

Upper Limb Amputation Rehabilitation: from Context to Standards and Guidelines



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The creation of this document was supported by the EU Horizon 2020 Authored by: Beth Sheehan, Prof. Laurent Frossard, Dr. Nils-Odd Tønnevold and Sandra Sexton

International Confederation of Amputee Associations WWW.IC2A.WORLD

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Four main groups contributed to the feedback process including a:

- (1) Global working group consisting of various rehabilitation personnel and service users
- (2) International Confederation of Amputee Association (IC2A) Board
- (3) Independent analysis and reviewers
- (4) OneHand project consortium.

(1) Working Group

Christine Nakimuli, Service User (Uganda) Jill Dobson, Physiotherapist (England) Kameron Maxwell, Prosthetist (Scotland) Karl Lindborg, Prosthetist (USA) Kate Lancaster, Physiotherapist (England) Katia Vermeire, Service User (Luxumbourg) Lindsay McGreal, Occupational Therapist (New Zealand) Louise Byers, Psychologist (England) Olivia Giles, Service User (Scotland) Rachel Humpherson, Physiotherapist (England)

(2) IC2A Board

Dieter Jűptner (Vice President, Germany) Christoffer Lindhe (Sweden) Isabelle Guerrero (F rance) Vincent Bohouo (Côte d'Ivoire)

(3) Independent review team

Greg Bowring, Rehabilitation Medicine Physician, Prince of Wales Hospital, Sydney, Australia. Hon Professor, Faculty of Engineering and Information Science, University of Wollongong. Conjoint Senior Lecturer, School of Population Health, University of NSW.

Dr Aleena Wojcieszek, Independent Consultant

Dr Tom Walsh, Independent Consultant

Leigh Thornhill, Graphic Designer

(4) Consortium

The Simulation Crew, The Netherlands University of Groningen, The Netherlands Ottobock, Austria Eric Jutten and Edward Bosma Prof. Corry van der Sluis and Dr Raoul Bongers Michael Russold and Daniel Meise

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2.0 Glossary of Terms

The following glossary of terms has been defined specifically in relation to the upper limb rehabilitation pathway and personnel involved. Many of these definitions may be applicable to other healthcare environments or conditions.

Anaesthetist	Relieving pain and providing comfort is central to the practice of anaesthesia. An anaesthetist is therefore a medical specialist who administers medications to minimise unpleasant sensations, including pain. They play a critical role during surgery.
Exercise Physiologist	A degree qualified allied healthcare professional who provides information and advice regarding exercise to help manage injuries and chronic conditions specific to your amputation and individual needs. They are particularly involved at the end stage or lifelong phases of the rehabilitation pathway for upper limb service users.
General Practitioner (GP)	A general practitioner is a doctor based in the community who treats patients with minor or chronic illnesses and refers those with serious conditions to a hospital or specialists. Sometimes referred to as a family doctor.
Limb Absence	An individual who was born without a limb (i.e. congenital) is referred to as having limb absence.
Limb Loss	When an individual has lost a limb due to an acquired amputation (e.g. trauma, cancer, disease etc) this will be referred to as limb loss.
Nurse	A person trained to care for the sick from hospital admission through to discharge at the hospital or healthcare centre.
Occupational Therapist	A degree qualified allied healthcare professional who focuses on function, training the amputee to utilise prostheses as well as other aids and equipment to achieve optimal independence to enable participation in the community, including vocational and/or recreational activities.
Pain Specialist	A doctor who specialises in diagnosing and treating people suffering from pain. They develop a treatment plan to relieve, reduce or manage pain.
Peer Support	An individual who has experienced an upper limb amputation and who can provide empathetic support and a lived experience for an individual who has recently undergone an upper limb amputation.
Physiotherapist	A degree qualified allied healthcare professional who assists in the treatment of disease, injury or limb loss through hands on therapy to optimise musculoskeletal function (e.g. optimising joint range of motion and muscle length and strength through stretching, strengthening and balance exercises). They are particularly involved at the acute phase of amputation and rehabilitation.
Prosthetist	A qualified allied healthcare professional who designs, fabricates and delivers custom made prostheses for those with upper and lower limb absences. Prosthetists working with upper limb service users must have had upper limb prosthetic experience.

Psychologist	A degree qualified professional who specialises in the study of mind and behaviour and the treatment of mental, emotional and behavioural disorders. They are experts in supporting users' adjustment to disability (e.g. limb loss), and other trauma.
Service User	An individual who requires upper limb amputation rehabilitation services.
Surgeon	A medical practitioner qualified to practise and experienced in surgery. For upper limb amputations they may have training in orthopaedic, plastic and reconstructive surgery.

3.0 OneHand Project Overview

The OneHand Project was funded by the <u>European Commission Horizon 2020 Research Funding</u> Program. Building from the strong drivers of upper limb amputee needs, currently unmet by the existing solutions in the market, the central goal of the OneHand project was to accelerate the market introduction of a disruptive user-centred approach to prosthetic hand use – OneHand solution.

The overall project aimed to develop and prepare the market for a virtual reality training platform that prepares upper limb amputees (service users) for the use of a myo-controlled upper-limb prosthetic device. It also aimed to highlight the needs of the service user during the rehabilitation continuum regardless of the technology available. The project therefore included commonly accepted series of clinical standards informing the rehabilitation for upper limb amputations.

The International Confederation of Amputee Associations (IC2A) were tasked with the creation of a best practice guide and accompanying documentation. Through the development of this project the various stakeholders agreed that this document would be a series of standards including commonly accepted clinical interventions aimed at informing rehabilitation personnel globally about key elements to consider throughout the rehabilitation journey, with the service user at the centre of all decision-making. The accompanying documents would be specifically aimed at the service user to assist in informing them and their carers about the rehabilitation journey for people with upper limb loss.

The authoring team acknowledges that in many low resourced countries access to personnel and resources may be limited. These documents therefore aim to be an example of best practice as outlined by experts within the global upper limb amputation and rehabilitation field, and a source for all upper limb amputation services globally to work towards.

PART 1

4.0 Context

Whether upper limb absence is congenital or acquired, living without a part of one or both upper limbs significantly impact and restrict an individual's independence, ability to function and perform basic manual tasks and activities of daily living. In addition to the financial burden associated with treatments, upper limb absence affects an individual's body image, self-esteem, mental health and their participation in society (1, 2).

Unfortunately, it is commonly acknowledged that necessary healthcare and socioeconomic resources allocated to support population living with congenital or acquired limb absence are often inadequate to address their personal, medical and socioeconomic needs particularly in underserviced regions as well as low- and middle-income countries (LMIC). Nonetheless, addressing these needs is essential to their overall well-being and quality of life.

As detailed below, the barriers to meet the actual needs of individuals living with upper limb absence might be, in part or in whole, due to the challenges faced by stakeholders such as service users, healthcare providers and policymakers, to extract relevant population statistics, allocate sufficient resources, find strong evidence of efficacy and safety of interventions, establish standards and guidelines informing best practice rehabilitation as well as the lack of practical information empowering service users.

Within this document, individuals living with upper limb loss, commonly called amputees, consumers or end users, will be referred to as service users. Furthermore, acquired upper limb amputations due to trauma or other causes (e.g., vascular disease, diabetes, cancer, inflection) will generally be referred to as "limb loss". Upper limb amputation due to congenital limb deficiency will be referred to as "limb absence". Habilitation for congenital limb absence will be addressed in another document specific to the service user and their carers and will not be covered in any detail in this document. Finally, we will use the term "guideline" referring to the non-exhaustive lists of clinical standards and guidelines currently acknowledge as best practice.

4.1 Lack of population statistics

Ideally, the knowledge of overall statistics describing the population of individuals living with limb loss in particular regions or countries is required to inform stakeholder, particularly policymakers. Typically, the number of individuals living with limb loss is described in terms of prevalence or incidence. Furthermore, the burden of disease representing the socioeconomic impact of limb loss is quantified in terms of quality-adjusted life years or disability-adjusted life years, considering financial costs, mortality, morbidity as well as function, well-being, quality of life.

McDonald et al (2021) estimated that 21.7 million people live with traumatic non-fatal upper limb amputation (i.e., falls, road injuries, other transportation injuries, mechanical forces) in 2017, with 66% of this population located in East Central Asia, Europe, and South Asia. (Table 1, Figure 1)(3, 4).

Typically, the reported incidence of upper limb amputations is rare and varies from 1.2 to 4.4 per 10,000 to 11.6 per 100,000 (1, 5).

Table 1. Total and regional distribution of individuals living with upper limb amputation due to non-fatal trauma (i.e., falls, road injuries, other transportation injuries, mechanical forces) extracted from (3, 4) % of ULA: Percentage of upper limb amputation in relation of total limb amputations.

		Т	otal	Upper limb			
Ranking	Region	(Million)	(% of ULA)	(Million)	(% per region)		
1	East Central Asia	17	38	6.46	30		
2	Europe	14	29	4.06	19		
3	South Asia	11	34	3.74	17		
4	Africa	5	25	1.25	6		
4	North America	5	41	2.05	9		
4	Middle East	5	26	1.3	6		
7	Central South America	4	40	1.6	7		
8	Southeast Asia	3	30	0.9	4		
9	Australia	1	1 34		2		
	Total	65		21.7	100		

Figure 1. Region distribution of individuals living with upper limb amputation due to non-fatal trauma (i.e., falls, road injuries, other transportation injuries, mechanical forces) extracted from (3, 4).



Unfortunately, extracting more recent and accurate statistics for a given region, let alone globally, is challenging because of the discrepancies between resources and structures across healthcare organisations. The mining of relevant data is hindered by the lack of standardization of clinical terms associated with limb loss and amputation (e.g., minor and major amputations), disparities between causes of amputation (e.g., congenital, traumatic, vascular disease, diabetes, cancer, inflection), absence of centralized and standardized registries (e.g., database, repository), underreporting due to limited access to healthcare facilities (e.g., underserviced areas) or privacy concerns (e.g., stigma associated with disabilities) as well as fast changes in population dynamics (e.g., rapid obsolescence of studies). Consequently, stakeholders of upper limb amputation rehabilitation are often left relying on more or less accurate estimates as well as extrapolations from accessible datasets and statistical models rather than precise counts.

4.2 Challenges to access to resources

The lack of accurate statistics often limits the allocation of sufficient resources toward advocacy and awareness programs (e.g., rights and needs of service users, social inclusion), public health interventions (e.g., campaign of prevention and education), healthcare programs (e.g., personnel, services, facilities), insurance and funding coverage policies (e.g., reimbursement rates for components and services) as well as research and innovation into new solutions (e.g., prosthetic devices, rehabilitation strategies).

4.3 Evidence of efficacy and safety of interventions

In theory, all aspects of upper limb rehabilitation, particularly the efficacy and safety of interventions, should be based on scientific evidence. In principle, publication in a peer-reviewed journal adds credibility to the research findings because the reviewing process is usually based on standardized critical appraisal of methodology and evidence. Altogether, scientific literature focusing on basic and applied aspects of a given treatment should provide critical insights into the potential clinical applications of the treatment.

Recently, PubMed, a free resource supporting the retrieval of biomedical and life sciences literature, was used to search the publications essentially focusing on upper limb rehabilitation. More than 100 individual searches considering combinations of over 180 selected keywords terms was performed. 2,619 articles that were published between 1943 and 2023 (Figure 2A) were found. Interestingly, the number of publications found doubled in the last 7 years, between 2016 and 2023 (Figure 2B). Clearly, there is a significant momentum in publication of scientific studies focusing on this topic.

Figure 2. Overview of (A) the individual number and (B) the cumulated number of articles (2,619) published yearly between 1943 and 2023 focusing on upper limb rehabilitations found in PudMed.





Furthermore, VOSviewer, a free software tool for constructing and visualizing bibliometric networks, was used to map the co-occurrence within and between nodes or clusters of related keywords. In the maps presented in Figure 3, the keywords and the most frequently cited titles and abstracts, were represented by the bigger circles. As expected, Figure 3A indicated that the most frequently cited keywords in the 2,619 published up until 2023 were clustered around four main well-correlated subtopics focusing on "signal" (Cluster 1: 237 keywords), "upper limb amputation" (Cluster 2: 214 keywords), "patient" (Cluster 3: 142 keywords) and "evidence" (Cluster 4: 129 keywords). Figure 3B showed that the most frequently cited keywords in the 1,105 (42%) articles published between 2018 and 2023 were organised around three more concise clusters. The map also confirmed the subtopic related to "patient" (Cluster 1: 26 keywords) and "amputation" (Cluster 3: 20 keywords). Interestingly, it also suggested a change of trends with strong focusing on "control" (Cluster 2: 23 keywords).

Figure 3. Co-occurrence maps of clusters of keywords associated with (A) the 2,619 articles (Cluster 1: "signal" – 237 keywords, Cluster 2: "upper limb amputation" – 214 keywords, Cluster 3: "patient" – 142 keywords, Cluster 4: "evidence" – 129 keywords, Cluster 5: "integration" – 5 keywords, Cluster 6: "targeted muscle reinnervation" – 4 keywords) published up until 2023 and (B) the 1,105 (42%) articles (Cluster 1: "patient" – 26 keywords, Cluster 2: "control" – 23 keywords, Cluster 3: "amputation" – 20 keywords) published between 2018 and 2023, produced by VOSviewer.



More in-depth analysis of the title and abstracts of the 614 most relevant articles published between 2018 and 2023 showed that only 335 (55%) publications involving cohorts of participants that included 192 (31%) case series studies involving 10 or less participants providing Level 2 evidence as well as 143 (32%) cohort studies involving more than 10 participants providing Level 4 evidence (Figure 4). These datasets suggests that the number of studies tend to decrease as the level of evidence increases.



Figure 4. Number and percentage of publications per category of study designs as well as associated weight depending on their corresponding level of evidence (L) for the 614 most relevant articles published between 2018 and 2023.

4.4 Current standards and guidelines

In principle, the treatments prescribed during the course of upper limb loss rehabilitation and beyond should follow some evidence-based standards of care or, even better, Clinical Practice Guidelines (CPGs). The standardisation of care based on best available evidence from research and clinical studies is critical to optimize efficacy (e.g., increase benefits) and safety (e.g., reduce arms) of treatments and interventions. Overall, clinical guidelines play a crucial role in ensuring that service users receive optimal care delivered in a standardized and consistent manner.

In searches of the literature between 2018 and 2023 corresponding to 42% of the overall publication, two systematic reviews focusing on clinical practice guidelines produced by Kwah et al (2019)(6) and Heyns et al (2021)(7) (Table 2) were found. In summary, these reviews highlighted that only a few guidelines are available. These reviews confirm that a best practice for upper limb loss rehabilitation should imperatively place service users at the centre of the rehabilitation journey (e.g., patient-centred care). However, the strength of their recommendations is typically limited because they are based on scientific studies with moderate level of evidence. Furthermore, Heyns et al (2021) stated that there is a need for more content about vocation and education, sexual and/or intimate relationships, activities of daily living or leisure activities, education concerning socket and liner fitting as well as the training and rehabilitation programs.

		Study
Reference	Kwah et al (2019) (6)	Heyns et al (2021) (7)
Title	Quality of Clinical Practice Guidelines for Management of Limb Amputations: A Systematic Review	Systematic Review of Clinical Practice Guidelines for Individuals with Amputation: Identification of Best Evidence for Rehabilitation to Develop the WHO's Package of Interventions for Rehabilitation
Year	2019	2021
Name and country of organizations	Singapore Institute of Technology, Singapore; University of Technology Sydney, Australia; Australian Catholic University, Australia; Tung Wah College, Hong Kong	University Hospitals Leuven, Belgium; University La Statale, Italy; Istituto Ortopedico Galeazzi, Italy; Fondazione Don Carlo Gnocchi, Italy; World Health Organization, Switzerland; Montecatone Rehabilitation Institute, Italy
Number of authors	4	6
Number of countries	3	3
Number of pages	13	6
Number of references	48	23
Number of CPGs considered	15	4
Aims of study	1. Identify CPGs for the management of limb amputations; 2. Appraise the quality of CPGs; 3. Synthesize recommendations from comprehensive CPGs of high quality	1. Report the results of the systematic search performed to identify interventions and related evidence for rehabilitation of individuals with amputation based on the current evidence from clinical practice guidelines
Findings	 Eleven CPGs were of low to moderate quality; 3. Four CPGs were of high quality; Strong recommendations from comprehensive and high-quality CPGs were few; 5. Recommendations focused on the development of individualized treatment plans, exercises for improving physical function and the ability to perform activities of daily living, and the assessment of physical function and prognostic factors 	 At total of 217 recommendations were provided (20 on assessments, 131 on interventions, and 66 on service provision); Recommendations concerned pain management, education, pre- and postoperative management, and residual limb care.; The strength of recommendation was generally weak to intermediate.
Conclusions	 Few CPGs for the management of limb amputations were of high quality; Few recommendations were strong; 3. Improvement the quality of future CPGs, guideline will require information to aid in the practical application of CPGs and use a systematic approach to search for evidence and derive strength of recommendations. 	1. The field of amputation is well covered for recommended interventions; 2. The level of evidence is generally low and is based mostly on expert opinion; 3. There is need for more information about vocation and education, sexual and/or intimate relationships, activities of daily living or leisure activities, education concerning socket/liner fitting and well as the contents of training and rehabilitation programs.

Table 2. Cross-comparison of systematic reviews of clinical practice guidelines about upper limb loss rehabilitation.

Noticeably, two more standards and guidelines have been published since these reviews. One from the British Society of Rehabilitation Medicine in 2018(8) and the other from the United States of America's (US) Department of Defense-Veteran Affairs (DoD-VA) in 2022 (9).

The Management of Upper Limb Amputation Rehabilitation (ULA) guidelines is the results of several decades of efforts made by DoD to address primarily the rehabilitation needs of former and active service members injured in conflicts (e.g., Vietnam War, Middle East conflicts). The basic and applied research generated by the US Department of Defense-Veteran Affairs (DoD-VA) <u>clinical guidelines</u>, through treating US veterans have led to incredible new literature and practical knowledge for the

communities of interest. This CPG is based on a systematic review of both clinical and epidemiological evidence. Developed by a panel of multidisciplinary experts, it provides a clear explanation of the logical relationships between various care options and health outcomes while rating both the quality of the evidence and the strength of the recommendation. This guideline includes a series of practical documents designed to particular stakeholders (e.g., Rehabilitation providers, Primary care providers).

In summary, the guideline made a series of 14 recommendations related to generic phases of rehabilitation including 3 for surgery and pre-prosthetic care, 3 for rehabilitation care, 5 for prosthetic restoration as well as 1 related to outcomes measures and 2 about psychosocial considerations (Table 3). A total of 10 (71%) and 4 (29%) recommendations were supported with an insufficient and a sufficient level of evidence, respectively.

Table 3. Series and level of evidence of the 14 recommendations made to Clinical Practice Guidelines for Management of LimbAmputations (DoD-VA) and Crunkhorn et al (2023) (10).

	Recommendations	Level of evidence					
Surgery an	d pre-prosthetic care						
1	Recommend assessing the impact of the level of amputation or amputation surgical procedure type on functional status and prosthesis-related outcomes	Insufficient					
2	Recommend the use any particular factors to predict the speed and quality of wound healing, successful prosthesis fitting, or need for revision surgery	Insufficient					
3	Recommend for or against the use of any particular recent treatment advances including hardware, software, surgical, technology, or supplemental surgical interventions (e.g., TMR, Insufficient RPNI, VCA, AMI, IMES, OI)						
Rehabilitat	tion care						
4	Recommend for or against any particular training protocol to improve function and outcomes	Insufficient					
5	Recommend the use of mirror therapy for the short-term reduction of phantom limb pain	Sufficient					
6	Recommend for or against any particular treatment setting, intensity, or service delivery model	Insufficient					
Prosthetic	restoration						
7	Recommend the use of a body-powered or externally powered prosthesis to improve independence and reduce disability of patients with major unilateral upper limb amputation (i.e., through or proximal to the wrist)	Sufficient					
8	Recommend for or against any specific control strategy, socket design, suspension method, or component	Insufficient					
9	There is insufficient evidence to recommend for or against a particular intervention for the prevention of phantom and/or residual limb pain.	Insufficient					
10	Recommend for or against any particular pharmacologic intervention for the management of phantom and/or residual limb pain	Insufficient					
11	Recommend for or against the use of noninvasive brain stimulation for the management of phantom limb pain	Insufficient					
Outcomes							
12	Recommend for or against the use of any specific assessment tool to guide the determination of prosthetic candidacy, the need for therapy, or for identifying improvement or worsening of function and quality of life	Insufficient					
Outcomes							
13	Recommend screening patients for cognition, mental health conditions such as posttraumatic stress disorder and depression, and pain during the initial evaluation and across the continuum of care	Sufficient					
14	Recommend offering peer support services	Sufficient					
Note: TMR: allotranspla	targeted muscle reinnervation, RPNI: regenerative peripheral nerve interfaces, VCA: vascularize antation, AMI: agonist-antagonist myoneural interface, IMES: implantable myoelectric sensor sy	ed composite /stem, OI:					

osseointegration

In all cases, one the most significant contribution of this CPG was to map out the typical rehabilitation care pathway including the description of 35 points of decision as outline in Crunkhorn et al (2023) (10). This pathway showed that 13 (37%), 8 (23%) and 2 (6%) of decision points involved care team, specialist and peers, respectively.

Table 4. Series of decision point mapping out the typical rehabilitation care pathway described in Clinical Practice Guidelines for Management of Limb Amputations (DoD-VA) and Crunkhorn et al (2023) (10).

Desision		Involvement				
point	Description	Care team	Specialist	Peers		
Rehabilitation	n providers					
1	Patient present with need for ULA care	0	0	0		
Perioperative	care					
2	Does the patient require perioperative care?	0	0	0		
3	Engage the amputation care team to conduct a comprehensive interdisciplinary assessment; offer peer support	0	1			
4	Is the patient ready for initiation of rehabilitation services?	0	0	0		
5	Refer the patient to appropriate services for care and management	1	1	0		
6	Develop a patient-cantered rehabilitation care plan	0	0	0		
7	Appropriate education regarding currently available technology, surgical, rehabilitation procedures and peer support options should be provided to the patient, family, and caregiver(s)	0	0	1		
8	Ensure patient achieves highest level of functional independence without prosthesis	0	0	0		
Pre-prostheti	c care					
9	Is the patient a candidate for pre-prosthetic training?	0	0	0		
10	Engage the amputation care team to administer pre-prosthetic training	1	0	0		
11	Confirm prosthesis candidacy and determine most appropriate prosthetic device(s)	0	0	0		
12	Write prosthetic device prescription including all necessary components	0	0	0		
13	Initiate upper extremity prosthesis training	0	0	0		
Prosthetic tra	ining					
14	Is the patient a candidate for prosthetic training?	0	0	0		
15	Engage the amputation care team to administer prosthetic training and education	1	0	0		
16	Does the prosthetic device improve functional status and meet realistic patient goals?	0	0	0		
17	Conduct final prosthesis check out including all appropriate members of the care team	1	0	0		
18	Does the patient require additional prostheses and/or terminal device(s)?	0	0	0		
Lifelong care						
19	Ensure patient achieve highest level of functional independence without a prosthesis	0	0	0		
20	Recommend lifelong care and the management of ULA	0	0	0		
21	Coordinate patient transition into lifelong and management (including patient transfer to new catchment area)	0	0	0		
22	Engage the amputation care team and provide routine scheduled follow- up at least every 12 months	1	0	0		
23	Provide education on current management and practice; refer patient as appropriate to address medical, prosthetic or rehabilitation needs	1	1	0		

Primary care	providers			
24	Patient with ULA presents for care	0	0	0
25	Is this the patient's initial visit?	0	1	0
26	Offer mental health referral; referral to amputation team	1	1	0
27	Is there new or worsening pain that limit functions; new or worsening residual limb condition; new or worsening non-amputated limb condition; or new risk factors for amputation progression	0	0	0
28	Referral to Physical Medicine and Rehabilitation specialist; referral to amputation care team	1	1	0
29	Are there changes or need functional goals; need for new or replacement of equipment; need for home or work environment modifications; or need for new or replacement assistive technology?	0	0	0
30	Referral to Occupational Therapist; referral to amputation care team	1	1	0
31	Are there new or worsening prosthesis fit and function issues; need for replacement prosthetic components or supplies; or need for new prosthetic componentry or technology to achieve functional goals?	0	0	0
32	Referral to prosthetics; referral to amputation care team	1	1	0
33	Are there changes in support system; new psychosocial stressors; or new emotional, behavioural, or psychological considerations?	0	0	0
34	Referral to mental health; referral to amputation care team	1	1	0
35	Actively promote and facilitate annual follow-up with amputation care team	1	0	0

Unfortunately, this valuable resource might be only partly relevant for other populations outside the US with an upper limb amputation who might experience different access to care (e.g., advanced treatments, provision of high-end components). Nonetheless, the seminal work does pave the way for future research to develop resources that extend beyond the military population. It is noted as part of future recommendations that development of clinical guidelines, beyond military personnel, is required once consolidation of literature, statistics and objective measures specific to upper limb amputations is solidified.

4.5 Lack of practical information empowering service users

In summary, global and regional accurate statistics about upper limb loss and documentation about standards, let alone guidelines, for trained personnel are sparse, particularly when compared to lower limb loss (8, 11). Currently, upper limb amputation management in each country or service system is depending upon funding systems, availability of skilled prosthetists and rehabilitation personnel. It needs to be noted that the number of rehabilitation personnel with experience in upper limb amputation rehabilitation needs to increase through appropriate training and therefore rehabilitation for upper limb cannot be treated the same as lower limb amputations.

Equally critical is the lack of accessible resources purposely designed to inform service users as well as parents, guardians and careers regarding rehabilitation pathways and clinical options that can empower them to made more educated decisions about their care. This is essential to facilitate shared decision-making model, patient-centred rehabilitation care and co-creation of prosthetic solutions.

Another consequence of the lack of basic information is the mismanagement of service user's expectation and a hight rate of abandonment.

5.0 Need for Rehabilitation Guidelines

Rehabilitation guidelines tend to be written by groups of experts for clinicians or decision makers within a given health care system. They use specific scientific terms that are not always clearly interpreted or easily accessed appropriate for the general public to read and interpret. Furthermore, rehabilitation guidelines and supporting publications are commonly published in English scientific journals with conditional access that, all combined, restrict access for non-English speaking and non-academic stakeholders. Clearly, there is currently a gap in the transmission of the current state-of-the-art knowledge to those the heart of the care.

Therefore, there is a need to create a set of documents that highlight best practice of upper limb amputation rehabilitation that enables personnel working globally in upper limb amputation to ensure there are points of references they can work with. The documentation would also include information that enables the persons with limb loss themselves to better understand the rehabilitation journey and clinical options.

A literature review undertaken as part of the OneHand project, already mentioned above, attempted to address some knowledge gaps within the literature for upper limb loss rehabilitation (e.g., lack of global statistics, limited research interconnecting key success factors and interventions, dominance of case series compared to cohort studies, challenge to recruit relevant sample size increasing reliance of able-bodied participants rather than service users, the dearth of specific objective measures, issue with multiple meanings of clinical words). From a service user perspective, it demonstrates the need for improved basic and practical knowledge about key success factors associated with neuromusculoskeletal pain, satisfaction with fitting of prosthesis, level of ambidexterity and the ability to function as well as their relationship with interventions critical stages of rehabilitation pathways (Figure 5, Table 5). It does also acknowledge emerging technologies and potential impact for functional performance.

Furthermore, the literature review demonstrates that by providing relevant information about the rehabilitation programs and expectation of outcomes is paramount to inform, thereby, empower clinicians and service users globally, particularly for those not supported by military funding.

This best practice guide has therefore been informed by the literature review and its thorough method, a working group comprised of service users and rehabilitation personnel that provided expert experience and real-life examples as well as being reviewed by external experts.

Whilst the rehabilitation process will be individualised, this guideline has been created with a particular focus on lived expert opinions (rehabilitation personnel and upper limb amputees) as well as peer-reviewed publications with various levels of evidence and strength of recommendations (i.e., expert opinion, design study, case series, narrative review, case control, cohort study, literature review, randomised trial, systematic review, practice guideline). It is important to note that those providing services may also utilise their own internal standards of care and guidelines alongside this best practice guide for upper limb amputation rehabilitation until consensus has been reached to develop an appropriate and a consensual clinical guideline solely on upper limb amputations is available.

PART 2 - Standards and Guidelines

6.0 Scope

Most upper limb amputation studies presented in scientific literature, predominantly include participants with traumatic amputations. This guide will focus primarily on acquired upper limb amputations. Congenital limb deficiency will be covered in a document specific to parents, guardians and carers of people with congenital limb deficiency.

These documents are not designed to include detailed information about the various types of prostheses and technology available. Nonetheless, acknowledging that hand reimplantation or arm transplants alongside exciting new interventions associated with attachment (e.g., 3D-printed socket, direct skeletal anchorage), prosthetic components (e.g., myo-electric, activity-specific device) and control mechanisms (e.g., targeted muscle reinnervation (TMR), regenerative peripheral nerve interfaces (RPNI)) are emerging. Each one will require specific guidelines once sufficient peer-reviewed evidence of efficacy and safety are published. In the meantime, these guidelines will primarily focus on the most rehabilitation interventions commonly accepted as standard of care for acquired upper limb amputations.

7.0 Objectives

The overall goal of this guideline and accompanying resources is to address the identified gaps and to enable rehabilitation teams and healthcare services globally, to strive towards a higher level of treatment for people with upper limb loss. The accompanying documentation will also enable upper limb service users, to gain a clearer understanding of the phases of rehabilitation following an amputation and to enable a more transparent rehabilitation journey.

Whilst there will be discrepancies between low-resourced to high-resourced regions and countries, the aim is to provide points of reference and benchmarks for stakeholders to work with and ensure that rehabilitation services are provided for the widest population living upper limb loss.

Practically, the objectives are to:

- 1. Highlight the typical pathways and phases that upper limb prosthetic service users experience, whilst emphasising the individual nature of upper limb loss.
- 2. Outline each key phase of upper limb amputation rehabilitation in adapted format to help improve the rehabilitation pathway for upper limb service users globally.
- 3. Provide clear documentation relevant for service users as well as rehabilitation personnel.

8.0 Organisation of standards and guidelines

The guideline is designed to discuss key features that services globally should incorporate for upper limb service users within each phase of rehabilitation. It acts as a benchmark for services regardless of the geographical setting.

At the start of each phase of rehabilitation, there is a 'goals' box that includes the primary information featured in each phase. Each phase outlines key information that should be translated and provided to the service user and their families or carers and ensures the service user is at the centre of the rehabilitation pathway. The best practice document is not intended to be provided to the service user however will be <u>available publicly</u> for anyone who wants a more detailed explanation of the phases of upper limb amputation rehabilitation.

Accompanying documents provided appendices section are intended to the service user to help improve their rehabilitation journey. These include:

- List of Prosthetic Options (Table 8)
- Rehabilitation Exercises Without a Prosthesis (Appendix 2)
- Peer Support Associations (Appendix 3)
- Frequently Asked Questions for People with Upper Limb Amputations (Appendix 4)

9.0 Upper Limb Amputation Rehabilitation

Upper limb amputation rehabilitation is determined by multiple factors. Intrinsic factors depending on the individual alone includes personal and medical factors. Extrinsic factors associated with the individual environment depend on physical living space and prosthetic care. The interactions between the intrinsic and extrinsic factors have direct consequences of the residuum health. Simply, residuum health is defined as the medical condition of a salvaged limb, considered as a single neuromusculoskeletal system, interconnecting individual's tissues including skin, adipose, muscles and bone as well as tendons, nerves and fascia (12, 13). Rehabilitation therefore requires a multifactorial approach.

Every individual who experiences upper limb loss will undertake a unique rehabilitation journey. Whilst aspects of the process will be individualised, the phases of upper limb amputation rehabilitation will have some similarities. Subsequently the phases of amputation rehabilitation aim to assist in guiding rehabilitation personnel to have an evidence based, systematic approach, yet service user centred to ensure that the individual needs and nature of recovery are considered. It is important to note that there is generally insufficient evidence to recommend for or against any particular treatment setting, intensity, or service delivery model (9). The recommendation for mirror therapy to alleviate phantom pain might be an exception giving that this efficacy of this treatment is well demonstrated in the literature. This guide therefore outlines best practice as determined by service users and rehabilitation personnel with experience in upper limb amputations.





10.0 Phases and Stages of Rehabilitation

Due to the individualised nature of rehabilitation, and thus the impacts of residuum health, the phases of upper limb rehabilitation cannot be based on time frames and will overlap during the rehabilitation and lifelong journey post initial amputation. Rehabilitation personnel are encouraged to consider the collaborative efforts required for rehabilitation to improve function, overall wellbeing and to ensure the rehabilitation journey meets the needs of the individual.

The rehabilitation pathway will be informed regularly by an individual's needs, functional goals, healing capacity, presence of pain, residual limb presentation, psychological state and financial resources (10).

Traditionally, the rehabilitation journey for upper limb amputations is logically separated into key successive phases of overall rehabilitation cycles (e.g., meso-cycles) including pre-amputation or perioperative, acute or postsurgical, subacute or pre-prosthetic training, prosthetic training phases as well as long-term rehabilitation or ongoing care (e.g., macro-cycles) (14, 15):

However, the stages of rehabilitation within these phases are fluid and based on the individual's overall heath, medical condition, response to treatments, etc. Practically, individuals tend to experience a series of successive shorter cycles (micro-cycles), alongside theoretical rehabilitation pathway, as represented in Figure 5. In principle, the rehabilitation pathway follows an upward or downward evolution depending on the favourable or adversary effects of interventions on individuals' experience with key success factors. We subjectively organised the intervention corresponding to the fitting of sockets as well as the fitting, training and use of passive, body powered and myoelectric protheses around nine fluent and dynamic stages of rehabilitation. It should be noted that hybrid and activity-specific terminal devices were not included although they can play an essential role to achieve particular outcomes. Key success factors are associated with neuromusculoskeletal pain (e.g., residuum, contralateral neck and should pain, back pain), satisfaction with fitting of prosthesis (e.g., experience with socket attachment, prosthetic components and terminal device), level of ambidexterity (e.g., use of prosthetic hand alone, contralateral hand and both hands together) and the ability to function (e.g., achieve dexterous tasks requiring with fine motor control, movement for gross motor skills and complex activities of daily living).

Scientific studies confirmed the clinical hand-on experiences showing that the upward (e.g., daily use) and downward (e.g., abandonment) rehabilitation trajectories are essential determined by the ability of the service users to handle the training required to learn how to use body powered and more importantly myoelectric prosthesis.

Incidentally, a series of searches was performed, purposely focusing on each key success factors and the interventions related to fitting of components and the control of the prosthesis within the 614 articles published between 2018 and 2023 identified as explained earlier. Individual publications were allocated a number of points according to the level of evidence of the methods (e.g., Unclear: 0 pt, Expert opinion: 1 pt, Design study: 1 pt, Case series: 2 pts, Narrative review: 2 pts, Case control: 3 pts, Cohort Study: 4 pts, Literature review: 5 pts, Randomised trial: 5 pts, Systematic review: 6 pts, Practice guideline: 7 pts). A score was then obtained summing the number of publications weighted their allocated point. The combination of few publications with low points lead to low score while the combination of many publications with hight points lead to hight score. Table 5 presents the heatmap of the scores obtained for each search focusing on the combination of particular factors and intervention, so that the spectrum from green to red was proportional to the high and low scores, respectively. Interestingly, this heatmap confirms that there is a lack of evidence about clinical outcomes for most interventions and contralateral and back pain, satisfactions about the socket and prosthetic components as well as use of prosthetic hand and reliance on contralateral hand. This might be because the efficacy of most interventions is mainly assessed through functional ability and outcomes measures more or less standardised. This information confirms the challenge to establish guideline considering the service user centred key success factors and outcomes.

Figure 5. Typical rehabilitation pathway following an upward or downward evolution across nine stages depending on the effects of interventions (e.g., fitting of sockets as well as the fitting, training and use of passive, body powered and myoelectric protheses) on individuals' experience with key success factors (neuromusculoskeletal pain, satisfaction with fitting of prosthesis, level of ambidexterity, ability to function.



Table 5. Heatmap the score (number of publications, point allocated for level of evidence) for 614 articles published between 2018 and 2023 focusing on combinations of key success factors and interventions were the spectrum from green to red is proportional to the high and low scores, respectively.

			omuscul	oskeleta	al pain	F	itting sa	tisfactio	n	A	mbidext	erity lev	vel		Function	al abilit	y
		All	Residuum	Contralateral	Back	AII	Attachment	Components	Terminal device	AII	Use of prosthetic hand	Use of contralateral hand	Use of both hands	AII	Dexterity	Gross motor skills	Daily activities
	Nb Pub	118	20	3	4	139	4	5	48	33	5	8	14	486	76	360	86
Intervention																	
Device																	
All	319	130	27	11	11	185	1	1	67	41	3	10	20	563	91	411	126
Attachment	44	38	9	7	7	57	1	1	6	5	1	0	4	82	14	72	26
Passive	22	10	2	0	0	21	0	0	10	2	0	0	2	37	6	32	8
Body powered	27	25	5	4	4	43	0	0	4	10	0	0	6	60	12	58	18
Externally powered	170	64	11	0	0	98	0	0	36	22	2	4	14	312	50	209	71
Hybrid	15	1	0	0	0	2	0	0	2	2	0	0	2	17	2	10	6
Activity specific	11	4	0	0	0	11	0	0	4	0	0	0	0	20	4	15	7
Control																	
All	449	177	37	0	0	213	4	1	90	56	8	16	19	744	113	499	140
Device	298	93	21	0	0	99	4	0	44	14	4	6	2	458	67	292	66
Feedback	384	155	37	0	0	171	4	1	72	44	8	16	11	657	100	437	112
Algorithms	285	86	15	0	0	128	2	0	55	26	2	8	14	487	75	330	93

Altogether, the rehabilitation efforts made by the service users and the rehabilitation team should be directed as much as possible towards sustaining the upward pathway to maintain low neuromusculoskeletal pain including phantom pain and low reliance of contralateral hand to achieve a high degree of function. For those who have a prosthesis this will also be dependent on a high quality of fit of the prosthesis.

It is however important to note that many upper limb service users will however utilise the residuum limb, with or without their devices, to perform specific tasks where the functional benefit or outcome is clear. This is more relevant for distal limb loss e.g., partial hand, where sensation is intact or for some below elbow service users. Maintaining a rehabilitation program is however imperative regardless of whether a prosthesis is or will be used.

Practically, individual rehabilitation pathways are much more multi-factorial and fluid. Bespoke rehabilitation programs require regular adjustments. Therefore, it is essential that people living with upper limb loss understand that whilst there are key phases of rehabilitation, their post-amputation journey may sometimes go backwards (e.g., further surgery, wound or skin irritation issues), stay within a state (e.g., training with a particular prosthetic component) before moving upward (e.g., improve dexterity and pain). This is where the education is important from the beginning of the amputation process for the service user, care giver and support team. Rehabilitation personnel are in a prime position to facilitate these educational opportunities and highlight the fluid and individual nature of upper limb amputation rehabilitation.

Abandonment of upper limb prosthesis is common and often occurs when service users experience a lack of comfort, poor cosmesis or appearance, lack of functional benefit or need to revisit certain stages of the rehabilitation journey. The rehabilitation personnel therefore need to work collaboratively with the individual to improve their rehabilitation journey, try to reduce abandonment or find alternative solutions to improve an individual's degree of dexterity, comfort and functional benefits.

For the purpose of clarity for rehabilitation personnel, these guidelines will be broken up into the key phases of rehabilitation but will refer to the states as outlined in Figure 5.

10.1 Pre-amputation or Peri-operative Phase

GOALS OF PRE-AMPUTATION PHASE

- » Patient centred approach with the individual's function, independence and support network being considered as part of upper limb amputation rehabilitation.
- » Determine amputation level (understanding of the structures and function that has been affected and whether future operations may be required).
- » Determine clinical pathway (personnel involved) and treatment approach with education and information being provided to the individual and their support network of family or care givers.
- » Assessment of patient's current health status, functional needs, goals.

Upper limb amputations are classified based on their level of amputation as described in Table 6 (16). An amputation will be required if there is excessive tissue loss, vessel occlusion, necrosis or potential sepsis.

International Standards Terminology	Common Terminology	Minor or Major Amputation
Forequarter	Forequarter	Major
Shoulder disarticulation	Through shoulder	Major
Transhumeral	Above elbow	Major
Elbow disarticulation	Through elbow	Major
Transradial	Below elbow	Major
Wrist disarticulation	Through wrist	Major
Partial hand	Through hand, ray	Minor
Thumb	Thumb	Minor
Digits (upper extremity)	Fingers	Minor

Table 6. Upper Limb Amputation Level Terminology

Due to the high percentage of upper limb amputations being traumatic in nature, unlike lower limb amputations, many service users do not receive the option of pre-amputation consultations and treatment (1, 8, 17).

For those unable to make an informed decision regarding amputation (for example due to trauma induced coma or an inability to communicate) many of these decisions will be made by the surgical team and the individual's family or care givers in order to save their residual limb, quality of life, function and potentially their lives (18). There is however insufficient evidence to assess the impact of the level of amputation or amputation surgical procedure type on functional status and prosthesis-related outcomes (9).

When an amputation is a clinical option for an individual's treatment and management plan, the preamputation or perioperative phase commences (8, 18). Unfortunately, aside from smoking, there are no significant factors that will predict the speed of wound healing, successful prosthetic fittings or the need for revision surgeries (9). It is therefore imperative that clear communication and coordination of care occurs between the multidisciplinary surgical and rehabilitation teams.

If pre-planned amputations are available, prescribing a pre-amputation individualised rehabilitation program will help with the long-term outcomes post-surgery. In the pre-amputation phase, early assessment and planning of rehabilitation (pre and post amputation) helps prepare the individual for the amputation and rehabilitation process.

In instances whereby both upper limbs are affected this will also impact the subsequent prosthetic or assistive technology required for the individual and impact their rehabilitation pathway (see Figure 1).

Table 7: Examples of assessments for pre-amputation phase

See Appendix 1 for full list of Objective Measures and Assessments

Assessments
Present health status
Level of function
Modifiable / controllable health risk factors
Pain assessment
Cognition and behavioural health
Personal, family, social and cultural context
Learning assessment
Motivational assessment (determining if individual is mentally prepared for training and rehabilitation)
One handed preparedness
Non-affected and trunk assessment
Prosthetic assessment (if applicable)
Vocational assessment
Peer support availability

For those that have elective or pre-planned amputations, examples of some key assessments utilised globally are listed in Table 7 and further detail is included in Appendix 1. A thorough initial assessment including biopsychosocial factors, history and impact for the individual should be included as part of the pre-amputation assessment for the individual prior to surgery being undertaken (9). These assessments are performed by multiple personnel (e.g. surgeon, physiotherapist, psychologist). It must be noted that further research is required to consolidate the number of assessments utilised and for the creation of future assessment tools to be targeted specifically for upper limb loss.

In some cases, multiple amputation procedures (unilateral or bilateral) may need to occur beyond the initial amputation to reduce complications for the residual limb and to maintain quality of life. The communication between the surgical team and support staff to optimize surgical and function outcomes will be critical (18). The surgical and rehabilitation team will be required to ensure the individual and their family or carers are made aware of the potential complications and ongoing treatment.

The time frame for this phase will be dependent on the individual, their condition, presence of comorbidities or disease as well as the longevity of the complications with the affected limb. Inclusion of specialist personnel for treatment of other co-morbidities may be required. Funding method and healthcare system available may also impact how long until the amputation occurs and will be country specific. If it was an emergency amputation, then these above factors may not be able to be considered. The pre-amputation or peri-operative phase ends when the amputation occurs.

Personnel Involved

For best practice, this pre-amputation phase requires a multidisciplinary approach and would involve the surgeon and surgical team (nurses, anaesthetist), rehabilitation team (occupational therapists, rehabilitation physicians, physiotherapists, exercise physiologists, psychologists) as well as a certified prosthetist with upper limb amputation experience (8).

Other key personnel required as part of the early pre-amputation phase of rehabilitation and treatment include:

• Psychological support offered to the individual to prepare for surgery, post-surgery rehabilitation process and coming to terms with their limb loss (8, 19, 20).

- Inclusion of the individual's family, carers or chosen support present during the consultations to assist with processing the information and education being provided (21).
- Provision of <u>peer support</u> offered for service users to assist in the psychological healing and adaptation to a change in function post amputation and improve long term outcomes for the individual (22).

Service User Information

The information provided during the pre-amputation phase can be overwhelming. For an individual who has had a traumatic experience, it will be challenging for information regarding the upcoming surgery and postsurgical treatment to be retained and processed until after the surgery has taken place and may require several information 'sessions' for the information to be processed. The ability to process the information and the next steps is highly individual and personnel are encouraged to individualise the approach for each service user.

When information is being provided, rehabilitation personnel are encouraged to ensure that a family member or carer is present with the service user to assist in processing the information provided. Information provided should be clear and concise and include both verbal information as well as graphics to assist service users in processing the loss of their limb(s). Examples of information provided could be in the form of pamphlets, websites and innovation applications.

Information provided to the service user during this phase include:

- Information regarding the rehabilitation pathway and key steps (from amputation through to long-term care).
- Understanding the prosthetic options for their level of amputation. This will include the different types of technology available within their country for their level of amputation as well as assistive devices to use for activities of daily living and other tasks specific to the individual (see Table 8).
- Education on pain and sensation (e.g. phantom limb pain, post operative pain etc).
- Mobility and functional expectations based on their amputation.
- Understanding of the type of exercise and rehabilitation program that will be provided including range of movement and strength training exercises pre-amputation (if amputation is planned) (see appendix 2 of exercises without a prosthesis).
- Psychological support options.
- Peer support options (See appendix 3 for peer support associations).

10.2 Amputation Phase

GOALS OF THE AMPUTATION PHASE

» Appropriate limb salvage.



This phase specifically refers to the time of amputation and immediately after, particularly for individuals who have not had a planned amputation.

As mentioned in the pre-amputation phase, amputation surgery should be undertaken by a specialist upper limb surgeon with knowledge in orthopaedic, plastic/reconstructive and vascular surgery (8) and supported by key surgical staff and multidisciplinary rehabilitation team to enhance the rehabilitation process and outcomes for the individual (8, 21, 23).

The level of amputation, without the opportunity for the pre-amputation phase, may be determined during surgery and will be dependent on what anatomical structures can be preserved (24, 25) with the aim to preserve as much mobility and function as possible for the residual limb (18).

Amputations are named by the level at which they have been performed as listed in Table 6. Starting at the distal end of the arm there is: trans-phalangeal, trans-metacarpal, trans-carpal, wrist disarticulation, trans-radial, elbow disarticulation, trans-humeral, shoulder disarticulation, and forequarter amputation (26). Depending on the complexity of amputation (e.g., due to infection or complex trauma), some individuals may require multiple surgeries before the final residual limb and level are determined. The level of amputation will subsequently affect residual function and dexterity, rehabilitation options, prostheses options and goals (2, 17, 21) as outlined in Figure 1.

Once surgery has occurred, psychological and peer support should be provided as an option (8, 22) but personnel need to acknowledge that the individual may not be ready for these services.

10.3 Initial Post-Amputation Phase

GOALS OF THE INITIAL POST-AMPUTATION PHASE

- » Optimise wound management.
- » Optimise pain management.
- » Prepare the residuum (e.g. volume management, shaping, desensitisation).
- » Prepare for pre-prosthetic training.
- » Education on prostheses and adaptive devices available within the service user's geographical location.



This post-amputation phase will refer specifically to the initial post-surgical management of the residual stump(s). Upper limb amputations generally heal faster than lower limb amputations however healing times will vary between individuals (8). Wound healing and management will be a significant part of this phase to ensure that the residual limb is ready for a prosthesis and adaptive devices. Referring to Figure 1, understanding the impact of pain, reliance of contralateral hand and functional performance ability will also contribute to the healing stages throughout rehabilitation.

The nursing team will be the primary providers of care during this phase and will facilitate training and advice regarding wound management and post-surgical care to ensure the individual and their family or carer(s) understand how to manage their residual limb(s) post-surgery.

Literature reports that to reduce abandonment there is the 'golden window' of fitting within 4 weeks of amputation (27, 28) however experts state this could be up to 8 weeks before the prosthesis, but ultimately prosthetic fit will be possible once the residuum is robust to withstand a prosthesis or device. This will be determined based on wound healing, surgical complications and skin irritations.

Before progressing onto the pre-prosthetic training, the service user must be cleared medically, surgically and psychologically to ensure prosthetic socket fitting can commence. If prosthetic intervention is not appropriate or not wanted by the individual then rehabilitation will still be required to optimise personal care and independence using alternative techniques, aids and environmental modifications.

Wound healing

Wound healing, oedema management and hygiene education are critical to reduce muscle contractures and enable better rehabilitation outcomes and prosthesis acceptance (29). To assist with oedema reduction and stump shaping, compression therapy will form an essential part of rehabilitation post amputation. Beyond hospital management, these tasks, through appropriate education, can be performed by the service user or with assistance (particularly for bilateral upper limb service users and those with more proximal level of limb loss) (29).

Upper limb service users will need to be provided with appropriate information to understand the different types of wounds and skin irritations that may occur post amputation but also during the rehabilitation pathway and beyond.

Pain

95% of upper limb service users report phantom limb sensation or pain (29). Understanding the different types of pain, phantom sensation, phantom limb pain and residual limb pain as well as pain associated with heterotopic ossification and neuromas (unusual bone formation and growths), will assist the rehabilitation personnel provide appropriate rehabilitation methods and help to educate the service user. For those with heterotopic ossification or pain associated with neuromas post-surgery (approx. 1 month or longer), medication and further surgery may be required.

A detailed explanation of the types of pain can be found in Appendix 4 FAQs for service users. There is however insufficient evidence to recommend for or against a particular intervention for the prevention of phantom and/or residual limb pain (9) and no sufficient evidence to support a particular pharmacological intervention for management of pain. (9) Taking an individualised approach and engaging with pain specialists, psychologists, and appropriate expert personnel to determine coping mechanisms and treatment relevant for the individual would be best practice.

Some experts and literature have supported the following treatments that may assist some individuals, not all and further research is required in determining effective and consistent phantom limb pain management.

- Desensitisation for residual limb hypersensitivity, which could be incorporated as part of the rehabilitation plan and supported by the multidisciplinary team (9).
- Appropriate compression bandaging has been shown to assist with pain management as well as visual feedback for example mirror therapy, mental imagery and finally virtual reality (29, 30).
- Other forms of treatment will include prescribed medications.
- Mental health techniques such as eye movement, desensitization and reprocessing (EMDR) therapy(30, 31). These can be incorporated in the early stages of the training and rehabilitation program post-surgery.

Physical therapy

During this assessment phase post amputation, objective measures or baseline measurements will be taken to record the development of rehabilitation throughout the phases. An example list of objective measures is listed in Appendix 1 based on each stage of rehabilitation. It is again important to note that there has been no consensus on the specific objective measure tests for upper limb amputations, compared to lower limb and predictive mobility tests like the AMPRO and AMPnoPRO(32). A collaborative upper limb special interest group is however being formed by the International Society of Prosthetics and Orthotics (ISPO) to try and work towards a more cohesive approach to upper limb rehabilitation and objective measures.

Prior to the introduction of an exercise program, a full musculoskeletal and neurological assessment will be conducted to assess the residual limb(s) as well as the adaptations to the remaining limbs and body positioning. These assessments (see Appendix 1) will be undertaken by qualified allied health professionals and usually have a background in physiotherapy, exercise physiology and occupational therapy.

Assessments will include range of motion measurements for each joint, postural based exercises as well as gross motor function and activities of daily living to determine the level of function and support required. These tests can also translate into specific early phase rehabilitation exercises to maintain movement, flexibility and reduce contractures in the residual limb(s) (29). There has been some early research into the role that virtual reality could have in assisting in rehabilitation to provide a smoother transition to prosthetics and assistive devices (5) (33).

The role that exercises play in the contralateral or unaffected limb(s) is just as important as the affected limb/s and regular assessment ensures that changes are observed and improved as well as ensuring that no overuse or compensations to the body occur that result in poor posture or movement patterns (29).

Upper limb loss increases the reliance on an individual's abdominal strength. The role that abdominal strength or 'core' strength plays in rehabilitation must not be overlooked and should be included as part of the overall rehabilitation program and considered as part of the baseline measures post amputation (Appendix 1). Ensuring a full body comprehensive exercise program is included in the overall rehabilitation program will help to improve adaptations in the body as a result of limb loss.



Functional training

As part of the physical therapy program, education regarding retraining for functional tasks will be included. Service users who have lost their dominant limb will require functional retraining of hand dominant tasks for example cutting, using scissors, writing etc. Understanding the impact of losing an upper limb on an individual's physical body and ability to perform everyday activities is critical. The body needs to learn to adapt, and understanding the physiological changes will be crucial in helping an individual come to terms with their limb loss. Rehabilitation personnel and service users need to ensure that functional training needs to monitor the use of the unaffected side to ensure overuse injuries do not occur.

Psychological support

Physical and functional training needs to be accompanied with psychological support relevant to upper limb loss(29). During initial assessments and across the continuum of care, screening individuals for cognition, mental health conditions such as posttraumatic stress disorder and depression, and pain. (9) Should an individual not be ready for psychological interventions or support, service users should still be offered this service as part of this and all rehabilitation phases.

Psychological support will be provided by trained therapists with experience in trauma related conditions and be provided by personnel such as a psychologist or psychiatrist if medication for mental health is required. Psychological and peer support ensures that the service user has support aside from their family and care givers.

Peer support

Offering peer support services is strongly suggested (9, 34). The provision of peer support in service delivery increases the motivation of users, may speed up treatment and contributes to improved outcomes (34). Through peer support provision, the service user can understand how others managed to adjust to their new situation after, for example, trauma or disease (35).

Service users should be encouraged to discuss both peer support and psychological interventions with their hospital personnel or doctor. A list of peer support groups and associations around the world can be found in Appendix 3 and at <u>www.ic2a.world</u>.

Prosthetic and assistive technology requirements

As part of the post operative phase, assessment of prosthetic requirements and prescription of prosthetic and adaptive technology/devices is required. There is insufficient evidence to recommend for or against the use of any specific assessment tool to guide the determination of prosthetic candidacy, the need for therapy, or for identifying improvement or worsening of function and quality of life(9). Further research is required to support the development of a collaborative tool specifically for upper limb loss.

It is also important to be aware that there is insufficient evidence to recommend for or against the use of any particular recent treatment advances including hardware, software, surgical, technology, or supplemental surgical interventions, such as: targeted muscle reinnervation (TMR), regenerative peripheral nerve interfaces (RPNI), vascularized composite allotransplantation (VCA), agonist-antagonist myoneural interface (AMI), implantable myoelectric sensor system (IMES) or osseointegration (OI). Is has however been suggested that for service users with major unilateral upper limb amputation (i.e., through or proximal to the wrist), the use of a body-powered or externally powered prosthesis will assist in improving independence and reduce disability.(9)

Individual preference, skills and functional need as well as in country availability of assistive technology and prosthesis(es) will determine the type prescribed for the individual (9). Understanding the needs and goals of the service user is therefore critical in determining prosthetic and assistive device prescription.

The service user will work with the occupational therapist and prosthetist to allow for any concerns to be addressed and their rehabilitation journey to be mapped in accordance with personal requirements, activities of daily living (ADLs), hobbies and interests as well as ensuring that the prosthesis(es) prescribed meets the functional needs of the individual. The prosthetist also discusses realistic expectations with the service user regarding the prosthetic technology available in their country.

As part of the prosthetic and adaptive technology assessment, technology/devices utilised within the home and potential return to vocation or translation and retraining of vocation needs to be considered. An assessment, usually undertaken by an occupational therapist will help determine the service user's requirements and skill adaptations needed and subsequently work with the prosthetists and service user to determine what types of prosthetic componentry and assistive devices the service user may also require.

Service User Information

Individuals who have undergone an upper limb amputation require education and demonstration regarding regular wound management (18). Individuals should be provided with key information on what to look for regarding wound care, hygiene and protection in order to progress the healing process and prevent any potential complications.

The pain experienced post amputation will vary between individuals. A multidisciplinary approach regarding pain management will help support the individual to better understand the types of pain which may occur and how to manage them. A multidisciplinary team will provide education and management around pharmacological treatment, when it is needed, as well as other interventions such as mirror therapy and desensitisation.

The service user will require education on the role of exercise and maintaining strength in the unaffected limb (s) as well as the residual limb. Understanding the role that exercise plays in each phase is essential in the progression of residual limb function, strength of the unaffected limbs, impact on postural control following limb loss and in improving independence and ability to perform activities of daily living. An occupational therapist will provide support to assist in adjusting to potentially altered limb dominance and its impact on to vocational and leisure activities.

As discussed in this phase, services users also need to be informed as to the type of prothesis(es) and assistive technology that is available for them and their functional needs.

10.4 Pre-Prosthetic Phase

GOALS OF OF THE PRE-PROSTHETIC TRAINING PHASE

- » Prepare the limb and body for a prosthesis or assistive devices.
- » Provide rehabilitation strategies to assist in reducing prosthesis rejection.
- » Maintain strength, function and independence.
- » Retrain hand dominance (if required).



This phase specifically prepares individuals for a prosthesis(es) or assistive devices specific to their functional needs and goals. If we consider Figure 1 and the upward and downward trend of upper limb loss and the rehabilitation care pathway, pre-prosthetic training will be critical in the rehabilitation journey due to the high rate of prosthesis rejection reported for upper limb service users once fitting and donning of the prosthesis(es) occur. Obtaining objective measures at the commencement of this phase will also enable a baseline for treating rehabilitation personnel to refer to and to demonstrate changes pre and post prosthetic use (see Appendix 1 for objective measures).

Prosthesis prescription, and/or assistive devices, will be determined with input from a multidisciplinary rehabilitation team that includes the prosthetist, rehabilitation personnel (such as physiotherapist, occupational therapist), family and/or carers as well as the service user to ensure their needs and goals are included and realistic expectations are discussed (8, 15, 21, 36). Consideration of multiple assistive devices or prostheses may also impact the rehabilitation program provided based on the technology that will be utilised. The type of prosthesis (body powered compared to externally powered prostheses – see Table 8) will also determine some of the training and rehabilitation activities or exercises that are required. Initially most individuals who will utilise a prosthesis will be fitted with a body powered prosthesis (i.e. cable and harness). Once the residual limb can maintain its volume and tolerate weight, other more advanced prostheses may be prescribed.

This guide does not cover the individual rehabilitation activities and exercises for the different types of prostheses. There is insufficient evidence to recommend for or against any particular training protocol to improve function and outcomes (9). Personnel are encouraged to work in collaboration with prosthetists to understand the relative functions and requirements of each type of prosthetic option to ensure the service user is educated and prepared for the prosthetic phase of rehabilitation and the subsequent exercise program adjusted accordingly.

Types of Upper Limb Prosthetic Options	Description of key design features
No prosthesis	n/a
Passive prosthesis	This prosthesis has no moving parts. It usually has a cosmetic hand that does not have any function.
Body powered prosthesis	Body powered (cable and harness) split hook (or hand) and can be fitted very early (i.e. at 4 weeks if all heals very well). Individuals usually stay with this prosthesis for 3-6 months.
Hybrid prosthesis	This prosthesis combines body powered components with myoelectric or externally powered components.
Externally powered prosthesis	Externally powered i.e. Myoelectric. In some countries they are not fitted initially because the individual needs a very stable residuum and will not be able to tolerate the weight of the prosthesis. In other countries they maybe the prosthesis utilised from the start. Check what is available within the country's health system.
Task specific prosthesis	Task specific prostheses - e.g. sport leisure or work – very popular if the individual loves certain activities like weight training, cycling, kayaking etc.

Table 8. Types of upper limb prosthetic options

As part of the rehabilitation program, an occupational therapist will assess the task specific requirements for functional independence, and later, community independence, leisure and vocational goals that will not only influence the type of final prosthesis prescribed (8, 21) but also assist in determining the type of exercise prescription required for the individual service user. A collaborative approach to rehabilitation between the occupational therapist, prosthetists and specific rehabilitation personnel (physiotherapist, exercise physiologist etc) is necessary.

Some literature suggests 2- 4 weeks for pre-prosthetic training, however consensus is that this phase may vary depending on time taken to achieve a robust residual limb (volume, sensitivity, range of movement, skin condition presence of complications) as well as psychological status (24). Comorbidities, multiple amputations or bilateral limb loss will also affect this time frame. The multifaceted considerations again are demonstrated in Figure 1 with the upward and downward trend of upper limb rehabilitation.

Wound and stump management

Alongside the rehabilitation program, continuing to monitor wound healing and hygiene will help ensure the limb is prepared for a prosthesis or assistive device (8).

Volume management via elastic bandaging or elastic tubular bandages is common. Prosthetic liners may be prescribed to help prepare the residual limb for a prosthesis and to assess skin tolerance. Information and options regarding stump shrinkers, liners, when to use them and how to don and doff these components will be provided by the treating team. This includes advising the service user on the early signs and symptoms of skin irritation, infection etc (2).

For the service user, adapting to and understanding the changes of the skin surface and regulating body temperature for the residual stump will require education and appropriate monitoring by rehabilitation personnel. This will help prepare the service user for when they are donning their prosthesis. Understanding the early signs and symptoms of skin irritation, infection etc (2) will help reduce long term skin issues and potentially reduce abandonment of their future prosthesis.

As exercise prescription and physical movement and activity increases, the body will have to regulate its temperature and subsequently may sweat more than the individual is used to. Educating the service user on the signs and symptoms to look for such things as overheating, changes in skin surface etc will be required. Temperature regulation becomes more important with higher amputations (e.g. transhumeral compared to a hand disarticulation) or multiple amputations that have occurred.

Prosthesis prescription

As discussed, prior to prosthesis prescription a number of objective measures or baseline tests may need to be taken to determine functional need and goals (see Appendix 1). The following elements should be considered for all post-operative rehabilitation and training for upper limb amputations to prepare for the intended prosthesis and may require an ongoing assessment and reassessment process (18):

- Residual limb volume
- Sensitivity
- Range of motion
- Skin condition of the residual limb
- Presence of pain
- Emotional and psychological status
- Changes in body weight
- Time for healing (based on the type of limb loss and impact on structures)

To ensure that a service user centred approach is considered, the goals of the individual are considered alongside what prosthesis(es) or adaptive devices are needed for to enable rehabilitation personnel to create realistic expectations for the rehabilitation process. The inclusion of activities of daily living, vocational expectations, reintroduction to sport and physical activity will influence the prescribed prosthesis and assistive technology and may be limited by what is available within that country and service provided.

When determining upper limb prosthesis prescription, the following should be considered for the service user (9):

- Design
- Control mechanism
- Amputation level
- Type of socket interface
- Type of socket frame
- Suspension mechanism
- Terminal device(s)
- Wrist unit (if applicable)
- Elbow unit (if applicable)
- Shoulder unit (if applicable)
- Funding available

Understanding the above requirements will then help to inform an appropriate type(s) of prosthesis required (see Table 8).

Exercise prescription

The exercise prescription for this phase continues to include range of movement and postural exercises, abdominal (core) exercise program, as well as strengthening and retraining of the residual limb and for activities of daily living (5, 8, 21, 37). This phase may also require re-training of a new dominant hand if their dominant hand has been amputated. Monitoring the overuse of the unaffected side (shoulder, neck and arm) also needs to be considered as part of the rehabilitation process.

During this phase, integration of virtual reality and simulation to assist with rehabilitation and replicating daily activities has been shown to improve later prosthesis adoption (38, 39). Utilising virtual reality where possible, to replicate activities of daily living may also add variety to the rehabilitation process as well as provide an option for training during the wound healing phase.

Home modifications

Home modifications should be considered and assessed during this phase. Ensuring that with or without a prosthesis, the individual can work towards independence at home with a variety of assistive technologies suitable to the level of amputation and functional loss (8, 21, 40). This will require not only a home assessment but ensuring that the rehabilitation program includes activities that can be replicated and adapted to the service user's home environment. In many countries this is performed by an occupational therapist.

Pain Management

Pain management for some service users will be required throughout the rehabilitation journey and will continue to be a factor for consideration during the pre-prosthetic training phase. For the service user in the pre-prosthetic phase, understanding the different types of pain (see appendix 4 of FAQs) and the types of pain control available will potentially impact the ability to don and doff a prosthesis and assist in reducing abandonment of the prosthesis (8, 17, 21).

Whilst there has been research into the reduction of phantom limb pain, the most documented to date, is the use of mirror therapy, where literature suggests it has been effective in the short-term reduction of phantom limb pain (9), and could be incorporated into an individual's rehabilitation program.

Regular consultation with rehabilitation personnel and pain specialists will contribute to the overall adaptation to limb loss and the rehabilitation journey.

Psychological and Peer Support

Psychological and peer support should continue to be offered in the pre-prosthetic phase (8, 20, 22, 41). Again, these interventions will help prepare the service user for life with a prosthesis or adaptive devices as well as continue to assist with the psychological and emotional impact of limb loss.

As part of the psychological support, services for the family or carers should be provided to assist with education for the family and the service user on adaptation to life with upper limb loss. These services or interventions will seek to provide the family unit with skills to help adapt to the service users changes in activities of daily living, skills, change in independence and support the service user through the rehabilitation journey (21, 41).

Peer support will continue to enable the service user to have support and understanding from those who have undergone a similar journey.

Service User Information

Overall, this pre-prosthetic phase is designed to equip the service user with:

- An individualised rehabilitation program preparing them for prosthesis fitting
- Education about the type of prostheses that will be prescribed and how the rehabilitation program will prepare them for the specific prosthesis or adaptive devices
- Ongoing education for wound management, skin irritation and pain management
- Home assessment and potential modifications to support independence following limb loss
- Psychological and peer support for the service user and their family or carers to assist in adaptations to limb loss
- Understanding this phase may need to be revisited should prosthesis prescription change, further surgery be required or functional needs change.

10.5 Prosthetic Training Phase

GOALS OF OF THE PROSTHETIC TRAINING PHASE

- » Adaptation to prosthesis(es)
- » Independent donning and doffing of prosthesis(es)
- » Functional training in ADLs and preparation for vocational and recreational skills
- » Maintain and improve strength
- » Progress rehabilitation program to specific vocational and recreational skills
- » Retraining of skills where required



Prosthetic training commences when the residual limb and amputation site has healed adequately to withstand the donning of the prosthesis.

The prosthesis(es) will be prescribed through a comprehensive assessment process undertaken by a trained upper limb prosthetist and multidisciplinary team (18). The devices will be determined by the level of amputation, design, control mechanism (e.g. body powered, externally powered etc), optimal socket design, prosthetic componentry as well as the technology and funding available within the service user's country. For those countries that have the option of a variety of prosthetic types, the rehabilitation team will need to discuss with the service user what elements they would like to consider as part of their prosthetic choices. Examples of decision-making components for prosthetic inclusion are listed in table 9.

There is insufficient evidence to recommend for or against any specific control strategy, socket design, suspension method, or component (9). The functional goals of the service user should be central to this decision-making process. A patient decision aid may also be helpful to assist in selecting the most appropriate prosthetic components for the functional needs of the service user as well as assisting in reducing the rejection or abandonment of upper limb prostheses (16). As mentioned, it may also highlight that multiple devices may be required and will also ensure that this is a service-user driven process.

Table 9: Decision-making components for service users' choice of prosthesis

 Adapted from Kerver et.al 2023 (16).

Elements to consider	Considerations
Appearance of prosthesis	 How would you like your prosthetic to look? (e.g., skin colour, robotic appearance) Do you want to utilise a variety of accessories (e.g., hook) or have a functional hand?
Wearing of prosthesis	 How long are you wearing the prosthesis per day? Are you only using it for certain activities? Are you only wearing it in public?
Activities required to perform regularly	 What will you need your prosthesis for? What tasks do you need to perform for your occupation or recreational activities? Will your prosthesis be needed in wet or dirty environments?
Prosthesis control	 How would you like to control your prosthesis? (e.g., body powered, myo-electric or no active function and just cosmetic)

Time and effort	\cdot How much time are you wanting to spend learning how to utilise your prosthesis?
	 Are you willing to spend time maintaining your prosthesis?

Once the type of prosthesis appropriate for the individual and their goals has been determined, prosthetic training can commence. It is important to note that the literature suggests the golden window for fitting of a prosthesis is within four weeks of amputation (27, 28) but will ultimately be determined by the residuum health.

The type of prosthesis may change over time should the goals and functional needs of the service user change or the initial type of prosthesis is not suitable. These could be a result of a number of issues that include, but not limited to, lack of functionality, poor fitting and skin irritation. This process aligns with the fluidity of the service user rehabilitation pathway that is outlined in Figure 1.

If a prosthesis is not required, or an individual requests to proceed without a prosthesis, this phase will include training with alternative assistive devices and/or home or environmental modifications. Service users may also opt to utilise a variety of protheses and assistive devices and this will need to be incorporated into the individual's training program. Most upper limb amputees will use the residual stump and assistive devices throughout their lives and appropriate rehabilitation and training is still required.

Rehabilitation process

The literature suggests that the time frame for this phase is between 2-5 weeks depending on the type of device or 4-6 hours daily therapy depending on the complexity of injuries (15). This remains individualised and can often be longer in traumatic cases and longer for those with bilateral or multiple limb loss.

When an individual changes their prosthesis or technology, appropriate rehabilitation and adaptation to the new prosthesis will be required. This phase therefore may be revisited multiple times during a service user's life. The following elements in Table 10 should be considered by the rehabilitation team during the prosthetic training phase (9):

Table 10: Summary of assessments and interventions for the prosthetic training phase for upper limb amputations

 Adapted from VA/DoD CPG for the Management of Upper Limb Amputation Rehabilitation (9)

Assessment / Intervention	Description
Physical Health Status	 Assess any changes in comorbidities Provide any updates in educational material
Functional assessments	 Determine any updates or changes in goals and functional need Continue with contracture management i.e. stretching program Maximise range of movement for prosthetic fit and use Progress exercise program to include gross motor strength and skills Review abdominal strength and balance based activities Review functional reach capacity of both upper limbs Review home exercise plan Determine cardiovascular ability and fitness and establish appropriate program for fitness as well as management/prevention of comorbidities Review of ADLs, donning and doffing of prosthesis and adaptive devices as well as daily activities such as driving Assess and incorporate recreational activities with the prosthesis Home evaluation review with a prosthesis
Pain management	 Continue to assess and treat phantom limb pain, residual limb pain and other sensations Review management plan
Behavioural and cognitive health	 Re-evaluate psychosocial symptoms and issues Continue to offer/include psychological and peer support

Patient education	Discussed in the next section
	Optimize residual limb shape/volume
	\cdot Educate on donning and doffing of prosthesis(es) and adaptive devices
Desidual limb management	\cdot Continue to educate how to utilise a stump shrinker appropriately
Residual limb management	Continue skin management education
	\cdot Progress (if appropriate) the time for wearing a prosthesis
	\cdot Continue with pain management and promotion of ROM and function restoration
	 Prosthetic fabrication, fitting, alignment and modification
Prosthetic management	Test/re-test prosthetic components
-	\cdot Consider activities and what changes may need to be made to prosthesis provision
	Conduct worksite evaluation
	 Identify workplace changes and consult with employers
vocational renabilitation	Provide vocational retraining where indicated
	Practice specific vocational tasks with and without prosthesis

During this phase, virtual reality could continue to support rehabilitation and strength training (5, 42-44) and assist with adaptations and changes to the rehabilitation program and changes in tasks both vocationally and recreationally. Throughout the rehabilitation and ongoing maintenance postural exercises will continue to ensure the body adapts appropriately to the prosthesis and ensure other areas of the body are not compromised or overloaded.

Strength training will include exercises to withstand the prosthesis(es) and maintain function as well as continue to work on hand dominance and strength (including abdominal strength). Cardiovascular endurance should also not be overlooked. Understanding an individual's cardiovascular capability and the cardiovascular requirements for vocational and recreational activities will need to be considered and included as part of the rehabilitation program.

Ongoing assessment and reassessment of activities of daily living with and without the prosthesis will be required to demonstrate progress and changes in functionality and independence. As part of this process there needs to be support provided for community reintegration (8, 15, 21) as well as ongoing psychological and peer support throughout this phase (41).

Ongoing pain management and education should continue to be provided (8, 21) to support the service user throughout the rehabilitation pathway.

Advanced functional training

In some of the literature, advanced functional training refers to training beyond range of movement and basic activities of daily living and specifically works towards reintegration into the workforce, previous recreational activities and/or retraining and learning of new skills. Many of the rehabilitation processes for this 'advanced' training has in this guide been included in the prosthetic training component. Adaptations to life changes such as progressing to school, change in hobbies, becoming a parent, learning to drive etc may require additional functional and translational training as well as a change in devices or the prosthesis(es) used.

This phase will continue to require a multidisciplinary approach with continued involvement of the rehabilitation team as well as psychological and peer support. This will be an ongoing part of rehabilitation and lifestyle changes and may require retraining regularly throughout their lifespan pending changes in technology, lifestyle and vocational changes as well as regular follow up assessments with the service user's prosthetist and rehabilitation personnel to optimize fit and changes in the residual limb and lifestyle.

Community support, integration and participation within society will continue to be important during this phase and family and carers would benefit from discussions with their community to help the service user transition back into society about the requirements or changes they may need.

Advanced functional training is an individualised process and will be based on the type of prosthesis and assistive devices required as well as the individual's goals based on lifestyle, occupation or need for retraining of skills (2, 14, 15, 39).

Virtual reality, if available, may continue to enhance functional training allowing individuals to visualise themselves performing various tasks from activities of daily living, vocational tasks or recreation specific activities as well as bilateral tasks (39, 43, 45).

Service User Information

A number of educational elements are provided during this rehabilitation phase to support activities of daily living, vocational and sport or lifestyle goals. The service user needs to feel comfortable, supported and ready to integrate back into the community (9).

Elements within this phase of rehabilitation should include:

- Appropriate donning and doffing of prosthesis prescribed to the service user
- Operational knowledge and education of the prosthesis based on the technology required for the individual (2, 21, 25)
- Education and training for the control mechanism chosen for the type of technology prescribed (2, 39)
- Understanding the need for improving limb tolerance to the prosthesis as well as ongoing management and care of the residual limb (8, 24, 39)
- Support and education regarding changes in body image and limb loss
- Education for skin management and maintenance residual volume with the use of prostheses
- Continued strength training

Service users are also encouraged to report any of the following issues (9):

- Ongoing pain in residual limb or associated with a prosthetic harness
- Skin breakdown
- Change in ability to don or doff the prosthesis
- Change in residual limb volume (weight gain or loss)
- Change in pattern of usage

10.6 Lifelong care

As this phase indicates it will be a lifelong approach and will need to be a continuum of care rather than a phase that ceases at any given time.

The adaptations to community reintegration and the need for peer support may require lifelong support. Support through peers, community initiatives and local agencies and organisations may be required for key life milestones and adaptations to the changes for example parenthood or entering the education system. Whilst psychological interventions or support may not be required by all service users, or in all phases of the rehabilitation journey, key life stressors or events may require

more support, thus ensuring psychological support is an option for all service users. Prosthesis prescription and adaptations will be lifelong and require continued involvement of prosthetic personnel with regular yearly reviews. Biannual or yearly reviews by their prosthetist will help to ensure continuum of care and ensure the individual maintains maximum functionality and independence as well as ensuring that the current prosthetic prescription is appropriate and meets the individual's function and goals. Reviews will also help to discuss changes in technology if required as well as the activity levels of the individual and body adaptations (for example change in residual volume or shape) or if ongoing surgery is required. Service users may also opt to no longer continue with a prosthesis or on the contrary may choose to explore prosthetic solutions or assistive technology at a later stage.

Employment and skill retraining may occur several times throughout a service user's life. Engaging with an occupational therapist and / or a vocational specialist with experience in upper limb amputations will help to support transitions to new vocations, skills and places of employment.

11.0 Summary and Future Considerations

Upper limb amputation rehabilitation is an individualised process. Each individual that undergoes an upper limb amputation will ideally experience each phase of rehabilitation with the support of a multidisciplinary team that has specific upper limb amputation experience. In countries where some rehabilitation personnel are not present, this document aims to guide those services with information to include throughout each phase of upper limb rehabilitation.

Whilst this guide provides a baseline for personnel working with upper limb service users, there is a need for research and clinical development to work towards objective measures specific to upper limb amputations, research exploring better management of the various types of pain experienced with amputations and as technology develops, there will also be a need for specific rehabilitation guidelines for each type of upper limb prosthesis available. Finally, there will be a need as research is consolidated and consensus reached, to develop a specific clinical guideline for upper limb research that encompasses all individuals with upper limb loss.

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University Medical Center Groningen