis is appropriate for meeting the agreed patient goals. Rehabilitation plans are determined based on the presentation of the patient, their goals, cognitive function, and functional level, and may include training in, and the provision of, medical devices such as prostheses, wheelchairs, and other assistive devices, physiotherapy, footcare, and pain control. It is accepted that people with amputation will require lifelong care, although there is little evidence to indicate how often patients should be reviewed, or for how long. Clinical guidelines for rehabilitation care following ULA are not as clear.

Prosthetic componentry prescription is a complex process that needs to consider factors such as function of the patient, clinical presentation, maintenance, and cost of a device. Decisions are often made based on clinical expertise resulting in variations of practice. Attempts to standardise practice have been made through the publication of prosthetic componentry prescription guidelines, but due to changes in technology these can quickly become outdated. Examples of prosthetic prescription guidelines include the *WestMARC Knee Guides* produced by SPARG, the Steeper *Best Practice Guidelines*, and the *Prosthesis Prescription Protocol of the Arm* being used in the Netherlands (Brady et al., 2020; Steeper, 2011; Wijdenes, Brouwers and van der Sluis, 2018).

Clinical guidelines for pre- and post-operative physiotherapy state the importance of having a knowledgeable and informed multidisciplinary team, and good communication with the patient and where appropriate their family or carers. Early assessment and goal setting are encouraged.

In Scotland, most people who undergo a major LLA will enter a rehabilitation pathway which includes services such as inpatient and outpatient physiotherapy, and assessment for prosthetic suitability. Outcomes from this pathway have been monitored and reported by SPARG, providing a good working knowledge about the methods used in Scotland. SPARG data collection, however, ceased in January 2024. Whilst the rehabilitation pathway after major LLA is known, the pathways for people undergoing other types of amputation are not as clear.

An aim of this thesis was to investigate the clinical pathway from amputation to rehabilitation for patients who underwent any level of amputation surgery in Scotland. Referral rates to prosthetic services after LLA and ULA were calculated in Study 2 using amputation figures supplied through an FOI request to NHS Scotland and data published by Limbless Statistics. From the rates calculated, it is apparent that there are variations in the patterns of referral to prosthetic services. Whilst referral numbers for people who have undergone major LLA have previously been published by SPARG, similar data could not be found for people undergoing other categories of amputation.

It was the intention of the investigator to include prosthetic service data, such as date of referral, referral source, date of assessment, date of fitting, and prescription, within Study 3 so that the patient's journey, from amputation to rehabilitation, could be analysed. Permission for this was obtained from prosthetic service managers, and ethical approval was granted by PPBP in the original ethical application approved in 2016. Data from prosthetic services in Scotland is stored in a bespoke platform called ReTIS (Rehabilitation Technology Information Service). The transfer of data to eDRIS, requested in 2016, was delayed due to staffing capacities and upgrades to the IT system. Despite attempts by the investigators and eDRIS to obtain the data, and offers of remediation, the prosthetic service data was never transferred. This accounted for significant delays within the study. In 2022 (in Amendment 4 of the ethics application), prosthetic service data was removed from the methods of Study 3 to enable the study to progress. To the investigator's knowledge, the upgrades to ReTIS have not yet been completed.

Prosthetic devices play an important role in reducing barriers to participation for people with limb difference. The inclusion of prosthetic service data is important when considering the outcomes of patients with limb difference. It is a recommendation from this thesis that a collaboration agreement is made between prosthetic services and

PHS to share information. Whilst this should not be required, as it is a legal right for investigators who have appropriate permissions, such as approval from PPBP, to use NHS data for legitimate research, a collaboration agreement could promote discussion between partners and encourage participation.

7.1.6 Protecting privacy of the individual

Researchers have a responsibility to uphold and adhere to high ethical standards in the conduct of their work. Upholding ethical standards not only safeguards the rights and wellbeing of research participants but also enhances the credibility and integrity of the research. WHO states that all research which involves human participants, including epidemiology studies, should be subject to scrutiny by a research ethics committee to ensure that risks to the individual are minimised (World Health Organization, 2011a). Further to this, Article 13 of the Convention on the Rights of Persons with Disabilities states that the processing, collecting, and maintaining of information must comply with legally established safeguards to ensure confidentiality and respect for privacy, and comply with internationally accepted norms to protect human rights, fundamental freedoms, and ethical principles in the collection and use of statistics (United Nations, 2006).

Privacy of the individual was at the forefront of decisions during the development and implementation of the studies reported in this thesis. Secondary use of data and big data have received negative press in recent years, with rumours of data being sold for commercial gain. As described in Section 5.2.2, studies which have examined public opinion on this matter have concluded that public trust can be gained if there are assurances that the data is non-identifiable and protected from misuse.

Study 2 and Study 3 both involved the secondary use of NHS data. This was collected by NHS Scotland under their legal basis for collecting and using personal information, and provided to researchers in a non-identifiable format to protect individuals' privacy.

When analysing anonymised data there is an increased risk that a person could be identified when datasets are linked together. For this reason, an additional layer of security was added in Study 3. Data for Study 3 was only available to view and process within the NHS Safe Haven. This is a secure digital environment which is accessible only from pre-determined locations. The Safe Haven contains a limited platform of software packages, and data cannot be exported from the Safe Haven without prior clearance from eDRIS managers. Whilst this provided additional

security, it presented some limitations to the methods of analysis which could be conducted, and the types of data presentation which could be used. In particular, it limited the guidance which could be sought during the data analysis, as only the investigator and one of her supervisors had access to the Safe Haven. Other limitations included having to retract some data before it was released due to the risk of identification. This restriction affected the outputs for less common levels of amputation, and people born with limb difference. Attempts were made to group some amputation levels to prevent identification of individuals.

7.1.7 Data management

Both studies in this thesis used routinely collected NHS Scotland data. Whilst Study 2 used an FOI request to access this data, Study 3 used the eDRIS services as the amount of information being requested was outside the remit of the Freedom of Information (Scotland) Act. eDRIS is a paid-for service provided by Public Health Scotland designed to facilitate research studies which use NHS Scotland data. The service was new when Study 3 was developed.

The researcher's experience of using eDRIS has been varied over the duration of Study 3. At times, particularly during the early phases of study design and approval, the support received was exceptional, with eDRIS staff providing informed and timely responses, working with the researcher to progress the study. However, the experience was also at times negative and inconsistent. It is acknowledged and understandable that during the Covid-19 pandemic, Public Health Scotland prioritised studies relating to the pandemic. This, however, adversely affected the progress of other ongoing studies. Issues with communication and timely responses were present before the Covid-19 pandemic but worsened during that period and continue to be an issue, and this has affected the outputs that could be generated from Study 3.

Considering the issues that were encountered during Study 3, it would be prudent, when considering a further study, to investigate other ways of accessing and managing NHS Scotland data.

7.2 Designing a follow-up study

The studies documented in this thesis have significantly contributed to our understanding of the prevalence of amputations and CLD births in Scotland, as well as the epidemiological characteristics of this cohort. Study 3 specifically established a baseline dataset encompassing all individuals who underwent limb amputation

between 1st January 2012 and 31st August 2022. Subsequent analyses showcased the potential of this dataset as a valuable resource for further research and understanding.

It is widely recognised in the literature and public health guidance that informed public health decisions should be rooted in epidemiological data, with a focus on addressing the needs of populations and reducing barriers to healthcare access. This underscores the rationale for conducting a longitudinal study aimed at monitoring the incidence, causes, and outcomes of amputations and CLD births over time.

The necessity for high-quality data regarding the limb difference population has been highlighted by organisations such as ISPO and the Amputee Coalition of America. There currently lacks a structured approach for systematically collecting and analysing such data in the UK. Past efforts have typically involved short-term observation of small cohorts. Scotland, with its sizable population, well-established network of EHRs, and universal healthcare access, is uniquely positioned to spearhead research in rehabilitation.

7.2.1 Scope of the study

Building on the work that has been presented in this thesis, a study should be designed to collate information about people with limb difference so that analyses on incidence, procedures, techniques and treatments, and social and economic impact can be conducted in the future.

As demonstrated in this thesis, Scotland's existing system of EHRs provides a good basis for the collation of data. As recommended by ISPO's LEAD and COMPASS projects, datasets should include information about the prosthetic prescription which a patient receives. As discussed in Section 7.1.5.1 above, this data is not readily available. An opportunity exists to standardise the data that is collected by prosthetic and rehabilitation centres and combine it with other health data so that treatment outcomes can be analysed.

A follow-on study should integrate the framework of core items for lower extremity amputation datasets and standardised outcome measures for routine clinical practice, as recommended in the ISPO LEAD and COMPASS report (International Society for Prosthetics and Orthotics, 2021). Implementation of these recommendations would facilitate collaboration in future larger-scale projects, adding quality data to support evidence-based practice. Although the LEAD and COMPASS projects only

considered LLAs, many of the recommendations are suitable for other cohorts within the limb difference population. However, additional standardised outcome measures will need to be included to measure clinical outcomes in other groups. Currently work is being conducted by organisations such as the ISPO Upper Limb Special Interest Group to standardise the outcome measures routinely used by clinicians, and these should also be integrated into the study.

A fundamental consideration in a study such as this should be to identify barriers that impede individuals' participation in society. When considering people with limb difference, there are various societal aspects that could affect their ability to access services. In addition, the existence of a limb difference may introduce barriers which interfere with an individual's ability to participate freely in society. Through investigating an individual's interactions with society it may be possible to determine if correlations exist, and identify barriers to participation.

A longitudinal study that includes health data will enable services and outcomes to be analysed; however, to fully understand the impact of disability, social and economic data about individual people should also be included. The incorporation of social service data could facilitate exploration of such relationships. Additionally, the importance of co-creation should be emphasised in devising the follow-on study. Involving the cohort in decision-making ensures that decisions are made with their involvement, adhering to the principle of 'nothing about us without us'.

7.2.2 Study methods

The purpose of a future study is to establish a long-term monitoring and reporting mechanism for the health and social status of individuals at the time of amputation or birth, tracking changes and events over their lifetime. An approach is recommended that incorporates data linkage of routinely collected health and social records alongside additional study data that will be collected by rehabilitation services. These methods will enable the observation of trends in amputation surgeries and CLD births, analysis of demographic traits, and quality audits of treatments and services. Incorporating data linkage of health records may also facilitate identification of confounding health conditions, exposures, or procedures, and measurement of their effects.

It is imperative that any new study does not exacerbate the burden on clinical staff, as this could compromise the quality of recorded data. To mitigate this concern, a

future study should be compatible with existing medical record systems so that any additional data can be easily and routinely inputted.

It has been demonstrated within Study 3 that data linkage of routinely collected data is a valuable tool and appropriate methodology for studies investigating cohorts such as people with limb difference. The limitations of Study 3 have been identified and include issues identifying aetiology and classification of amputation level. Recommendations for these were made in Section 7.1.4.2 and should be incorporated where possible into a follow-on study.

When devising methods for a follow-on study, it is essential that rehabilitation services data, including prosthetic services, is included. Scotland's prosthetic services currently use the dedicated IT platform ReTIS for patient documentation and outcome measures. Ideally the data held by ReTIS could be linked with other medical and administrative datasets to provide important information about prosthetic fittings. This would need to be discussed in detail with NHS Lothian, the current handlers of ReTIS, and contractual agreements made. In the event that it is not possible to link ReTIS data, some data could be obtained through other NHS systems. This would require consultation with stakeholders, including prosthetic managers.

Given that diabetes is a known cause of LLA, integrating aspects of the proposed study with the existing national diabetic registry is warranted. The Scottish Care Information – Diabetes Collaboration (SCI-DC), a national registry developed from a collaboration between the Diabetes Audit and Research in Tayside Scotland study and the Scottish Care Information programme, facilitates web-based sharing of patient records and clinical information. It is routinely used by clinicians in the day-to-day management and screening of diabetic patients and can be used to generate reports. Linking to SCI-DC would enable tracking of the clinical journey of patients with diabetes from pre-amputation to lifelong rehabilitation. This presents an opportunity to investigate the effects of pre-amputation procedures, such as revascularisation, on patients who later undergo amputation. Furthermore, linking with SCI-DC may facilitate recording and analysis of information regarding patients who undergo amputation but do not receive prosthetic services, such as some people with minor LLAs.

Another existing registry which could be linked with a future study is CARDRISS. Combining the information already recorded on CARDRISS about congenital limb births with information about rehabilitation services, such as prosthetic fittings,

occupational therapy, psychological services, and outcome measures, could provide a new depth of knowledge and discussion about how we treat people who are born limb different and the barriers which they may encounter in society.

7.2.3 Ensuring longevity of the study

Previous UK studies which have examined this cohort have ceased, citing issues with funding. Most recently, SPARG closed its database due to a lack of funding. Over its 30-year history, SPARG has relied on generosity and goodwill to fund data storage. Following the closure of its database, SPARG intends to continue some of its work by collecting data from vascular centres and storing the data on protected Excel worksheets. Whilst this method of data storage reduces costs, it would not be suitable for a comprehensive data linkage study as the potential impact of an accidental or malicious data breach would be too high, risking the disclosure of personal data.

The loss of clinical information due to closure of the SPARG database is detrimental for the field of amputee rehabilitation. It is envisioned, however, that this clinical data could be incorporated within a future data linkage study.

Data linkage studies have lower costs than studies which rely solely on the collection of new data. Through using the existing EHR system, it is expected that running costs can be minimised. However, it is necessary to consider the IT costs and labour associated with running a health registry. These costs will include annual costs for hosting of the registry on the Safe Haven, or a similar secure platform, data linkage costs when data is refreshed, and the cost of an analyst to manage the data and produce outputs. Additional funding may be required to fund data collection at rehabilitation centres, although it is anticipated that this will be done as part of patients' routine care.

7.2.4 Partners in the study

The follow-on study which is being proposed is ambitious in size and scope. The design should be flexible to enable involvement in future global studies. There is an opportunity for Scotland to capitalise on a system of existing electronic medical records and excellent prosthetic services to lead research and best practice in the area of amputee rehabilitation.

Success of the study will require cooperation and collaboration from many bodies. In line with other health registries in Scotland, it is expected that Public Health Scotland would own and operate the dataset, and the structure would be similar to existing

registries such as SCI-DC. A steering group should be established to further explore the scope of the study, and collaboration agreements made across all parties. Stakeholders may include people with limb difference, the NHS, surgeons, prosthetic centres, vascular centres, plastic surgery centres, SPARG, amputee charities, and interested researchers. Through actively involving stakeholders at early stages of the study design, and throughout its execution, it is anticipated that issues related to data access and management can be mitigated and good communication maintained.

7.2.5 Should a registry for limb difference be established?

Interest in limb-fitting registries has increased during recent years, and registries such as SwedeAmp and the Limb Loss Preservation Registry have been established to track national trends in prescription and outcome. In 2021, ISPO published a list of recommended items for inclusion in a lower extremity amputation dataset, with a view to aligning datasets to facilitate international collaboration. There is agreement between many of the core items recommended for inclusion in a dataset and the items which were examined in Study 3. The LEAD report (International Society for Prosthetics and Orthotics, 2021), however, recommends that data is completed by treating clinicians, and thus there is potential for inaccurate data to be recorded. It does not address the issues raised with determining cause of amputation, continuing to rely on patient and clinician judgment, and uses some traditional language to describe amputation levels rather than procedure codes or ISO classifications for amputation.

A future study which would incorporate linked routinely collected medical and social data with data from rehabilitation services and other databases could open the possibilities for research opportunities. The method described would include data about every person in Scotland who is identified as belonging within the cohort, and thus would become a powerful audit and research tool, exceeding the minimum requirements recommended by ISPO.

This methodology differs from that used in other countries where national datasets have been established. National registries have been established in Sweden and the USA. In both examples, patient data is provided by hospitals or prosthetic clinics who have opted in to provide data for the register. Both registries have conducted extensive publicity drives to raise awareness of their work and have experienced slow increases in registration numbers since their formation.

Extending the existing electronic health system to include a registry of people with limb difference fits well with the Scottish Government's vision to use data to improve health and wellbeing in Scotland (The Scottish Government and COSLA, 2023).

Considering the recommendations made by ISPO, there is support for the establishment of a registry in Scotland to record patient data including personal information and clinical outcomes. Based on the evidence provided in this thesis, there is a significant opportunity for the establishment of a national registry for limb difference, which would enable Scotland to become a leader in amputee rehabilitation research and lead the development of best practice guidelines. By following these steps and fostering collaboration among stakeholders, Scotland can capitalise on its strengths to drive significant advancements in amputee rehabilitation research and improve outcomes for individuals with limb differences.

8. Conclusions

Understanding a population and identifying inequalities are critical steps toward reducing barriers to equal participation in society for people with disabilities. This work aimed to deepen our understanding of limb difference in Scotland by investigating the frequency of limb amputation and congenital limb differences, as well as the demographics of the affected population. A three-step process was used, involving a scoping review of the literature, a retrospective review of publicly available amputation, birth, and prosthetic referral data, and a linked data study.

The scoping review mapped global and regional trends in limb amputation and congenital limb difference, focusing on incidence and prevalence rates, aetiology, and key factors such as sex, age of amputation, social deprivation, and comorbidities. It revealed a decrease in major lower limb amputations in regions with improved diabetic foot care services. However, global studies remain limited, and disparities in data collection and reporting pose challenges for cross-population comparisons. Additionally, while international registries exist for congenital limb differences, this cohort remains under-reported in the literature, particularly in the context of Scotland.

This thesis argues for a more comprehensive consideration of the limb-different population in health and social care policy decisions. Excluding certain groups—such as those who do not attend prosthetic services or those with minor amputations—may lead to missed opportunities for improving services and outcomes. A holistic approach that encompasses the entire population of people with limb differences is crucial for designing policies that ensure equitable access to rehabilitation services.

Studies 2 and 3 provided new insights into limb difference in Scotland, offering a clearer picture of the population's demographics and the extent of the issue. Study 2 examined amputation data from NHS Scotland, identifying trends in the incidence of limb amputations over a 24-year period. The incidence of lower limb amputations peaked at 45.42 per 100,000 in 1993, then declined to 33.96 per 100,000 by 2011. A similar pattern was seen in upper limb amputations. Prosthetic referral rates were also explored, showing a general increase in referrals over time, with upper limb referrals rising significantly.

Study 3 employed a novel linked dataset, which included records from the Scottish Medical Records, NRS Deaths, and the Scottish Birth Record, to analyse the frequency of limb difference at different levels and the demographic characteristics of the population undergoing amputation and those born with congenital limb differences. Findings of a ten-year review provided detailed information about frequency of different levels of amputation and revealed demographic disparities, with higher amputation rates in more deprived areas and at younger ages, as well as varying survival outcomes based on the level of amputation.

This research has contributed valuable knowledge about the types and levels of amputation in Scotland and provided a framework for using linked data to investigate limb differences. The uniqueness of this study, with its comprehensive dataset covering every amputation and limb-difference birth within a decade, underscores its significance. The findings will aid policymakers and the prosthetics industry and may be applicable to other nations with similar populations.

In conclusion, this thesis has demonstrated a method for obtaining detailed data on limb difference using a universal electronic health record system. Future research should focus on enhancing data collection methods, particularly regarding aetiology and comorbidities, and on integrating this information into a registry to support audits of clinical outcomes and the lifelong care of individuals with limb differences.

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Appendix A

Table A Data Extraction

Limb difference	Region	First Author	Year	Article type	Study design	Date range of data	Data source	Country/region	Population	Number of subjects	Incidence /Prevalence	Sex ratio	age at amputation	Diabetes	Ethnicity	Social deprivation	Rehab outcome	Survival
	Global	Ephraim	2003	Journal paper	Literature review		18 databases		LLA, ULA, CLD	No of articles = 95	x	x		x				
		Moxey	2011	Journal paper	Literature review	1989 - 2010	Pubmed, Cochrane Library		LLA	No. articles = 57	x			x	x			x
		Unwin	2000	Journal paper	Multi-centre	07/95-06/97	10 centres	6 countries	LLA		x	x	x	x				
		McDonald	2021	Journal paper	secondary analysis		GBD 2017	28 countries	LLA, ULA, traumatic non-fatal		x		x					
		Yuan	2023	Journal paper	secondary analysis	01/90-12/19	GBD 2019	204 areas	LLA, ULA, traumatic		x	x	x			x		

LLA	UK and Republic of Ireland	Gough	2014	Report	Multi-centre	10/12-03/13	Hospitals where rehab services following major LLA. NHS, independent sector	England, Wales, N. Ireland, Channel Islands, Isle of Man	Major LLA, vascular	760				x			x	x
		Smith	2019	Conference abstract	Multi-centre	1/15-12/15	Physiotherpist	Scotland	Major LLA	705		x		x				
		Moxey	2010	Journal paper	Multi-centre	04/03-03/08	HES	England	LLA	48,142	x			x				x
		Holman	2012	Journal paper	Multi-centre	04/07-03/10	HES	England	LLA	34,109 amputations (16,693 diabetic patients)	x			x	x			
		Kennon	2012	Journal paper	National data	01/04-12/08	SMR, SCI-DC	Scotland	nontraumatic LLA, diabetic	2382	x			x				
		Krishnan	2008	Journal paper	Single-centre, regional hub	1995-2005	HCP	Ipswich, England	non traumatic, non-tumour LLA	/	x			x	x			
		Schofield	2009	Journal paper	Regional	01/00-12/06	SCI-DC	Tayside, Scotland	LLA, diabetic	397 amputations	x	x	x	x				

		Yu	2010	Journal paper	3 centres	2001 - 2005	Hospital records	Calgary, Canada	TT, KD, TF	307							
		Vamos	2010b	Journal paper	National data	1996 - 2005	HES	England	non-traumatic LLA	84597	x	x	x	x		x		x
		Paisey	2018	Journal paper	Regional	2007 - 2015	podatrists, hospital records	S Devon, England	Major LLA, diabetic	/	x			x				
		Rossi	2010	Conference abstract	Single-centre hub	2000 - 2008	Hospital records	London, England	LLA, diabetic	64	x	x		x				
		Macriyiannis	2015	Conference abstract	Single-centre	01/09-12/13	Hospital records		LLA	/	x			x				
		Vamos	2010a	Journal paper	National data	04/04-03/08	HES	England	non-traumatic LLA, age over 16		x	x	x	x				
		Ahmad	2014a	Journal paper	National	04/03-03/09	HES	England	LLA, age 50-84	25308 amputations	x			x	x			
		Ferguson	2010	Journal paper	Single-centre hub	01/03-01/09	hospital records		LLA, PVD	552 amputations						x		
		Davie-Smith	2019	Journal paper	Regional	03/14-02/15	hospital records, physiotherpist	West Scotland	Major LLA	171			x	x		x	x	x
		Gujral	1993	Journal paper	Regional	1980 - 1985		Leicestershire, England	LLA		x		x	x	x			
		Leggetter	2002	Journal paper	4 centre	1992 - 1997	HES, Global LEA Study	London, England	LLA, diabetic	215 amputations	x	x	x	x	x			

		Ahmad	2014b	Journal paper	National	04/03-03/09	HES	England	LLA, age 50-84	25312 amputations	x		x			x		
		Ahmad	2016	Journal paper	National	04/03-03/13	HES	England	LLA, age 50-84	94819 amputations	x	x	x	x				
	Scandinavia and the Nordic Countries	Alaranta	1995	Journal paper	Regional	1992	Hospital records	S Finland	LLA	345	x	x		x			x	x
		Pohjolaine	1988	Journal paper	Regional	1984 - 1985	Hospital records	S Finland	LLA	705		x	x	x				x
		Ikonen	2010	Journal paper	National	1997 - 2007	National Hospital Discharge Register			9481 amputations	x	x	x	x				x
		Eskelinen	2006	Journal paper	Regional	1992 - 2002	Clinical records	Helsink, Finland	Major LLA, vascular	1094	x			x				
		Winnel	2013															
		Roikjer	2020	Journal paper	National	1997 - 2017	National Patient Register	Denmark	LLA	17265 amputations	x			x				x
		Witso	2010	Journal paper	Single site hub	2004 - 2007	Hospital records	Trondheim, Norway	LLA	113 amputations	x	x	x	x				
		Larsson	2008	Journal paper	Single site hub	01/92-12/01	Hospital records	Lund-Orup, Sweden	LLA, diabetic	1978	x		x	x				x
		Ebskov	1986	Journal paper	National	1972 - 1984	National register	Denmark	Major LLA, Major ULA			x	x	x				

		Kamrad	2020	Journal paper	National	2011 - 2018	Swede amp	Sweden	LLA	5762		x	x	x			x	
	Europe (excluding UK and Republic of Ireland)	Trautner	2007	Journal paper	3 centres	1990 - 2005	Hospital records	Leverkusen, Germany	nontrumatic LLA	692	x	x	x	x				
		Van Houtum	2004	Journal paper	National	1991 - 2001	National Medical Register	Netherlands	LLA	~900 year	x	x	x	x				
		Fortingham	2013	Journal paper	14 centres	01/03-12/04	Medical records	N Netherlands	TT, KD, TF	342	x	x	x	x				
		Nijenhuis-Rosien	2017	journal paper	National		Insurance database		non traumatic LLA, diabetic		x			x				
		Calle-Pascual	2001	Journal paper	Regional	1989 - 1999	Hospital records	Madrid, Spain	LLA		x	x	x	x				
		Lopez-de-Andres	2015	Journal paper	National	2001 - 2012	National hospital discharge	Spain	LLA	138012 amputations		x	x	x				
		Jimenez	2017	Journal paper	Single site hub	2008	Hospital records	Madrid, Spain	LLA, non-traumatic	664 amputations	x			x				
		Kolossvary	2020	Journal paper	National	2004 - 2017	Hospital records	Hungary	LLA, vascular	89423	x	x	x					
		Lombardo	2014	Journal paper	National	2001 - 2010	National hospital discharge record	Italy	LLA	11639	x	x	x	x				
		Pit'hova	2015	Journal paper	National	2010 - 2014	General Health nsurance company	Czech Republic	LLA, diabetic					x				

		Malyar	2014	Journal paper	National	2005 - 2009	Government data	Germany	LLA, ischemic			x	x					x
		Heyer	2015	Journal paper	National	2006 - 2012	Health insurance	Germany	LLA, diabetic		x	x	x					
		Kroger	2017	Journal paper		2005 - 2014	Government data	Germany	LLA, PAD/diabetic		x	x		x				
		Sequeira	1996	Journal paper	National	1990 - 1993	hospital records	Portugal	LLA		x	x						x
		Fosse	2009	Journal paper	national	2002 - 2003	national hospital discharge records	France	LLA, diabetic	15353	x	x	x	x				
		Petrasovic	1996	Journal paper	61 centres	1995	questionnaire	Slovakia	LLA	2116 amputations	x			x				
		Nazim	2001	Journal paper	Regional	1/96 - 12/96	hospital records	Krakow, Poland	LLA, nontraumatic	290	x		x	x	x			
		Lindegard	1984	Journal paper	Regional	1971 - 1980	Hospital records	Gotland/Umea, Sweden	LLA, diabetic	182	x			x				x
		Dozsa	2020			2016 - 2017	National health insurance	Hungary	LLA, PVD		x		x			x		x
	North America	Imam	2017	Journal paper	National	04/06-03/12	National discharge dataase	Canada	LLA	44430 amputations	x	x	x	x				
		Kayssi	2016	Journal paper	National	2006 - 2009	National discharge dataase	Canada	LLA	5342		x	x	x				

		Hussain	2019	Journal paper	Regional	04/05-03/16	health databases	Ontario, Canada	LLA, diabetic/PVD	20062	x	x	x	x				
		Wrobel	2001	Journal paper	306 regions	1996-1997	Medicare claims	USA	Major LLA	83710 amputations	x	x	x	x	x			
		Peacock	2011	Journal paper	Regional	2005-2008	Hospital discharge records	Minnesota, USA	LLA, ischemic	4302 amputations	x	x	x	x				
		Stevens	2014	Journal paper	Regional	2009	Hospital discharge records	California, USA	LLA, diabetic	6828	x	x	x	x	x	x		
		Amin	2014	Journal paper	Regional	04/02-03/09	Health databases	Ontario, Canada	LLA, diabetic		x	x		x		x		
		Prasad	2018	Journal paper	Regional	2014	Hospital discharge records	Texas, USA	LLA, nontraumatic	13241 amputations		x	x	x				
		Nowygrod	2009	Conference abstract	Regional	1998-2007	Hospital discharge records	New York State, USA	LLA		x		x	x				
		Stapleton	2017	Journal paper	Regional	1999-2014	Administrative database	New York State, USA	LLA, ischemic						x			
		Rowe	2010	Journal paper	National	1998-2006	Nationwide Inpatient Sample		Major LLA, PAD					x	x			
		Traven	2020	Journal paper	National	2011-2017	national Surgical database		BK/AK, ischemic						x			

		Rizzo	2018	Journal paper	National	2006-2013	Hospital discharge data		LLA, PAD						x	x		
		O'Connell	2010	Journal paper	Regional	10/04-09/05	Insurance database	Arizona, USA	LLA	42143		x	x	x	x			
		Weber	2011	Journal paper	National		National Trauma Database		LLA, traumatic fracture		x	x	x		x			
		Player	2017	Conference abstract	National		SEER database	USA	LLA, sarcoma, age over 18			x	x		x	x		
	South America	Lacle	2012	Journal paper	Regional	2001-2007	Health records	Costa Rica	LLA, diabetic	572	x	x	x	x		x		
		Ascencio-Montiel	2017	Conference abstract	2 centres	2005-2015	Hospital discharge records	Mexico	LLA, diabetic		x	x	x	x				x
		Cascao	2012	Journal paper	Regional	2000-2003	National hospital databases	Rio de Janeiro, Bazil	LLA, diabetic, age over 30, deaths	977				x				x
		Barbosa	2016	Journal paper	32 hospitals	1985-2008	Hospital discharge records	Ribeirao Preto, Brazil	LLA	3274	x	x	x					
		Montalvo	2017	Journal paper		01/12-12/16	Hospital records		Major LLA	160		x		x		x		x
	Asia	Jones	1990	Journal paper	3 States	1981-1984	State morbidity data	Australia	Major LLA		x	x	x	x				

		Dillon	2014	Journal paper	National	2000 - 2010	National hospital morbidity database	Austalia	LLA		x		x					
		Wright	2019	Journal paper	national	2001 - 2015	National hospital morbidity database	Austrailia	LLA, adults, PAD		x		x	x				
		O'Rourke	2012	Journal paper	Regional	1998 - 2008	Hospital records	North Queensland, Australia	Major LLA, diabetic		x			x				
		Baba	2015	Journal paper	Regional	1993 - 1996 / 2008 - 2011	Hospital records	Western Australia	LLA, diabetic		x			x	x	x		
		Robinson	2016	Journal paper	National	2000 - 2012	hospital records	New Zealand	LLA, diabetic	892 amputations	x	x	x	x	x	x		
		Chen	2006	Journal paper	National	1997 - 2002	Insurance database	Taiwan	LLA, diabetic		x	x	x	x				
		Lai	2015	Journal paper	National	2001 - 2010	Insurance database	Taiwan	Major LLA, diabetic, nontraumatic	1588 amputations	x	x						
		Sheen	2018	Journal paper	National	1998 - 2007	Insurance database	Taiwan	LLA, diabetic, nontraumatic		x	x	x	x		x		
		Li	2020	Journal paper	National	2009 - 2013	Insurance database	Taiwan	LLA, diabetic, age over 55	9236	x	x	x	x		x		
		Ohmine	2011	Journal paper	Single site hub	01/05-	Hospital records	Central Japan	LLA, PAD	33		x	x	x				

						12/10											
		Nagashima	1993	Journal paper	Regional	1984-1988	Disabled certificate	Okayama Prefecture, Japan	LLA, dysvascular	114	x		x				x	
		Ohmine	2012	Journal paper	Regional	01/01-12/05	Disabled certificate	Kitakyushu, Japan	ULA, LLA	349	x	x	x	x				
		Suvapan	2015	Conference abstract	National	10/13-09/16	Government database	Thailand	LLA	15684		x	x	x			x	
		Narang	1982	Journal paper	Single site hub	1954-1978	Hospital records	Pune, India	LLA, ULA, CLD, civilian			x	x	x			x	
		Ahmad	2016	Journal paper	Single site hub	09/13-01/16	Hospital records	Lucknow, India	LLA, ULA, traumatic, age under 18	53		x	x					
	Middle East	Al-Turaiki	1993	Journal paper	Single site hub	1977-1990	Hospital records	Riyadh, Saudi Arabia	LLA, ULA	3210		x	x	x				
		Shahine, E	2022	Journal paper	Single site hub	06/10-06/20	Hospital records	Riyadh, Saudi Arabia		1409		x	x	x			x	
		Al-Thani	2019	Journal paper	Single site hub	2000-2014	Hospital records		LLA, ULA	871	x	x	x	x	x			
		Agha	2017	Journal paper	Single site hub	01/15-04/16	Hospital records	Bahrain	Major LLA	45		x	x	x				x
		Alshehri	2022	Journal paper	Single site hub	2013-2018	Hospital records	Riyadh, Saudi Arabia	LLA, ULA	412		x	x	x			x	
		Badri	2011	Journal paper	Single site hub	2005-2009	Hospital records	Jeddah, Saudi Arabia	LLA, ULA	222		x	x	x	x			x

		Alzahrani	2012	Journal paper	Review		MOH reorts			4325				x				
		Salman	2010	Journal paper	17 centres		Medical records	Amman, Jordan	LLA	371	x	x						
		Yaghi	2012	Journal paper	92 hospitals	01/07-12/07	Hospital records	Lebanon	LLA, ULA	661	x		x	x				
		Janmohammadi	2008	Journal paper	Single site hub	01/99-09-07	Hospital records	North Iran	LLA, ULA, traumatic	358		x	x					
	Africa	Solagberu	2001	Letter	Single site hub	07/94-06/99	Hospital records	Ilorin, Nigeria	LLA	40		x	x	x				
		Ajibade	2013	Journal paper	Single site hub	01/06-12/10	Hospital records	Kano, Nigeria	Major, LLA, ULA	132		x	x					
		Akinyoola	2006	Journal paper	Single site hub	01/98-12/04	Hospital records	Ile-Ife, Nigeria	LLA, ULA, children	107		x	x				x	x
		Enweluzo	2010	Journal paper	Single site hub	01/07-12/09	Hospital records	Lagos, Nigeria		127		x	x	x				x
		Sarfo-Kantanka	2019	Journal paper	Single site hub	01/10-12/15	Hospital records	Ghana	LLA, diabetic		x	x	x	x				
		Khan	2020	Journal paper	Single site hub	01/13-07/18	Hospital records	Pietermaritzburg, South Africa	LLA	348			x	x	x			x
		Solagberu	2001	Journal paper	Single site hub	07/94-06/99	Hospital records	Ilorin, Nigeria	LLA, ULA	56		x	x	x				

ULA	Ostile	2011	Journal paper	National	01/06-05/08	Company / Hospital records	Norway	ULA, proximal to wrist, aquired, age over 18	390	x	x	x		x		x	
	Ziegler-Graham	2008	Journal paper	National	1988 - 1999	National inpatient sample	USA	ULA, LLA		x	x	x	x	x			x
	Vakhshori	2019	Journal paper	44 states	01/97-12/12	Inpatient database	USA	ULA, traumatic, age under 20	6130		x	x		x			
	Bakker	1973	Journal paper	National	1969		Natherlands	ULA, LLA	103							x	
	Andersen-Ranberg	1988	Journal paper	National	1978 - 1983	Danish Amputation Register	Denmark	ULA, excl digits	457	x	x	x					
	Kim	1996	Journal paper	Single site hub	01/70-06/94	Medical records	Korea	ULA, LLA, CLD, new amputation or attending prosthetic training	4258		x	x	x				
	Alsheri	2022	Journal paper	Single site hub	2013 - 2018	Hospital records	Saudi Arabia	ULA, LLA	412		x	x				x	
	Ro	2019	Journal paper	National	2004 - 2013	Insurance database	South Korea	ULA, industrial injury	49,535		x	x					
	Liang	2004	Journal paper	National	1999 - 2001	Workers compensation database	Taiwan	ULA, industrial injury	2950	x	x	x					
	Kim	2019	Journal paper	Single site hub	02/11-12/14	Hospital records	Korea	ULA, power tool injury	30		x	x					

	Pomares	2018	Journal paper	Single site hub	01/04-12/13	Medical records	France	ULA, traumatic	1715		x	x					
	Toma	2018	Journal paper	Single site hub	2014 - 2018	Hospital records	Arad County, Romania	ULA, LLA non-traumatic	10 ULA, 693 LLA		x	x	x		x	x	x
	Moini	2009	Journal paper	National	2000 - 2004	National Trauma Database	Iran	ULA, LLA traumatic	164		x	x					x
	Kyberd	1997	Journal paper	Single site hub	Feb-92	Hospital records	Oxford, England	ULA	341 patients		x	x				x	
CLD	Irvine	2015	Journal paper	National	2007	National surveilance report	Canada	CLD		x							
	Bedard	2015	Journal paper	Regional	1980 - 2012	National surveilance report	Alberta, Canada	CLD, livebirths, stillbirths, termination >20 weeks	795								
	Klungsoyr	2019	Journal paper	National	1970 - 2016	Medical births register	Norway	CLD, livebirths, stillbirths >16 weeks, termination > 12 weeks	1206	x							
	Mano	2018	Journal paper	1767 departments	01/14-12/15	Hospital records	Japan	CLD		x							
	Kim	2013	Journal paper	Regional	1983 - 2007	Malformations registry	New York State, USA	CLD		x				x			
	Makhoul	2003	Journal paper	Single site hub	1985 - 2001	Hospital records	Haifa, Israel	CLD, livebirths	24	x	x			x			
	Kallen	1984	Journal paper	National	1965 - 1979	Malformations registry	Sweden	CLD			x						x

	Heinke	2020	Journal paper	10 states	1997 - 2011	Births Defects Study	USA	CLD, livebirths, stillbirth >20 weeks, termination		x						
	Goutas	1993	Journal paper	Single site hub	1986 - 1990	Post mortem autopsy	Athens, Greece	CLD, stillbirth, termination		x						
	Stewart	1995	Journal paper	Single site hub	1965 - 1984	Hospital records	Dundee, Scotland	CLD	68	x					x	

Appendix B

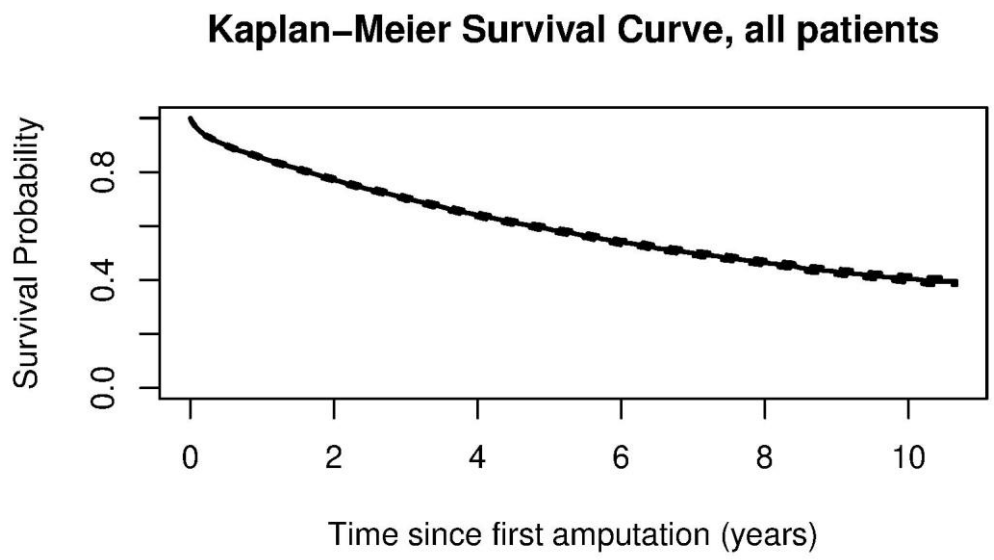

Figure B.1 Kaplan–Meier survival curve, all patients

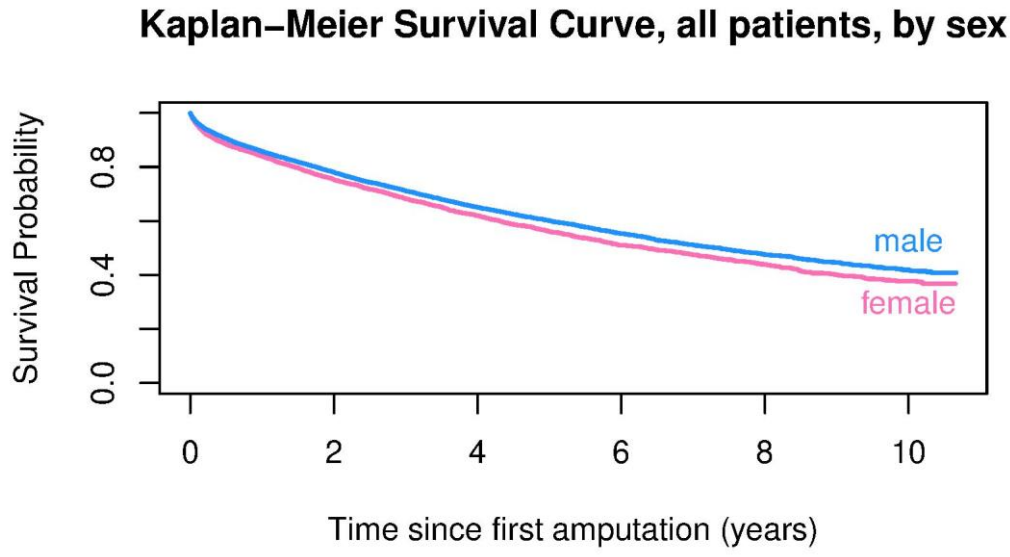

Figure B.2 Kaplan–Meier survival curve, all patients, by sex

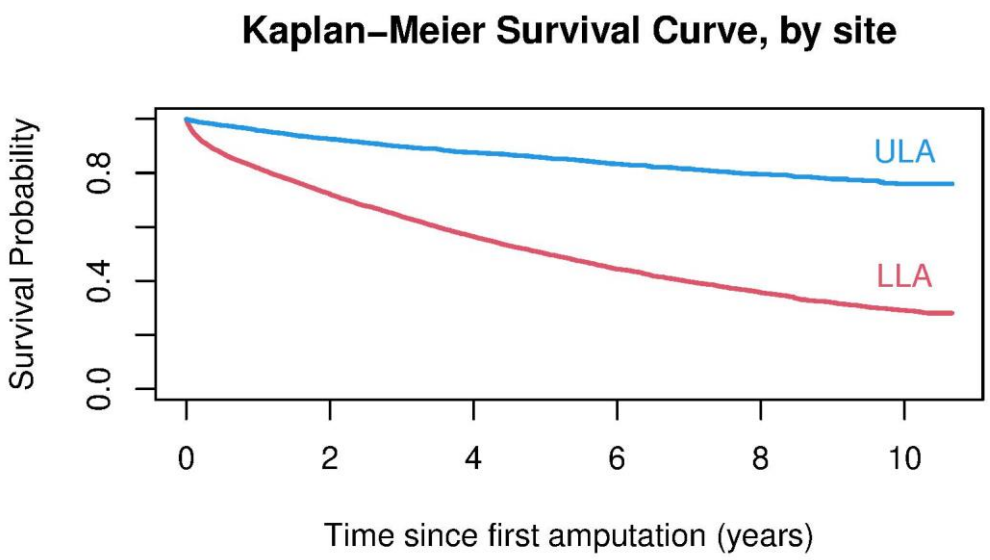

Figure B.3 Kaplan–Meier survival curve, by site

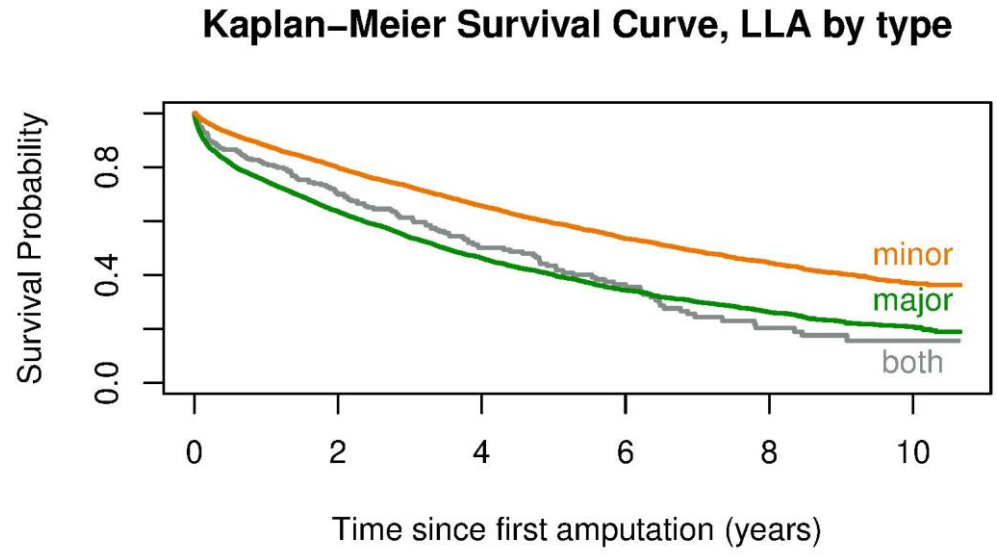

Figure B.4 Kaplan–Meier survival curve, LLA by type

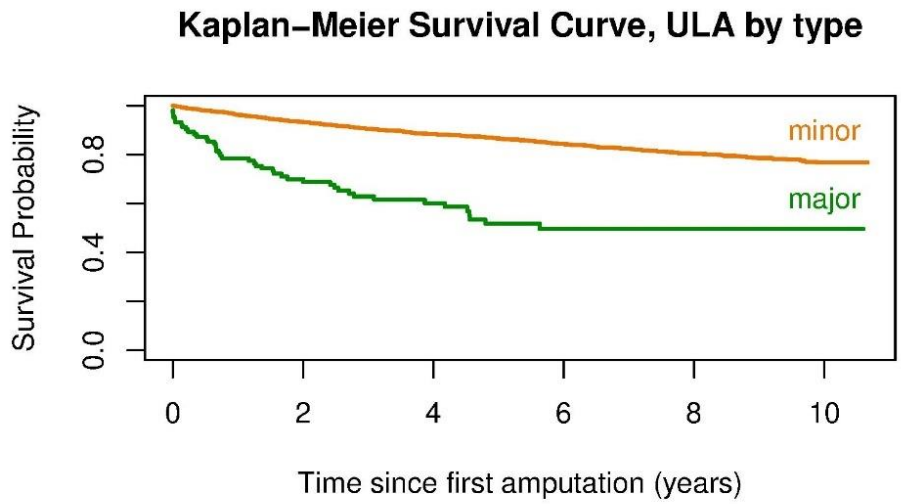

Figure B.5 Kaplan–Meier survival curve, ULA by type

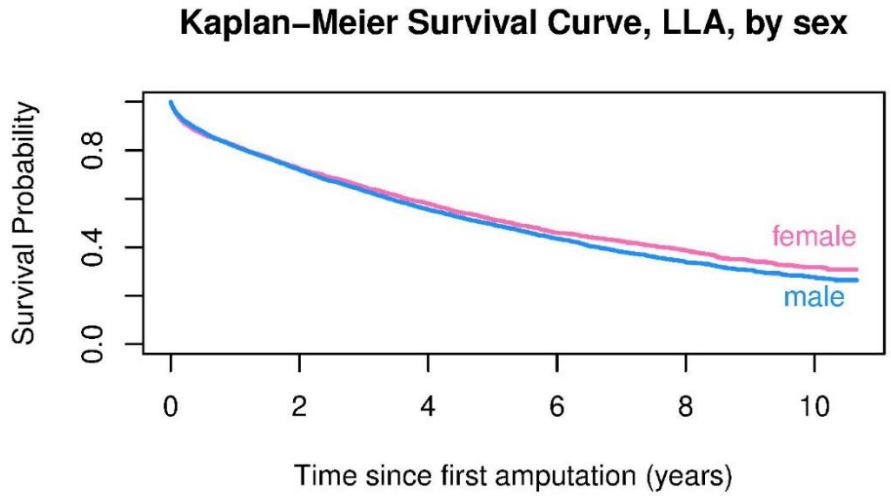

Figure B.6 Kaplan–Meier survival curve, LLA by sex

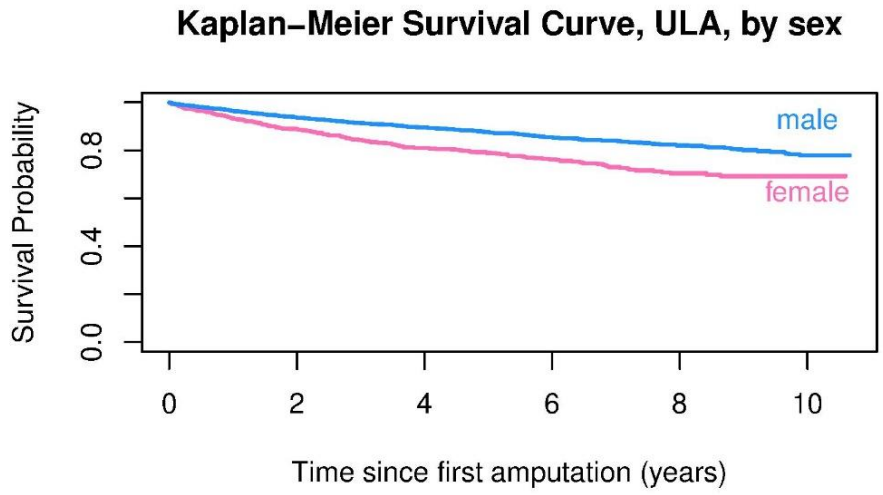

Figure B.7 Kaplan–Meier survival curve, ULA by sex

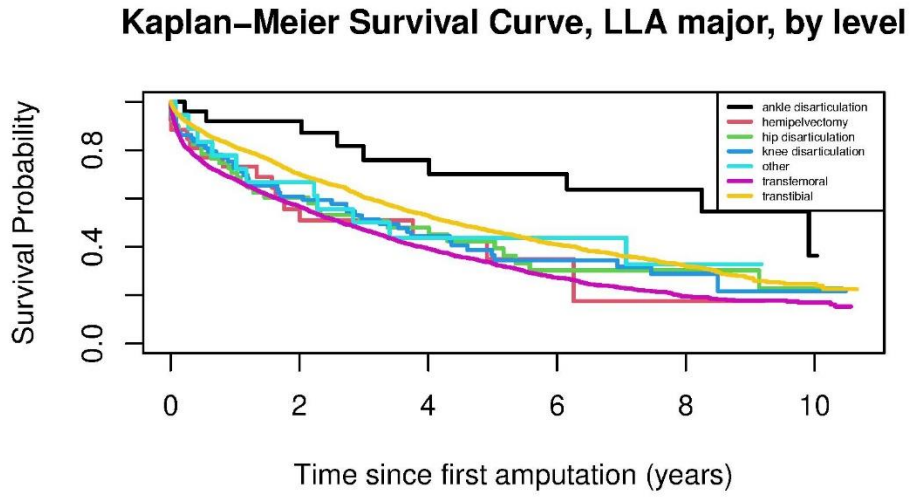

Figure B.8 Kaplan–Meier survival curve, LLA major, by level

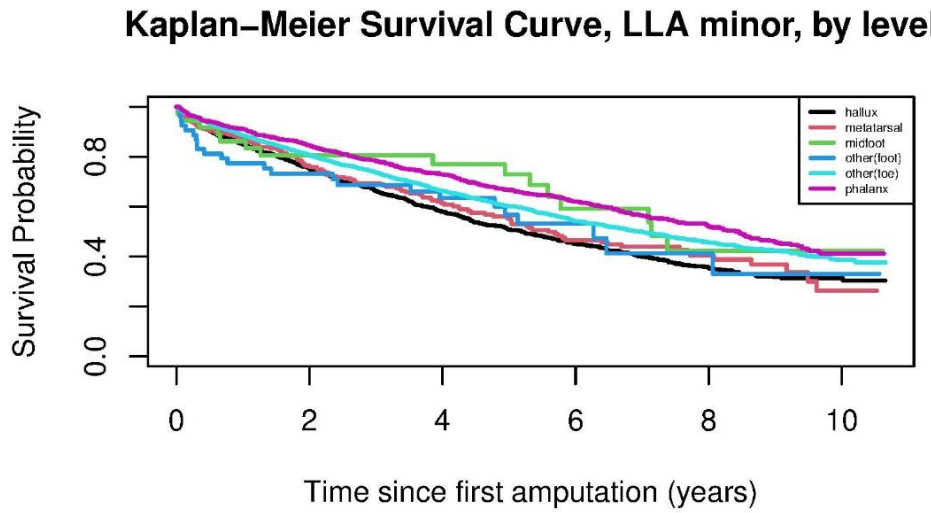

Figure B.9 Kaplan–Meier survival curve, LLA minor, by level

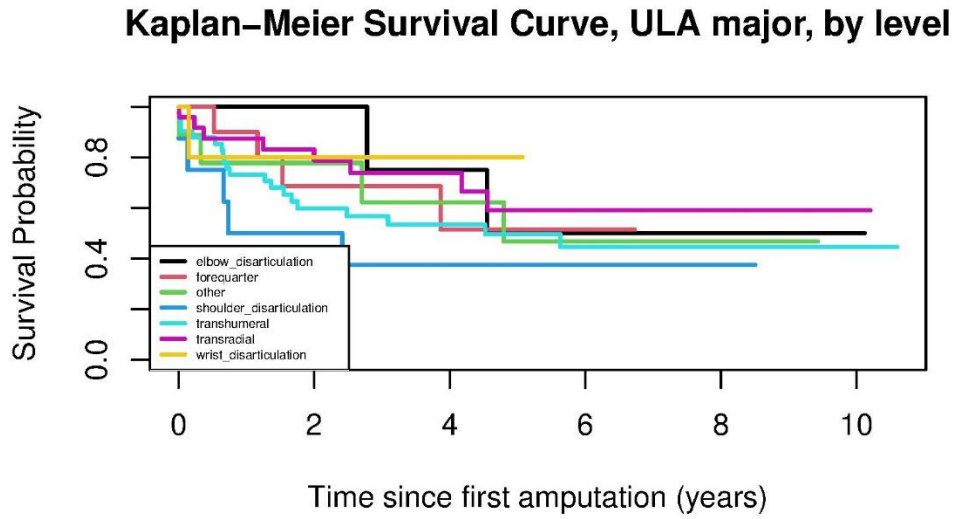

Figure B.10 Kaplan–Meier survival curve, ULA major, by level

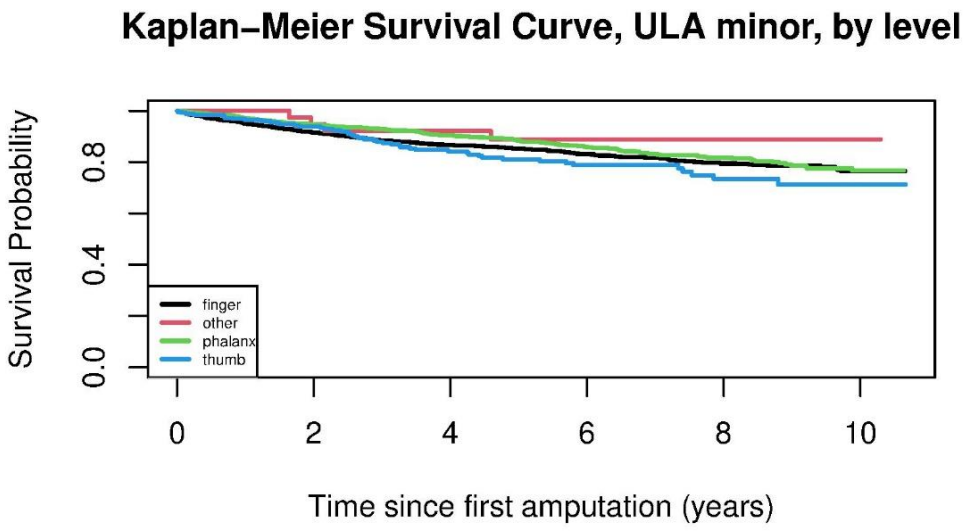

Figure B.11 Kaplan–Meier survival curve, ULA minor, by level

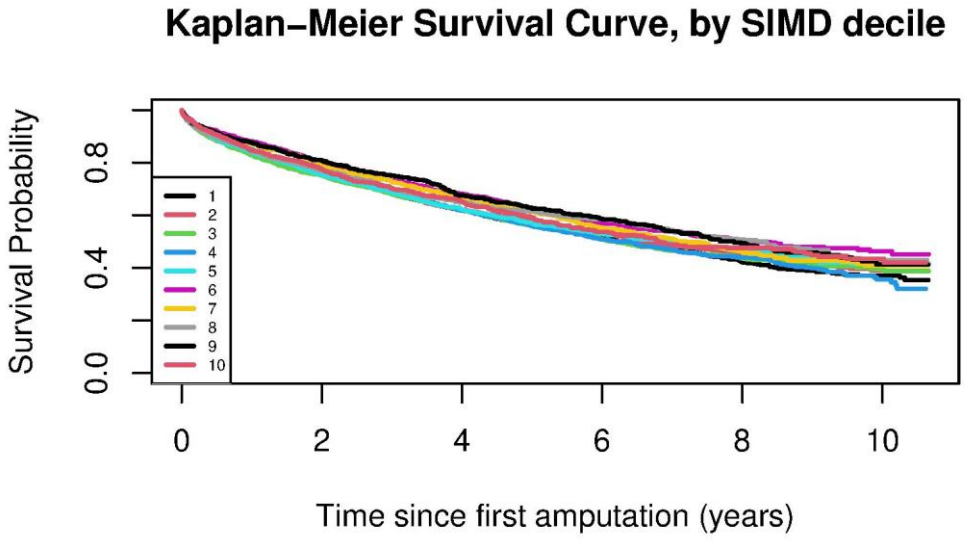

Figure B.12 Kaplan–Meier survival curve, by SIMD decile

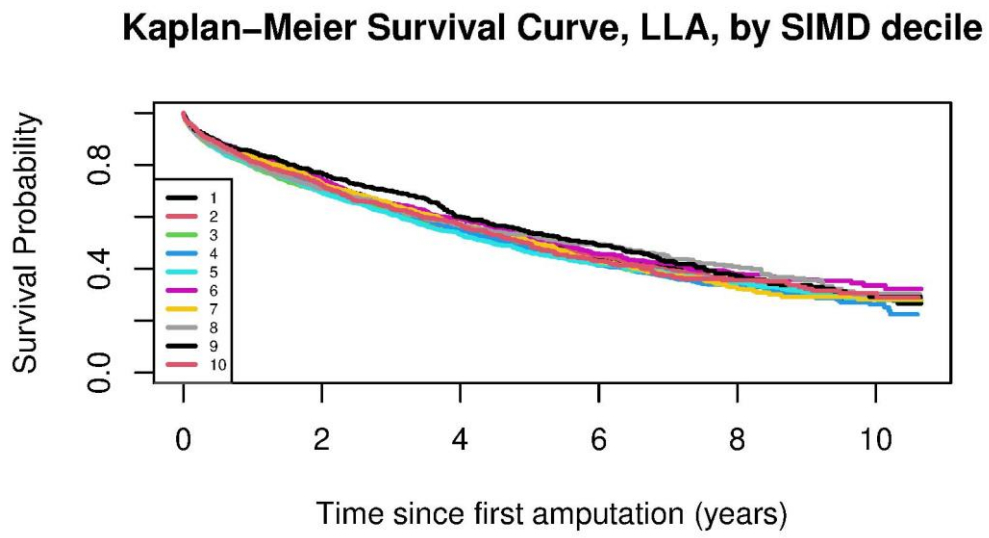

Figure B.13 Kaplan–Meier survival curve, LLA by SIMD decile

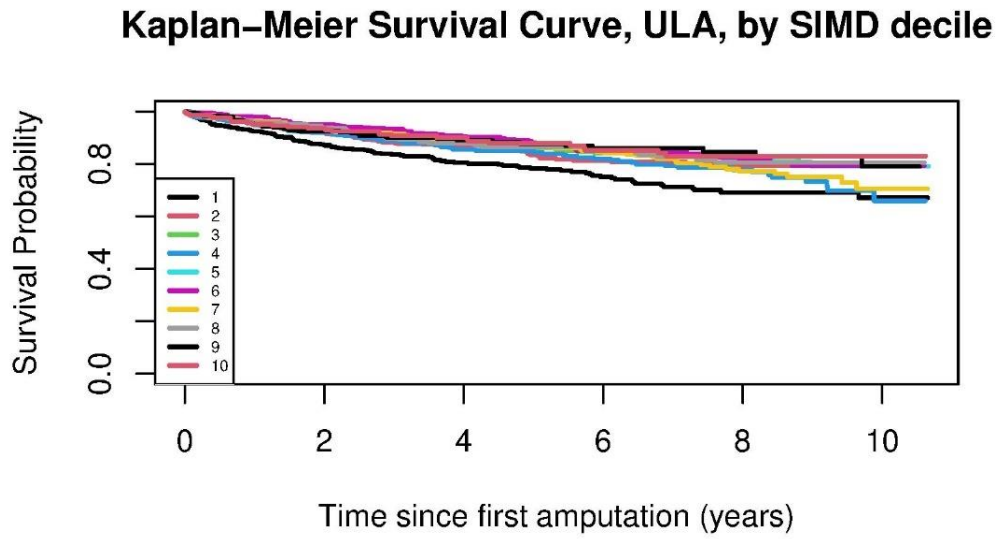

Figure B.14 Kaplan–Meier survival curve, ULA by SIMD decile