



**British Society of
Rehabilitation Medicine**

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Amputee and Prosthetic Rehabilitation – Standards and Guidelines (3rd Edition)

A Report of the Working Party of the British Society of Rehabilitation
Medicine

Published by the British Society of Rehabilitation Medicine in 2018

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Co-Chairs: Professor Rajiv Hanspal & Dr Imad Sedki

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2018
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The British Society of Rehabilitation Medicine (BSRM) is the society which represents the specialty of Rehabilitation Medicine. It promotes an understanding of the specialty through education and the development of clinical guidelines and standards. Membership is open to all registered medical practitioners interested and concerned with its objectives.

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Amputee and Prosthetic Rehabilitation Standards and Guidelines (3rd Edition)

Membership of the Working Party

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Full details of working party members and consultees are in Appendix 1.

Acknowledgements

The Working Party are grateful to all participants of the consultation process without whom it would not have been possible to develop these updated standards and guidelines. The assistance of the BSRM's Special Interest Group for Amputee Medicine (SIGAM) was particularly valuable in updating the standards themselves. SIGAM is the Society's special interest group for members interested/working in the field of Amputee Medicine Chaired by Professor Jai Kulkarni (2009-12), Dr Imad Sedki (2012-15) and Dr Lorraine Graham (2015-2108).

Foreword

I am delighted to write this Foreword to the updated (3rd) edition of the Amputee and Prosthetic Rehabilitation – Standards and Guidelines. This is particularly pertinent as the World Health Organisation's own standards for prosthetics and orthotics provided a valuable resource to the British Society of Rehabilitation Medicine (BSRM) working group and played a key role in this updated document.

Despite differing health service structures throughout the world, the similarities and uniformity in the underlying recommended standards and guidelines internationally are striking. The objective of this document is to ensure people receive the best quality of prosthetic rehabilitation and other allied health services to remain independent, productive and healthy by maintaining a basis upon which a service of excellence can be delivered to all those with limb loss. Access to all forms of assistive technology is the thrust of the WHO's Global Co-operation of Assistive Technology (GATE) Initiative and Prosthetics is an essential part of assistive technology.

The importance of standards both national and international should not be underestimated and this 3rd edition of 'Amputee and Prosthetic Rehabilitation – Standards and Guidelines' provides a valuable tool for both commissioners and providers of services in the UK and beyond.



Chapal Khasnabis

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1. Introduction

- 1.1 The British Society of Rehabilitation Medicine (BSRM) is the Society which represents the specialty of Rehabilitation Medicine. It promotes an understanding of the specialty through the education and development of clinical standards and guidelines. The Special Interest Group for Amputee Medicine (SIGAM) represents members of the BSRM with an interest in Prosthetic and Amputee Rehabilitation.
- 1.2 The BSRM is devoted to:
- Promoting the development and good practice of Rehabilitation Medicine as a medical specialty
 - Enhancing undergraduate and postgraduate education in rehabilitation and disability issues
 - Supporting rehabilitation research
 - Liaising with related medical, paramedical and voluntary organisations to further these aims.
- 1.3 The BSRM recognises that certain areas of service, including Prosthetics and Amputee Rehabilitation, require their own specific set of standards. In 2003, the BSRM published the second edition of the Amputee and Prosthetic Rehabilitation Standards and Guidelines.¹

Overall objective of the standards

- 1.4 The standards are based on the best-published evidence or agreed national guidelines and policies whenever possible in order to maximise the mobility, independence and quality of life of amputees and individuals with congenital limb deficiencies.
- 1.5 The overall objective of the standards and guidelines is to establish a basis for the provision of a service of excellence to the amputee population, both users of prostheses and non-users, with equity of access throughout the UK.
- 1.6 This document also aims to assist clinical governance and service development with standards presented in a format easily accessible for audit purposes.

Target audience

- 1.7 These standards are targeted towards the range of professionals involved in the management of people with acquired and congenital limb loss, including:
- Doctors and Allied Health Professionals, including referring clinicians, involved in the clinical management of people with limb loss
 - Commissioners, service providers and managers of these services
 - Manufacturers who supply the prosthetic hardware and other equipment prescribed by these services
 - Voluntary and charitable organisations that work with these services.

The patient group

- 1.8 The patient group includes all patients who have an acquired limb loss or congenital limb deficiency, irrespective of age or aetiology and patients for whom amputation may be considered as a treatment option.

The third edition

- 1.9 It is now 15 years since the publication of the revised Amputee and Prosthetic Rehabilitation- Standards and Guidelines Report.¹ Many changes and developments to national services for amputees have occurred; these include increasing roles in different disciplines, enhanced multidisciplinary collaborations and a rapid expansion of technical aspects.
- 1.10 However, this also corresponds with many challenges such as a palpable decline in available resources and higher expectations of prosthetic users.² The London Paralympic Games focused a very positive light on disability in general and prosthetic users in particular, it brought changes to society's attitudes and further raised users' expectations. The publication of the Murrison Report³ and the recent efforts to facilitate the transition of amputee veterans from military rehabilitation services to the NHS are considered as a great opportunity to improve the level of services nationwide. Nevertheless, the transfer of the veterans to the NHS prosthetic service also adds many challenges, including concerns of creating a two-tier system and the inability of the NHS to meet the complex needs and high expectations of some veterans. The agreed mechanism for funding of microprocessor prosthetic knees (MPKs) by NHS England has been a very welcome improvement for some prosthetic users. The MPK policy⁴ was approved in Dec 2016 with immediate effect, making MPKs available to hip disarticulation, trans-femoral amputees under specific qualifying criteria and indications.
- 1.11 Other significant changes include: funding prosthetic services in England through the NHS Specialist Commissioning Board from April 2013 and subsequent development of national service specifications,⁵ workforce changes in training numbers and expertise in different disciplines. This has also been accompanied by the changing patterns of referrals.^{5,6} There are many other evidence-based standards mostly for individual disciplines. ISPO International and WHO held a consensus conference in 2015 (funded by USAid), based on evidence, from which WHO global standards were produced and published in 2017 (collaboration between WHO, ISPO and USAid).⁷
- 1.12 Rather than have a parallel exercise, a need for UK based standards relevant for the service delivery in the country was considered. In clinical practice and service delivery in Rehabilitation Medicine there are aspects that may be common sense, obvious and irrefutable even though there is no published high level evidence. This has to be recognised and considered.

Methods

- 1.13 The last edition of the Amputee and Prosthetic Rehabilitation - Standards and Guidelines¹ was published in 2003 and its development followed the BSRM guidelines of achieving consensus as supportive evidence (expert evidence). A consultation process was carried out as recommended⁸ in three stages and similar to the process followed by BSRM for the development of standards for specialist in-patient and community rehabilitation.^{9,10} The format of presentation including sectional numbers was identical to the previously published BSRM standards. A review of standards was recommended.
- 1.14 It was recommended as essential that the report was updated to include new evidence from peer reviewed literature and evidence from other published reports to complete the recommendations for practical service delivery. A team of SIGAM members was established for the literature search, to review and update the report. Members of other professional disciplines were consulted. This was followed by a wide consultation to include all professional disciplines through their professional organisations, users and other stakeholders. The format of presentation however has been kept similar to the 2003 Report.
- 1.15 The report is in two parts. Part I consists of general information including background information and recommendations on Amputee and Prosthetic Rehabilitation that has been updated with current information from published literature. Part II consists of recommended standards and guidelines based on national consensus and updated and reviewed by the working party.

- 1.16 The guidelines are based on best-published evidence from a literature review so far as resources allow. Extensive use was also made of pre-existing reviews especially previously published guidelines and standards and their supportive evidence. The working party decided not to label each standard with a formal level of evidence tag because of the recognised problems of these levels of evidence for standards in rehabilitation.
- 1.17 This report cannot be directive and it is not within the remit of the report to designate the status of any provider unit. However, it is hoped that the recommendations are considered to plan and develop clinical services and the service specifications for prosthetic services nationally.
- 1.18 The report is funded by the BSRM whose aims and objectives are similar to the objectives of this report. The members of the working party are senior professionals in the NHS and listed in Appendix 1. All contributors have signed a form declaring any potential conflict of interest.
- 1.19 The BSRM plan to update the report on their website if any significant change of NHS policy, service specifications or guidelines make it advisable. A formal review of the whole document could therefore be deferred to seven years.

References

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9. Turner-Stokes L, Williams H, Abraham R, Duckett S. Clinical Standards for Specialist Rehabilitation Service in the UK. *Clin Rehabil* 2000; 14(5):468-480.
10. Turner Stokes L, Williams H, Abraham R. Standards for Specialist Community Rehabilitation Standards in the UK. *Clin Rehabil* 2001; 15:611-623.

2. History

- 2.1 The Artificial Limb Service in England was first set up by the War Office during the First World War. Artificial limb 'shops' had been set up at Roehampton and at the Charterhouse Hospital (near Smithfield). Some 25,000 amputees had been treated at the 900-bed hospital for the war wounded. Many other Limb Fitting Centres were also opened in the country during the 1914-18 war, eg Cardiff, Manchester, etc.
- 2.2 In 1932 the Limb Fitting Service came under the Ministry of Pensions. In 1948, with the advent of the National Health Service, amputees other than the war wounded, were accepted as patients at the Centres. In 1953, the Service was transferred to the Ministry of Health and subsequently to the Department of Health and Social Security. Further Centres known as Artificial Limb and Appliance Centres (ALAC) were opened (29 in England and 3 in Wales), and all were run by the Department of Health and Social Security (DHSS), and later by the Department of Health (DoH).
- 2.3 Advances in technology and materials, fabrication and concepts of modular prostheses allowed local production of artificial limbs. Though the service was first set up to serve the relatively young war wounded soldiers, by the 1960s the majority of new amputees were patients who had lost their limbs due to causes other than trauma - mostly elderly patients with vascular disease and diabetes who often had inter-current illness and disabilities.
- 2.4 In Scotland the service was NHS based from the early 1950s, leading to the establishment of the Dundee Limb Fitting Centre in 1964, as a model service for the UK. In 1970, the Denny Report¹ recommended further improvements and encouraged the adoption of a holistic approach to rehabilitation.
- 2.5 In response to the 'McColl' Report² published in 1986, the management of the Artificial Limb and Appliance Service was transferred to the Disablement Services Authority. A Special Health Authority was set up to run the service until March 1991 with the responsibility to oversee the transfer of the ALAC services to the National Health Service regions by 1 April, 1991.
- 2.6 Since 1991 the Prosthetic and Amputee Rehabilitation services have been provided through NHS Trust Hospitals, either as regional, supra-district or local and satellite services.³ In the last decade there have been considerable developments with an increase in the range of prostheses available. There have also been changes in the models for both delivery of the service and contracts with prosthetic companies. The funding of prosthetic services was ring fenced for a period of two years only. Prosthetic services now have to compete with all other NHS services for funding. This has led to a variation of services across the country.
- 2.7 Amputee Rehabilitation is now an integral part of Rehabilitation Medicine and is a core subject in the specialist training curriculum. The Amputee Medical Rehabilitation Society (AMRS), formed in 1990 with a membership consisting of almost all the Consultants in Rehabilitation Medicine practising Amputee Rehabilitation in the UK, in close collaboration with the British Society of Rehabilitation Medicine (BSRM) has been in the forefront of many of these changes. The AMRS merged in 2001 with the BSRM to become the Special Interest Group for Amputee Medicine (SIGAM).
- 2.8 The training of prosthetists has changed - all are now graduates. They have developed as a profession under the aegis of the British Association of Prosthetists and Orthotists (BAPO) formed in 1995 after amalgamation of the Association of Prosthetists and Orthotists (APO) and the British Institute of Surgical Technicians (BIST).
- 2.9 The therapists have their own special interest groups, BACPAR (British Association of Chartered Physiotherapists in Amputee Rehabilitation) and LLPOT (Lower Limb Prosthetic Occupational Therapist) and ULPOT (Upper Limb Prosthetic Occupational Therapist) formerly attached to CIGOWP (Clinical Interest Group Occupational Therapists for Wheelchairs and Prosthetics) group, which dissolved in August 2003. LLPOT and ULPOT are now attached to RCOT-SSTO (Royal College of Occupational Therapists Specialist Section in Trauma and Orthopaedics).
- 2.10 There is also a National Forum for Amputee Rehabilitation Counsellors (NFARC).
- 2.11 The Rehabilitation Engineers have the Prosthetics and Orthotics Interest Group (POIG) of RESMaG (Rehabilitation Engineers Management Group) and also the Rehabilitation Engineering and

Biomechanics Special Interest Group (REBSIG) of the Institute of Physics and Engineering in Medicine. The two interest groups work closely and have liaison membership on their committees.

- 2.12 The Prosthetic Service Managers have a well established network for communication and to share innovations and ideas. They meet twice yearly - once at a joint conference with the Prosthetic Service Provider Companies within the British Health Trades Association (BHTA) and once independently.
- 2.13 In April 2013, NHS England established Specialist Commissioning for around 60 different services that included Complex Disability Equipment Services. This encompassed Prosthetic Services commissioned directly by NHS England to ensure equity of service nationally for 'high cost low volume' services like prosthetics. Clinical Reference Groups (CRG) were set up to advise NHS England. The CRG for Complex Disability Equipment, which included Prosthetic/Amputee Rehabilitation Services for National Commissioning led on the development of the service specifications for commissioning.^{4,5} Other services under this umbrella were assistive electronic technology and assistive communication aids. This CRG was also tasked to formulate clinical service delivery models, care pathways, and outcome measures from April 2013 onwards. As part of their remit, they have also led on development of policies for prescription of microprocessor knee units, multi-articulated hands and high definition silicone cosmeses. At the time of writing only the microprocessor knees policy has been approved and the CRG has merged with the complex disability and spinal services CRGs into the Rehabilitation and Disability CRG.
- 2.14 The Royal College of Physicians published the Future Hospital Commission report⁶ in 2013. The report set out the commission's vision for hospital services structured around the needs of patients, now and in the future, and its findings and recommendations influenced the Standards update.

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3. Prosthetic Advisory Group to Minister for the Disabled. A Report of the Working Party (Chair Carter-Jones, L). College of Occupational Therapists; 1994.
4. <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-d/d01/>
5. The NHS Specialised Services. <https://www.england.nhs.uk/commissioning/spec-services/>
6. Future Hospital Commission. Future Hospital: Caring for Future Patients. Royal College of Physicians. 2013.

3. Epidemiology

- 3.1 National statistics for amputations were previously available via the National Amputee Statistical Database (NASDAB) Steering Group,¹ supported by the Special Interest Group for Amputee Medicine (SIGAM) via the British Society of Rehabilitation Medicine, the Disablement Services Centres (DSC's), British Healthcare Trades Association (BHTA) and the NHS Purchasing and Supplies Agency (PASA). NASDAB ceased its input in 2006/2007 and the University of Salford took up this responsibility by forming the United National Institute for Prosthetics and Orthotics Development Group (UNIPOD) from 2010 onwards on a free of charge basis.
- 3.2 The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) published their report 'Lower Limb Amputation: Working Together'² in November 2014 as a review of the care received by patients who underwent major lower limb amputation due to vascular disease or diabetes.
- 3.3 Hospital Episodes Statistics (HES) for 2009/10 showed a total number of 5,498 recorded episodes for lower limb amputations in England. This includes 530 deaths during in-patient stay in England alone.³ These rates have remained relatively constant over the last decade although the proportion undergoing above knee amputation has decreased.³ Previous reports indicate that the mortality for major lower limb amputation is high, both within 30 days of surgery (12.4%)⁴ and at one year (38-48%).⁵ This possibly reflects the presence of multiple co-morbidities of this patient group.
- 3.4 UNIPOD has reviewed the minimum data set from referrals nationwide to all Prosthetic and Amputee Rehabilitation Centres (PARCs) and UNIPOD would encourage all PARCs to submit this data on an annual basis by the end of each financial year. All PARCs should submit this data set and assist UNIPOD with national data collection.
- 3.5 There is significant variation in the referral patterns between health regions/ PARCs. This may reflect the population demographics and geographical areas covered by each PARC, in addition to the noticeable variation of activities in different vascular units. All those with major limb amputations should be referred to a PARC to be seen by a Consultant in Rehabilitation Medicine, regardless of their potential to use a prosthetic limb. Those who adopt a more aggressive approach to limb salvage would have fewer amputations. Similarly, some Centres perform a higher proportion of below knee amputations⁶ compared to above knee.
- 3.6 There are 43 PARCs across the UK, each receiving 50-350 new referrals per year.
- 3.7 The last published UNIPOD report⁷ for 2011/2012 showed a total of 5,906 new referrals to prosthetic services in the UK for the year ending 31 March 2012. Lower limb amputations accounted for 91% of total amputations. The gender breakdown of new referrals is similar to previous years, with female referrals accounting for 30% of all new referrals to prosthetic services centre. Males (70%) present to the prosthetic services at an earlier age than females and the national median age of referrals for males is 65 years and for females it is 69 years of age. The commonest cause (52%) of amputation is due to vascular disease, nearly 42% of these with diabetes mellitus. Trauma accounts for 11% of all amputations and tumours for 3%, most patients in these categories are of a younger age. We note that there were no data reported on causation in 1,047 (17%) of all cases.
- 3.8 To address concerns expressed by NHS England and the CRG regarding the accuracy of data, the NHS Tariff Development Group are mandating regular data collection for all Centres. This will provide the much-needed statistics for service development.
- 3.9 The most common level of amputation for referral continues to be at transtibial level accounting for almost half of the referrals. Nationally 50% of lower limb referrals are at transtibial level and 34% at transfemoral level, with variations between regions/PARCs.

- 3.10 In 2012, upper limb amputations accounted for 8% of the total amputations and the commonest cause was trauma (an increase compared to 4% in 2007). Referrals with congenital limb deficiency accounted for just over 2% of all referrals. Upper limb referrals tend to be in the younger age group reflecting the traumatic aetiology of the condition. Almost 68% of all upper limb referrals were younger than 55 years. 53% of all upper limb referrals were transhumeral or transradial amputations. Partial hand and digit amputations account for 37% of all upper limb referrals.
- 3.11 Patients with multiple, more than two, amputations require significant resources for rehabilitation and reintegration. The aetiology for multiple amputations is usually vascular (with or without diabetes) but could also occur in the younger patient due to infection (eg meningitis and other causes of septicæmia) and trauma.

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6. The Vascular Society of Great Britain and Ireland. Provision of Services for Patients with Vascular Disease. 2011.
7. UNIPOD. Limbless statistics - annual report. University of Salford 2011/2012.

4. Services for limbless people

- 4.1 Guidance from the Government and the Department of Health in recent years has demanded the development of standards and guidelines within all areas of the NHS. These standards and guidelines must be evidence-based or developed by professional consensus. The following documents influenced the development of high quality Specialist Rehabilitation services and form the backbone of this document:
- Department of Health. A First Class Service: Quality in the New NHS. London: HSC. 1998.¹
 - Department of Health. The NHS Plan - A plan for investment. A plan for reform. The Stationery Office London: 2000.²
 - HSC 1998/198 - Commissioning in the New NHS.³
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 - Department of Health Procurement and Supplies Agency. Amputee Care - Guidelines for Commissioners. Prosthetic Strategic Supply Group: 2001.⁶
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 - A better Deal for Military Amputees. Dr A Murrison 2014.¹¹
 - National Confidential Enquiry onto Patient outcome and Death. NCEPOD - Lower limb amputation. November 2014.¹²
 - CRG National Service Specifications: Complex Disability Equipment: Prosthetics (All Ages).¹³
- 4.2 Publications 3-9 above support the recommendation that rehabilitation services for those with limb loss should remain a Specialised Rehabilitation Service (defined as a multidisciplinary service having input from a Consultant in Rehabilitation Medicine),¹⁴ commissioned at a level above that practicable by clinical commissioning groups. This is for a number of reasons:
- The number of new amputee referrals is relatively small (4,530 for England), a number likely to be on average less than 212 new amputees per year for each CCG¹⁵ or 0.56 new amputees per year per GP practice (8,088 GP practices in England). An estimated 5.6 amputees per GP practice, (45,000 amputees in England).¹⁵
 - Large, expensive and technically sophisticated clinical and workshop facilities are essential to support the service.
 - A high level of specialist and professional expertise is required in medical, prosthetic, technical and therapy staff.¹⁶ The clinical expertise needed does not form part of the undergraduate education of any of the professional groups involved, with the exception of prosthetists; however, placements for medical, nursing and allied healthcare professionals are common place and highly valued.
 - A 'critical mass' of patient population through specialist services is essential for achieving and maintaining high standards and cost-effectiveness.
- 4.3 Since 1 April 2013, Prosthetic Services have been commissioned directly by NHS England. This ensures a commissioning process which is patient-centred and outcome based, that is fair and consistent and ensures patients have equal access to services.
- 4.4 Two of the publications (5 and 10 above) and the current National Service Specifications¹³ further recommend the development of the hub and spoke models of service delivery, where groups of

services (Centres) establish formal affiliations with focused clinical leadership and further specialisation coming from one tertiary referral centre. This ensures the establishment of appropriate clinical governance arrangements.

- 4.5 In the past there has been much discussion on the geographical distribution of patients that may make a limited number of tertiary centres impractical, especially regarding the management of children with amputations and congenital limb deficiency. However, publication 5 above⁵ discusses the subject in some detail and recommends that between eight to ten such Centres in England would be appropriate. As it is unlikely that these Centres would be 'officially designated' by the NHS, it was accepted that the natural flow of referral patterns would dictate the development of these Tertiary Centres. The current Prosthetic Service Specification¹³ supports this concept and recommends the development of 'alliance' and 'patient pathways'. It is imperative that the development of nine Centres for the Veterans should not be confused with Centres specialising in other aspects of prosthetic rehabilitation eg congenital limb deficiency.
- 4.6 This document supports these recommendations and further recommends that in future, Prosthetic and Amputee Rehabilitation Centres (PARCs) should have the staff, equipment and facilities appropriate to the level of service they have been commissioned to provide.

Specification of Prosthetic and Amputee Rehabilitation Centres (PARCs)

It is envisaged that the Prosthetic and Amputee Rehabilitation services will be delivered at three levels as follows:

Tertiary referral PARC

- 4.7 A Centre of expertise for upper limb, congenital and multiple limb loss, able to provide the full range of advice and Prosthetic Rehabilitation for all levels of upper and lower limb loss. The multidisciplinary team must be led by a suitably experienced Consultant in Rehabilitation Medicine. All team members should have specialist experience, and the appropriate training to manage upper limb amputees and children with acquired or congenital limb loss, (see Composition of the Team - Table 4.2). A tertiary referral PARC must have designated facilities for children, equipped to allow for assessment appropriate to their age.
- 4.8 Tertiary referral centres should hold specialist clinics, in conjunction with surgeons and/or Paediatricians, for:
- Congenital limb deficiency
 - Children
 - Complex limb loss.
- 4.9 Tertiary referral centres must be preserved to ensure specialist expertise in the future, both for rare and expensive conditions for teaching, education and research¹² and to support other Centres if and when required.

The PARC

- 4.10 The standard PARC provides a service for:
- All lower limb amputees
 - Straight forward upper limb amputees and those with congenital limb loss, provided that staff with appropriate expertise are available
 - More complex patients whose condition is stable.
- 4.11 The PARCs will be fully staffed and equipped to deal with all levels of limb loss, though without the specialist expertise for the most complex patients, for whom they are expected to have established links.

The Lower Limb PARC

- 4.12 The Lower Limb PARC should be a Consultant-led service with experienced prosthetists, physiotherapists, occupational therapists, psychologists and/or counsellors, nursing support and podiatry input, providing facilities only for lower limb rehabilitation.
- 4.13 These Centres will be affiliated to a tertiary referral centre on a 'hub and spoke' basis.
- 4.14 It may also be appropriate for any Centre to hold visiting clinics, dependent on local need and arrangements.
- 4.15 In 2013 the commissioning was taken from local level to national level under Specialist Commissioning. As a result, all users of these services have the right to choose where they receive their initial rehabilitation, ongoing support and equipment provision, and should be informed of the options available to them. This should include advice about the most clinically appropriate site.

Prosthetic and Amputee Rehabilitation Centres (PARCs)

- 4.16 Prosthetic and Amputee Rehabilitation Centres (PARCs) should be sited on the ground floor and be fully compliant with the Disability Discrimination Act. Road access needs to be good and public transport within easy reach of the Centre. Ready access to appropriate food and drink is also essential especially for users who have Diabetes Mellitus. All areas must be accessible to wheelchair users and the particular needs of limbless people must be taken into account in the design of services (eg lavatories, fitting and waiting rooms, choice of chairs etc). Suitable chairs and wheelchairs must be available for those who need them.
- 4.17 Although for many patients the sharing of fitting rooms is acceptable and indeed may be beneficial, alternative facilities should be available to permit amputees to be treated in individual rooms, or to be accompanied by a relative, friend or carer, if they wish or need this extra privacy. There should be separate suitable accommodation, in an appropriate environment, for children and the particular needs of adolescents must be considered - 'there should be physical separation between children and adult patients, so that children are not exposed to potentially frightening behaviour'.¹⁷
- 4.18 An inflexible transport system is often quoted as being a limiting factor to a good clinical service.⁹ This report recommends that any transport contract should specify the timely delivery and departure of patients around pre-set appointment times and should not be constrained by the custom and practice of other services.
- 4.19 The PARC should be part of, or closely linked to, a more general regional rehabilitation unit.
- 4.20 The prosthetic workshop should have facilities for the adjustment, repair, and assembly of prostheses. However, the manufacture of prostheses may by agreement be located elsewhere, subject to local arrangements, providing time-scales that are appropriate and effective quality control. It is however recognised that for some services, central fabrication and manufacture may be necessary.
- 4.21 There should be a dedicated care pathway for all amputees beginning ideally in the pre-amputation phase, extending during the acute phase post amputation and up until and including the assessment by the Multidisciplinary team at the PARC.¹⁸
- 4.22 The specialist Amputee Rehabilitation team should have access to prompt radiology, haematology and microbiology services and ideally in-patient rehabilitation beds for amputees. Arrangements should be in place to allow rapid referral to other appropriate social and health services particularly podiatry, orthotics, counselling, practitioner psychology and social work.
- 4.23 Amputee Rehabilitation is multi-disciplinary, and for it to be successful there must be close cooperation between staff in the hospital in which amputation is carried out (the surgical and local Rehabilitation team), the PARC (the Specialist Rehabilitation team) and community services. Good communication and close liaison between staff at these three areas, crossing organisational barriers, is vital.^{19,20} The amputee is the central member of all the teams, and with the carer should be involved in all decision-making. The anticipated relationship and interactions are outlined in Amputee Care-Guidelines⁶ and the expected involvement of service users in the NHS Plan.

- 4.24 The job and duties expected from a leader in a Prosthetic Centre include leading on external liaison with other specialties in the hospital and the NHS in general, leading on clinical audit within the whole multi-disciplinary team, leading on research, development of the services in addition to their specific clinical duties. The career path and training structure of medical consultants makes them best placed to fulfil all these duties. NHS Consultants, because of their career structure are also best placed to provide long term continuity that is essential in a service where 80 to 90% of patients are long standing patients. The Consultant is expected to be fully involved in financial planning and commissioning-related issues and works closely with the Centre Managers in that regard. Some important and essential members of the multi-disciplinary team are employed by a private service provider through contracts tendered every three to five years in the current service model in the UK. The NHS medical Consultant remains best placed to provide leadership and develop the unit within the NHS framework.

Composition of the team

- 4.25 The clinical team based at the referring hospital should consist of the disciplines in Table 4.1 below.
- 4.26 Provision must be made for the continuing rehabilitation of all amputees including those who will not be able to benefit from prostheses such as frail, dysvascular amputees and particularly those with a trans-femoral amputation. For the elderly, this could be under the care of a Consultant in Rehabilitation Medicine or a Physician in Care of the Elderly Medicine, bearing in mind that some of these patients will benefit from active rehabilitation to address transfer techniques etc, while others may require long-term hoisting and a larger care package. Community hospitals also play an important role for some of these patients.
- 4.27 It is the responsibility of the consultant surgeon or his/her team to refer all patients to the Consultant in Rehabilitation Medicine at the PARC.
- 4.28 All patients should have access to a Consultant in Rehabilitation Medicine for assessment of rehabilitation needs including advice on need for focused therapy, pain management, a lower limb prosthesis for cosmetic appearance only or transfer and necessity for referral to other members of the multi-disciplinary team, eg a practitioner psychologist.
- 4.29 Pre-amputation consultations should be offered where possible. This helps to prepare the patient, answer their questions and allow them to see examples of prosthetics allowing for appropriate expectations. It also allows for advice from the Consultant in Rehabilitation Medicine, and other team members as required, regarding amputation level and other rehabilitation options often not sought by the referring team.
- 4.30 The specialist team at the Prosthetic and Amputee Rehabilitation Centre should include the disciplines in Table 4.2 below.
- 4.31 The Centre must provide adequate information regarding the services it supplies, the equipment provided and care for equipment.²¹ Service users value information about Social Services provision, voluntary organisations and self-help groups. Information should be available in a choice of languages, audio tape and Braille.

Table 4.1 - Composition of the team at referring hospital

Surgeon	The Surgeon must be suitably trained and experienced in amputation surgery ^{22,23,24} and have a practical knowledge of current basic Prosthetic and Rehabilitation principles, so that the most suitable amputation residual limb can be fashioned - particularly with reference to the recommendations for those likely to and those not likely to benefit from prosthetic wear. Ideally, commissioning authorities should commission designated units with responsibilities for amputation surgery. (These would often be Vascular Surgeons, but could well be Orthopaedic or Plastic Surgeons). ¹³
Nurses	Nurses looking after the patient in the surgical or general rehabilitation hospital ward must be trained and have adequate knowledge of the principles of Amputation and Prosthetic Rehabilitation, including care of the amputation residual limb and oedema control; they must also be aware that many elderly amputees will not be best served by a prosthesis and be able to engage them in realistic discussion about future rehabilitation. ^{25,26} Nursing staff should be aware of the services available from/at their local PARC and the appropriate referral pathways. However, all amputees should be seen by the Consultant in Rehabilitation Medicine to ensure care with regards to on-going pain, initiating or changing pain relief, rehabilitation needs such as access to psychology or use of cosmetic limbs, can also be offered.
Physiotherapists	Physiotherapists must be adequately experienced in the field of amputee management, and have basic knowledge of the principles of prostheses, and experience of the use of early walking aids (EWAs) and the control of residual limb oedema. The physiotherapists should use the relevant evidence-based clinical guidelines ²⁷ produced by the British Association of Chartered Physiotherapists in Amputee Rehabilitation (BACPAR) and the Scottish Physiotherapists in Amputation Research Group (SPARG). Each referring hospital should have a designated physiotherapist with responsibility for co-ordinating the management of all amputees in that area. This will allow the provision of realistic advice to the patient regarding future mobility, ²⁸ and help in improving liaison with the PARC. This will equate to a minimum of Specialist Band 7 level physiotherapist at the PARC. ^{16,27} The physiotherapists at the Prosthetic Centre should have established lines of communication with the physiotherapist at the referring hospital and the community rehabilitation services.
Occupational Therapist	All amputees must have access to an occupational therapist (OT), who should work in close liaison with the physiotherapist, with special reference to meeting the functional needs of the patient, and the assessment and provision of a suitable wheelchair. The OT should, where indicated, undertake a home visit with the new amputee and make appropriate recommendations prior to a safe discharge home. This would equate to a minimum level of Band 6 occupational therapist specialist. ¹⁶ Alternatively they should ensure that appropriate assessment is undertaken by the local OT or community services.
Social Worker/Care Manager	A Hospital Social Worker/Care Manager should be available to establish the appropriate links with Social Services, identify any continuing health care needs, give advice regarding benefits and other financial matters, and to be involved with plans for discharge from the acute hospital.

Table 4.2 - Composition of the specialist team at the PARC

Consultant in Rehabilitation Medicine	The Consultant should be responsible for the overall clinical care of the patient, although it is appropriate for other team members to lead on specific areas of care. In the current NHS structure, the consultant physician is generally considered to be the most appropriate team leader. ^{4,6} The role of the Consultant in Rehabilitation Medicine is well described in the Royal College of Physicians' and BSRM Report, Medical Rehabilitation in 2011 and beyond ⁸ and the Clinical Governance Supplement of Clinical Rehabilitation. ¹⁴ Supporting medical staff may include Specialty Physicians for service provision, and a Specialist Registrar in Rehabilitation Medicine undertaking training. The Consultant in Rehabilitation Medicine should have completed the accredited training for a Consultant in Rehabilitation Medicine (currently CCT in Rehabilitation Medicine includes three months mandatory training in Amputee Rehabilitation). However for an appointment at the Tertiary Referral PARC the Consultant should have extra training and experience particularly in the management of congenital limb deficiency, complex and multiple limb loss and more specialised prosthetic techniques. ²⁹ The additional training required for consultants at Tertiary Centres is being reviewed by a subgroup of SIGAM. It is also recommended that Consultants in RM at Tertiary Centres should have at least five sessions per week for Prosthetic Rehabilitation. This ensures that they maintain their expertise and specialisation in Prosthetic Rehabilitation to manage all complex cases.
Prosthetists	Prosthetists are all registered Allied Health Professionals with the Health Professions Council and have undertaken an accredited training period of 3 or 4 years or equivalent with a degree in prosthetics and orthotics. Prosthetists should be conversant with the guidelines published by the British Association of Prosthetists and Orthotists (BAPO, 2000) ³⁰ and available on their website (www.bapo.com). Designated Prosthetists should manage or oversee the prosthetic care of patients with the rarer types of limb loss (eg congenital limb deficiency or upper or multiple limb loss) in order to develop and maintain the specialist experience necessary to meet the needs of these patients. This approach should be considered for all children and is supported by the Prosthetic Paediatric Consortium.
Physiotherapists	Physiotherapists (Specialist Band 7 level) ^{16,27} at the PARC should be experienced in amputee management, including (lower limb) prosthetic training, have a good understanding of prosthetics, be able to look after amputees with complex problems, and be conversant with the evidence-based clinical guidelines produced by BACPAR. ²⁷ They should have established channels of communication and be able to liaise with and advise the physiotherapists in the referring and rehabilitating hospitals. Education of colleagues is particularly important. It is recommended that at least one physiotherapist within each Centre has a relevant post-graduate accredited qualification in Amputee Rehabilitation and should be graded as a clinical specialist. In Tertiary Referral Centres knowledge of upper limb prosthetics and paediatrics is also necessary.
Occupational Therapists	Occupational Therapists (specialist Occupational Therapist who is HCPC registered) ³¹ undertake training of lower limb patients in regard to safe transfers with or without a prosthesis on, also prosthetic limb training for patients with upper limb amputation or congenital deficiency, including training in one-handed activities where relevant. ³¹ They also undertake training for activities of daily living for both upper and lower limb amputees and arrange home or school visits in liaison with physiotherapists and community therapists. A suitably experienced occupational therapist (LLPOT and ULPOT) should be a member of the core clinical team at all PARCs.
Clinical Nurse Specialists	Clinical Nurse Specialists [Nurse advanced (Band 7) or specialist (Band 6)] are nurses trained in the holistic care of amputees. They should have undertaken training in tissue viability and wound management and have a good understanding of prosthetics and Amputee Rehabilitation. The role of the CNS in rural areas incorporates the maintenance of close links between hospitals and the PARCs.

Counsellor/Practitioner Psychologist	A counselling and psychology service must be provided by the PARC. This may consist of a counsellor and a psychologist who have experience of working in a rehabilitation setting, although mostly by a psychologist. Although basic counselling will indirectly be provided by many members of the Amputee Rehabilitation team, patients at all Centres should have the option of seeing a counsellor ^{32,33} or psychologist. They should also be available to see relatives or carers of the amputee. The psychologist will have registration with the Health and Care Professions Council, should have experience in dealing with the particular problems of patients with physical disabilities and should be readily available to see selected patients. ³⁴
Rehabilitation Engineer	A Rehabilitation Engineer should be available to advise on technical matters related to the quality, risk management, maintenance and disposal of prosthetic devices. Rehabilitation Engineers can be either Clinical Scientists or Clinical Technologists.
Podiatrist	A Podiatrist should be available to provide care for the remaining foot/advice on medical footwear in unilateral, lower limb diabetic or dysvascular amputees, or appropriate links with local podiatric services must be established. ³⁵
Employment Advisor/Vocational Rehabilitation Service	Appropriate links should be established with the local Disability Employment Case Worker as early as possible for those amputees employed at the time of becoming an amputee. Ideally, there should be access to Vocational Rehabilitation. ^{36,37} There is a higher incidence of amputees returning to work in mainland Europe where Vocational Rehabilitation is better established. ^{38,39}

- 4.32 All members of the clinical team must undertake continuing professional development/education and are expected to keep abreast of relevant developments in prosthetics generally and in their own field.
- 4.33 Lower Limb PARCs, Satellite Centres or Visiting Clinics will not necessarily have all the above staff, but as a minimum, the amputees should be under the care of a Consultant in Rehabilitation Medicine with a good knowledge of prosthetics, suitably experienced prosthetists, and a specialist physiotherapist and occupational therapist. Relevant information should be readily available, and arrangements should be in place for referring patients to staff of other disciplines when required or other Centres if clinically appropriate.

In the community

- 4.34 It is important that there are close links between the specialist team at the Prosthetic and Amputee Rehabilitation Centre and the support services in the community, which include:
- General practitioner
 - Community physiotherapist
 - Community occupational therapist
 - Community podiatrist
 - Community nurse
 - Social worker
 - Local Authority social services
 - Relevant voluntary organisations.

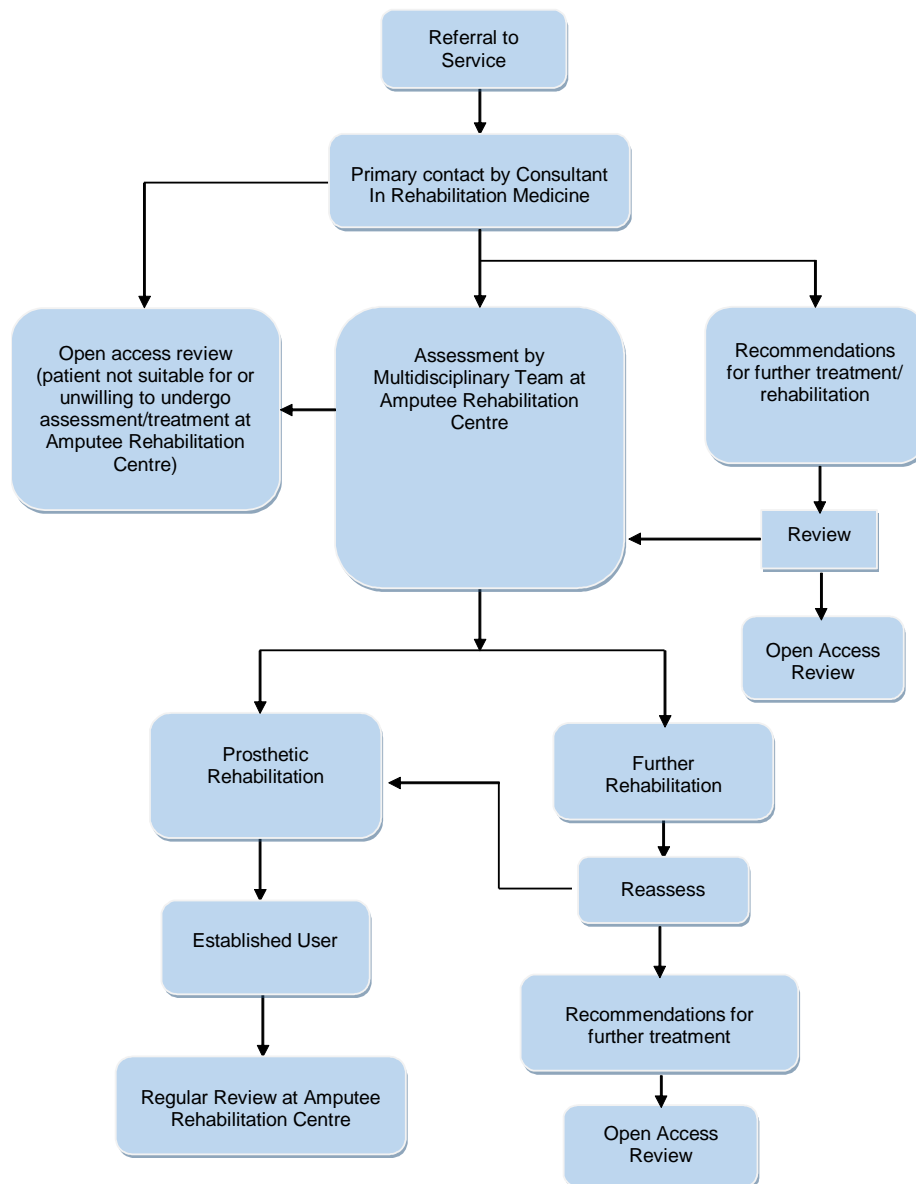
Clinics

- 4.35 Each Centre should have an adequate number of clinics held by the Consultant in Rehabilitation Medicine, supported by other members of the rehabilitation team. All patients attending the PARC should be under the care of a named consultant and prosthetist. Although the initial referral of a new patient to the PARC must be by or with the support of a medical practitioner, established patients must be able to self-refer back into the system. A structured appointment system is necessary, with suitable provision for dealing with genuine emergencies.
- 4.36 In addition to the main Amputee Rehabilitation clinic, some or all of the following special clinics may be held, depending on the workload and organisation of the Centre.

Table 4.3 - Description of special clinics

Children's Clinic	A Children's Clinic may be offered at Tertiary Referral Centres including those with acquired amputations and those with congenital limb deficiency, as the needs of this group of patients, and particularly the needs of their families, are different from the majority of adult amputees. This also provides an opportunity for parents to meet other children and their families with similar problems, bearing in mind that these types of limb loss or deficiency are rare.
Combined Clinic with Orthopaedic or other Surgeon	Combined Clinic with Orthopaedic or other Surgeon. At Tertiary Referral Centres it is helpful to have one or more joint clinics, eg with a Paediatric Orthopaedic Surgeon or other Surgeons (Plastic, Orthopaedic or Vascular, as appropriate), to discuss the management of patients with rare or unusual conditions or particular problems, so that surgical and prosthetic management may be combined most effectively. The same principles would apply to patients with multiple injuries or where amputation is a treatment option rather than a necessity.
Combined Multi-disciplinary Clinic	Multi-disciplinary case conferences and a formal goal planning process should be available, if not routinely, particularly for those patients with complex needs.
Pain Management Clinic	Phantom pain is a recognised complication of amputation ⁴⁰ sometimes bearing a relationship to pre-amputation pain ⁴¹ and for a notable subset, pain may be quite disabling. Pain after amputation should be viewed from a broad perspective that combines anatomic factors as well as the impact of functioning. ⁴² Where required, particularly for phantom pain, prompt access to Specialist Pain Management Services should be available, either at the PARC or a Specialist Centre, it being recognised that there is a need for more investment in Specialist Centres. Currently the provision, by health professionals, of information and support for amputees in dealing with phantom limb phenomenon is inadequate. ⁴³

Figure 4.1 - The care pathway for an amputee from referral



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5. Lower limb amputation

- 5.1 The management and rehabilitation of people who have had or will be having a lower limb amputation should be multi-disciplinary and the benefits of an organised service are recognised.^{1,2,3} It should be considered in the following phases:

- Pre-Amputation
- Amputation
- Post Amputation
- Primary Amputee Rehabilitation
- Amputee Review and Maintenance.

Pre-amputation

- 5.2 The pre-amputation phase starts when amputation becomes a clinical option in the patient's management.
- 5.3 If amputation is a treatment option, a second opinion should always be sought from a Consultant in Rehabilitation Medicine specialising in the management of amputees.
- 5.4 Whenever possible, given that their clinical condition allows, the patient should be consulted on the decision and be given appropriate advice and adequate information on the treatment options.
- 5.5 A pre-amputation consultation with a Consultant in Rehabilitation Medicine specialising in amputee rehabilitation and prosthetics and appropriate members of the PARC multi-disciplinary team, should be arranged, especially
- when further clinical advice about amputation and patient management is required, particularly when amputation is a treatment option as opposed to a treatment necessity or when congenital limb deficiency or deformity are involved
 - when an elective amputation is planned
 - when the patient requests more information than the local hospital team can provide.
- 5.6 The pre-amputation consultation should include discussion of realistic rehabilitation goals, prosthetic options and projected outcomes including advice to the surgeon regarding the ideal length of the residuum. Early advice from the specialist amputee occupational therapist will also provide valuable advice to the patient regarding adaptive equipment and general advice regarding the possible need for environmental changes at home eg downstairs sleeping arrangement. Alternatives to amputation and its consequences should be discussed.
- 5.7 A therapy programme should be started pre-operatively to establish a basis for post-operative rehabilitation and to introduce the patient to the specialist amputee physiotherapist.⁴
- 5.8 Pre-operative pain control should be adequate and may include pre-operative epidural anaesthesia.^{5,6}

Amputation

- 5.9 Amputation should be considered as the formation of a potential new organ of locomotion and thus, the first stage of a new episode of patient management rather than the end stage of the previous episode of treatment.⁷
- 5.10 The amputation should be performed by a surgeon experienced in appropriate techniques^{8,9,10} in a setting where there is adequate access to Prosthetic and Amputee Rehabilitation services. It is advisable that there be a designated vascular or orthopaedic surgeon whose clinical responsibility includes amputation. This responsibility should extend to establishing and maintaining links with the appropriate PARCs and to act as a member of the local team. Surgery should be timely and given priority on a surgical list.¹¹ Surgery should follow a recognised operative technique¹² and be planned to optimise future rehabilitation potential including prosthetic limb use.^{13,14,15} The aim of surgery

should be to form a residual limb of appropriate length with preservation of joints, to allow natural healing of the skin and to avoid excess soft tissue distally, using appropriate techniques like the Skew flap,¹⁶ or the long posterior flap¹⁷ in trans-tibial amputations and lateral myodesis in trans-femoral amputations¹⁸ for improved alignment. The bone end must be shaped to avoid spikes or sharp edges. Where there may be doubt about the level of amputation or technique, the surgeon should consult with the local Consultant in Rehabilitation Medicine in order to form a residual limb capable of comfortable weight bearing and ambulation in a prosthetic socket without breakdown. There is no evidence to show a benefit of one type of incision over another in vascular patients with a transtibial amputation.¹⁹ If prosthetic rehabilitation is planned the knee joint should be preserved, if at all possible.^{20,21}

- 5.11 It is recommended that the ratio of the incidence of trans-tibial and trans-femoral amputations in vascular units should not be less than 2.5:1.²¹ The optimum level of bone section in a trans-tibial residual limb is 8cm per metre of height. A shorter below-knee residual limb (7cm), if necessary to assist wound healing is acceptable because the residual limb length in trans-tibial amputees has no relationship to the relative outcome in unilateral below-knee amputees for peripheral vascular disease.²²
- 5.12 A knee disarticulation can be a quicker operation than a trans-femoral amputation for patients and avoids disruption to important hip joint agonists and antagonists. It affords patients a longer lever arm if mobilising with a prosthesis and also, if restricted to wheelchair – a better base of support for sitting and transferring. There is a prosthetic, cosmetic cost which should be discussed with the patients who will be expected to wear a prosthesis.^{23,24,25} If a person is unlikely to be a prosthetic user, a knee disarticulation assists with bed-mobility and transfers and should be considered as an option especially if the person may become a bilateral amputee in due course. A knee disarticulation also preserves the lap, which is beneficial for carrying items in the wheelchair.

Post amputation phase

- 5.13 The post amputation phase consists of the post-operative period, which bridges with the pre-prosthetic and prosthetic phases. Barsby and Lumley²⁶ published a useful check list which covers all these phases.
- 5.14 Good post-operative analgesia is essential to control neuropathic and nociceptive residual limb pain and allows the patient to actively participate in their post-operative rehabilitation as soon as possible. Early involvement of the pain team is recommended.
- 5.15 Post operatively rigid dressings, plaster of paris or vacuum or pneumatic, can be beneficial for trans-tibial amputations in a specialised unit, but require more than one change. Adequate support and awareness from the nursing team in the ward is essential to avoid complications.²⁷ A rigid dressing affords control of residual limb oedema and maintenance of a straight knee joint. In other circumstances a soft tissue dressing is preferable.²⁸
- 5.16 After removal of the dressings originally applied in the operating theatre, residual limb support should initially be gentle and can be provided by the correct use of lightly elasticated tubular support (eg Tubifast™) but not Tubigrip™ that is too tight. Residual limb oedema management is crucial in the post-operative phase. Constant usage of compression shrinker socks in the post amputation phase improves comfort and reduces oedema. The general use of residual limb bandages^{15,28} for this purpose is not recommended.
- 5.17 All amputees should have access to adequate therapy services; physiotherapy, occupational therapy and psychological support from a practitioner psychologist or counsellor. There should be close consultation between the surgeon and physiotherapist regarding the timing of rehabilitation and in particular the use of early walking aids (EWAs). These therapists should be adequately experienced in amputee management and rehabilitation and have access to appropriate equipment and facilities to optimise their input. A variety of early walking aids should be available for assessment as appropriate.^{29,30,31} They should also carry stocks of compression shrinkers/socks to facilitate the reduction of residual limb oedema. A wheelchair and suitable residual limb support³² for trans-tibial and knee disarticulation amputees, footplates, anti-tippers and appropriate pressure management cushion must be provided in the early post-operative phase.

- 5.18 All amputees should be considered for rehabilitation with a prosthetic limb and have a multi-disciplinary^{1,2} assessment by suitably experienced staff. Where a prosthesis is not going to be beneficial, general advice for strength maintenance, phantom pain control and use of transfer techniques rather than hoisting is appropriate. Advice also on household equipment and wheelchair and seating is valuable. The assessment may take place at the patient's local hospital or at the PARC depending upon local arrangements. The timing of the assessment should be guided by the patient's general post-operative status rather than the state of healing of the amputation in isolation.
- 5.19 Hospitals with a significant number of amputees for rehabilitation should have a hospital Amputee Rehabilitation Team to co-ordinate their care. The team should be able to call for support from Social Workers and Practitioner Psychologist colleagues. The new amputee and relatives and carers should be informed about local and national support groups and amputee organisations eg Limbless Association, BLESMA (British Limbless Ex-Service Men's and Women's Association) and how to contact them. While satisfaction levels with information about the reason for amputation and details about operation are generally acceptable, levels of satisfaction with advice on service, appliances and other rehabilitation aspects are poor.³³
- 5.20 All amputees should be offered referral to the Centre. In some cases the objective of rehabilitation is to enable the patient to be independent without a prosthesis eg some elderly dysvascular amputees in particular will not benefit from a prosthesis.³⁴
- 5.21 Hospitals should have referral forms for the appropriate PARC available. The form should record all information relevant to decisions about Amputee Rehabilitation for the patient and should be completed on behalf of the referring consultant by a designated member of the hospital Amputee Rehabilitation team. Referral to the local PARC should be encouraged either for advice or Amputee Rehabilitation.
- 5.22 Life expectancy of a vascular amputee is short^{34,35} and in the elderly is associated with a considerable morbidity and deterioration of functional and residential status.^{36,37} Amputees with extensive co-morbidity are less likely to walk,^{38,39,40} though many still use their prosthesis daily for help with transfers (transtibial level only) and cosmetic purposes, especially those with associated musculo-skeletal impairment eg rheumatoid arthritis. Similarly, Prosthetic Rehabilitation can be successful in patients with prior stroke, especially in terms of independence, life style and self-respect.⁴¹ The ability to perform activities of daily living (ADL) tasks is the most important predictor for well-being and quality of life. Patients who are confused or have cognitive impairment are less likely to benefit from a prosthesis but should be formally assessed.^{42,43,44} Other factors that are significantly related to less prosthetic use are age, female gender, possession of wheelchair, level of physical disability, poor compliance and self-perception and the amputee's dissatisfaction.⁴⁵ The majority of elderly amputees currently prescribed a prosthesis do achieve useful function with a prosthesis with some decrease in dependency, which justifies the expense of this form of rehabilitation.^{38,46} However, a referral to the PARC would allow thorough assessment and expert advice in terms of alternative methods of achieving mobility and independence, and provide access to counselling.⁴⁷ All amputees should have access to an appropriate wheelchair.
- 5.23 Discharge from the hospital should be based on a locally negotiated hospital discharge policy. These policies should ensure that:
- Any cognitive difficulties have been taken into account
 - Adequate pain control has been established
 - Arrangements have been made for wound care
 - Arrangements have been made for regular podiatry follow-up for vascular patients
 - The patient is safe and functionally independent, if necessary from a wheelchair or set up with an appropriate package of care
 - If undergoing Amputee Rehabilitation, the patient should have necessary appointments with a local physiotherapist and referral to the PARC
 - The patient has a written home exercise programme to prevent contractures
 - Nutritional needs have been met, with meals provided if required
 - Appropriate housing assessment, equipment and minor adaptations are in place and that the appropriate arrangements have been made for further major adaptations as required.
- 5.24 If any of the above are lacking, adequate alternative support must be provided.

Primary prosthetic amputee rehabilitation

- 5.25 The primary prosthetic amputee rehabilitation phase starts with the decision that rehabilitation with a functional prosthesis is appropriate. It extends to when the patient has a stable fitting for their artificial limb and is a confident and competent user of the device, not requiring close support and supervision, or when prosthetic use is abandoned.
- 5.26 The aim of Amputee Rehabilitation is to enable the patient to achieve maximum functional independence, taking into account the patient's pre-amputation lifestyle, their expectations and limitations. Relevant prognostic factors for successful Prosthetic Rehabilitation can be identified at the beginning of rehabilitation treatment.^{48,49}
- 5.27 At the PARC, the amputee should be fully assessed by a Consultant in Rehabilitation Medicine and the multidisciplinary team. The physician should have all relevant information from the acute hospital therapists and surgical team.
- 5.28 The decision to prescribe a prosthetic limb is the responsibility of the Consultant in Rehabilitation Medicine and should be made in consultation with others in the team. The choice of limb prescription should be decided in consultation with the prosthetist and other members of the team. Whilst the last decade has seen an increasing number of new prosthetic components introduced into clinical practice, clinicians are increasingly required to adopt an evidence-based approach to their clinical practice. There is therefore an urgent need for controlled, prospective trials of the use and effectiveness of various prosthetic components and hardware in prescription.^{50,51,52} National policies for guidance on prescription of prostheses, if available should be followed.
- 5.29 The outcome of the assessment should be discussed with the patient and the process to be followed in making their artificial limb. They should also be instructed in what to expect and more importantly what not to expect from an artificial limb. The anticipated level of outcome in terms of mobility varies between individuals: this may range from assistance for transfers or limited indoor walking for some to normal gait and lifestyle including return to work and participation in physical sport and leisure.^{53,54} Realistic rehabilitation goals for prosthetic use should be set at this stage in consultation with the patient and agreed with them. The accuracy of the team in predicting outcome and setting goals should be monitored.
- 5.30 The patient's GP and the referring consultant should be kept informed of the outcome of the assessment, the treatment given and progress.
- 5.31 The completed prosthesis should be delivered as soon as possible. Meanwhile the hospital Amputee Rehabilitation team should continue to improve the patient's skill using an early walking aid (EWA). Once the patient has received their prosthesis, gait training must be continued under the care of the local or specialist physiotherapist and occupational therapist as appropriate, according to local arrangements.
- 5.32 During the early stages of a patient's prosthetic limb use, there may be significant changes in residual limb volume in a short space of time requiring frequent adjustments to the prosthesis. Provision must be made for this at the PARC or by visiting arrangements. Effective communication between local and specialist occupational therapists and physiotherapists is important. The frequency of therapy sessions is found to be related to prosthetic use.⁵⁵
- 5.33 Inpatient rehabilitation programmes for amputees are likely to prove more satisfactory than prolonged outpatient rehabilitation with regard to patient survival and also likelihood of being discharged to the home setting. Longer periods of inpatient rehabilitation can be associated with improved physical functioning.^{56,57} Patterns of recovery during the early milestones must be recognised and adequate time given for therapy and rehabilitation.⁵⁸
- 5.34 Contrary to general belief, the benefits of computerised laboratory gait analysis in routine prosthetic fitting and alignment adjustments remains doubtful,^{59,60} thus limiting its use mainly to research purposes. For complicated alignments and optimum prosthetic leg length determination, however, it can be very helpful.
- 5.35 Diabetes Mellitus accounts for about 45% of new lower limb amputee referrals.⁶¹ Peripheral vascular disease is a major contributor to pathogenesis of foot ulceration among diabetics⁶² and in neuropathic patients, there is a seven-fold risk of foot ulceration.⁶³ In this situation the quality of life is higher following Amputee Rehabilitation in comparison to people with chronic diabetic foot

ulcers.⁶⁴ The rate of lower extremity amputation has been considered to reflect the quality of diabetic foot care.⁶⁵ Fifty percent of unilateral diabetic amputees will develop a serious contralateral lesion within two years.⁶⁶ With the significant two year mortality post amputation for patients with diabetes, timely rehabilitation is essential. The team approach to the care of diabetic amputees is strongly recommended.⁶⁷

- 5.36 Regular podiatry review and consideration of appropriate footwear is crucial for the diabetic ambulant amputees and the non-ambulant.^{68,69} Foot care advice is essential.
- 5.37 For patients with multiple limb loss, a referral to a specialised rehabilitation centre (preferably to a Tertiary Referral PARC), should occur as soon as the acute injuries have been dealt with, so that realistic goals and expectations can be established.⁷⁰ Any limb that is sufficiently healed may be fitted with a prosthesis while further surgical intervention in other limbs is ongoing. A delay in referral may set the scene for failure in rehabilitation, which may be difficult to rectify in the long term.
- 5.38 Multiple limb amputations involving both upper and lower limbs are uncommon. While the majority of the protocols used for single limb amputations are appropriate for multiple limb amputees, their complexity mandates a holistic approach to rehabilitation in a Centre where experienced, specialised staff are available.
- 5.39 Whilst some multiple amputations are due to trauma and would require a closer collaboration with the plastic and orthopaedic surgeons, multiple amputations following septicaemia are becoming commoner among both adult and the paediatric and adolescent age groups who require close multi-disciplinary team work with the paediatricians. Timely prosthetic fitting is crucial to the long-term successful outcome for prosthetic use as is appropriate psychological counselling and support. These patients not only require a multi-disciplinary team, with experience in upper and lower limb amputations but also require input from other agencies to re-integrate them into the community.
- 5.40 A diverse selection of programmes and patient related outcome measures are used. Outcomes could be better compared if all Centres used similar outcome measure. Function and mobility achieved with or without a prosthesis should be documented using validated outcome measures.⁷¹ The BSRM currently recommends the validated prosthetic SIGAM Grades.⁷² Timed tests and balance tests can also be recorded. In the rehabilitation of amputees, aspects other than mobility may also need to be measured in the outcome - wheelchair skills and level of dependence. Various outcome measures that may be useful are described in the National Service Specifications for Prosthetics.

Amputee review and maintenance

- 5.41 Once the amputation residual limb has stabilised, the patient has acquired basic skills with their prosthetic limb and achieved the initial goals, the amputee moves on to the established user phase. This usually commences by 18 months post prosthetic delivery. In this phase the patient is empowered to use the services of the PARCs as and when they consider it necessary. Some, especially elderly patients, may never reach this stage and will need ongoing advice and review. The need for continued prosthetic maintenance and rehabilitation is recognised.⁷³
- 5.42 Skin and soft tissue problems in the residual limb⁷⁴ continue to be common and troublesome despite good hygiene and the use of newer socket materials, such as silicone.⁷⁵
- 5.43 Falling and fear of falling are pervasive amongst amputees.⁷⁶ Balance confidence is the only variable factor associated with mobility capability and performance in social activity⁷⁷ and early education, advice regarding prevention and ongoing intervention is recommended.^{78,79} The residual limb may be more vulnerable to trauma due to associated osteoporosis.⁸⁰
- 5.44 Patients may need to attend the PARC for the management of symptoms directly, or indirectly associated with their amputation. Co-morbid cardio-vascular disease is common and should be considered in light of the increased energy requirement for walking with a prosthesis.⁸¹ Back pain or phantom limb pain or weight gain may also need to be addressed at subsequent medical reviews.⁸² There is a significantly increased risk of osteoarthritis in the intact limb at the knee and hip for all levels of amputation for traumatic amputees.⁸³ However there is no evidence of increased incidence of major joint replacement surgery in amputees and this is probably because they are managed conservatively. Gait patterns of highly active trans-femoral and trans-tibial amputees have been shown to differ from the able-bodied in greater loading on the intact limb.⁸⁴ Evidence is growing for

the positive effect of more adaptive componentry and the resultant reduced pressures on the sound limb.⁸⁵

- 5.45 To attain and sustain personal control in their prosthetic limb care pathway, without which they cannot be considered truly rehabilitated, patients require information about equipment and lifestyle options and support to gain confidence in their decision-making and in their dealings with the team at the PARC. All this requires access to an effective properly constituted multi-disciplinary team at the PARC and associated rehabilitation unit. The team needs to be approachable and facilitate the patient's education. The team should be led by a Consultant in Rehabilitation Medicine but to enhance access, patients should have direct access to individual team members as appropriate in any situation. The development and delivery of expert patient programmes are particularly relevant in rehabilitation services.
- 5.46 The team at the PARC should meet the patient's needs in all aspects of their prosthetic use and include prosthetists, physiotherapists, occupational therapists, nurses, medical staff and practitioner psychologists.
- 5.47 The patient should be educated in the need to attend the PARC for attention to the limb at suitable intervals for reasons such as:
- Mechanical maintenance and repair of the prosthesis⁷³
 - The provision of more appropriate equipment to meet changing needs due to life-style changes - recreational or occupational, ageing and concomitant medical conditions.
(Younger and more able amputees may benefit from a change to prosthetic componentry aimed at higher activity amputees, or different socket styles, as they progress. Newer designs of components may have physiological functional benefits regarding enhanced safety and decrease in energy expenditure)⁸⁶
 - Adjustment to fit due to normal or abnormal changes in the patient's residual limb conformation
 - The availability of appropriate, newer technology for limb components
 - The prevention of complications
 - To maintain mobility, function and independence.
- 5.48 A reliable same day repair and replacement socket fitting service is useful for various reasons including avoidance of prescribing a duplicate limb in many cases.
- 5.49 During clinical follow up appropriate referrals to specialist clinics such as the diabetic foot clinic, plastic surgery and pain management clinics etc may be indicated. Attendance for regular podiatry check-ups is essential for all vascular amputees especially those with diabetes. Suitable footwear often hospital derived is frequently needed.
- 5.50 A review of the care received by patients who underwent major lower limb amputation due to vascular disease or diabetes, emphasised the importance of early rehabilitation at the post-operative stage.¹¹
- 5.51 Adequate and appropriate attention should be given to the appearance and cosmetic finish of the prosthesis.

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6. Upper limb amputation

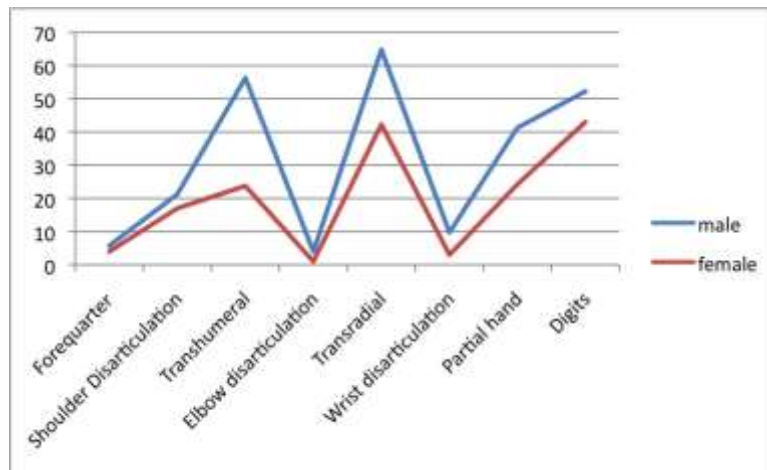
- 6.1 There are significant epidemiological differences between the rehabilitation of upper and lower limb amputees.
- 6.2 Upper limb amputations are much less frequent (average of 409 new amputees per year from 2007-2011) than lower limb amputations.¹ Trauma remains the main cause of upper limb amputation (31.5%) congenital limb deficiency is the second highest (26%), see table 6.1 below for full breakdown.

Table 6.1 - Breakdown of cause of new cases of upper limb deficiency (collated data from 2007-2011 limbless statistics)

Cause of limb loss/ deficiency	Trauma	Dys-vascularity	Infection	Neuro disability	Neoplas	Congenital	No data	All sum
Annual average no. of new patients (2007-11)	128.8	18.5	22.3	7.0	27.8	106.3	98.3	408.8
Percentage (%)	31.5	4.5	5.4	1.7	6.8	26.0	24.0	

- 6.3 Amputee Rehabilitation is one of a few specialties where patients may be cared for from cradle to grave and since the advent of ultrasound prenatal diagnosis, the patient might access the service before birth as prenatal appointments should be offered to all parents with a prenatal diagnosis of limb deficiency.²
- 6.4 The congenital limb deficiency group and traumatic nature of amputations affect a younger age group compared to lower limb amputations. In addition, the average life is longer due to less associated comorbidity in comparison with the lower limb amputees. This also means upper limb amputees require the service for more years than lower limb amputee patients.
- 6.5 The gender bias is illustrated in Figure 6.1 below, demonstrating a higher proportion of males with upper limb amputations at all levels but especially at the transradial and transhumeral level. This is explained by trauma being the main cause for upper limb amputation.
- 6.6 There are approximately 11,000 upper limb amputees in England requiring maintenance of their prostheses.
- 6.7 The alternative to an artificial limb for lower limb amputees would be the use of a wheelchair or crutches, with upper limb amputees there are also adaptations, orthotics and alternative methods to minimise the impairment and maximise participation. This means that there is a proportion of amputees who do not use artificial limbs but do use other appliances and services provided by the amputee rehabilitation services.
- 6.8 The low incidence of upper limb amputation and congenital limb deficiency means that if all Centres in the UK were to have equal numbers of upper limb patients then each of the 44 Prosthetic and Rehabilitation Centres (PARCs) would only see nine new patients a year which would not reach a 'critical mass' to ensure standards, expertise and satisfactory overall service delivery. However, the geographic area of the UK requires a significant number of Centres to allow for realistic access for patients. Thus the specialist service dictates that upper limb prosthetic services are provided predominantly at Tertiary Referral PARCs, (see paragraph 4.7). Standard PARCs may provide a service for straightforward upper limb amputees, if appropriate expertise is available.

Figure 6.1 - Gender bias in upper limb loss



Rehabilitation

- 6.9 The acute care referring teams tend to be the Orthopaedic or Plastic and Reconstructive surgical teams for trauma, infection or tumour. Obstetric and radiology services refer for prenatal and postnatal diagnosis of limb deficiency. At the PARCs, the Consultant in Rehabilitation Medicine and prosthetist should have a good knowledge of upper limb prostheses and appliances in addition to general prosthetic and rehabilitation techniques.
- 6.10 It should be noted that the occupational therapist has a key role in the rehabilitation of upper limb prosthetic users. The occupational therapist will advise on independent living and also train the amputee to use the arm prostheses or appliances. Whilst prosthetists are trained in both upper and lower limb prosthetics, it is suggested that PARCs should have designated prosthetists specialising in upper limb prosthetics and conversant with upper limb orthotics.
- 6.11 The amputee must be fully involved in discussions and decisions regarding his or her rehabilitation at all stages.

Acquired upper limb loss - pre-amputation

- 6.12 It is recognised that when upper limb amputations are due to trauma, the amputation may have to be undertaken as an emergency procedure. In cases of elective amputation, pre-amputation consultation with the PARC team is strongly advised because:
- Adequate pre-operative psychological preparation has major beneficial effects on the patient's ability to come to terms with the operation and to accept and learn to use the prosthesis
 - The surgical team could get appropriate tailored advice regarding the most suitable level of amputation for future successful use of the prosthesis and/or appliances
 - It will help to ensure that adequate pain relief and other peri-operative therapies have been instituted. This is essential with a patient group such as upper limb amputees where frequency and experience of procedure and inpatient management is limited
 - The prognosis and future course of rehabilitation can be discussed with the patient especially with a view to planning work, social and leisure activities
 - Meetings with established amputees can be arranged, if appropriate
 - Pre-operative therapies to maintain range of movement and muscle power in limbs can be instituted.

Acquired upper limb loss - amputation

- 6.13 This should be carried out using currently recognised amputation techniques, by a specialist upper limb surgeon with knowledge of future prosthetic considerations of the individual.³ The operating team should obtain the opinion of a Consultant in Rehabilitation Medicine as soon as possible.
- 6.14 Joint consultation between the rehabilitation team and the surgical team is ideal to decide on the level of amputation.
- 6.15 Some surgical advances like Direct Skeletal Fixation⁴ and Targeted Muscle Re-innervation (TMR)⁵ have provided promising initial results. However, these are not yet established clinical practises and further research is required to establish the long-term outcome and cost effectiveness. Full circumduction of the shoulder due to the lack of a socket is a recognised advantage of direct skeletal fixation in selected trans-humeral amputees who have demonstrated proficient use of a functional prosthesis. TMR has the potential to facilitate enhanced control with additional electrode sites for patients who are able to demonstrate good function using conventional myo-electric prostheses. Both osseointegration and TMR demand lengthy periods of rehabilitation and potential candidates will require assessment for suitability by teams specialised in these techniques.

Acquired limb loss - post amputation

- 6.16 It is recognised that in general upper limb amputations heal more quickly than lower limb amputations.
- 6.17 It is highly important to ensure adequate pain relief (before and after amputation). If necessary, a regional block or patient controlled analgesia by pump may be appropriate.
- 6.18 Residual limb bandaging is generally not recommended. Tubular elastic support (eg Tubifast™) is preferred and should be used night and day until the artificial limb is fitted. Unlike the lower limb, suitable ready-made elasticated residual limb socks may not be available but can be custom made. Residual limb oedema can also be controlled by elevating and exercising the arm or, in some cases, by the use of devices such as alternating compression devices, eg Flowtron™.
- 6.19 Psychological support, either from a specially trained counsellor or psychologist in the local hospital or PARC, may be indicated and this should be arranged if appropriate. A greater need has been identified in upper limb amputees.⁶
- 6.20 Physiotherapy should be started immediately following amputation to maintain posture, joint mobility and muscle strength in the limb proximal to the level of the amputation and to control oedema. The probability of rapidly developing a one-arm lifestyle makes it necessary to introduce activity of the residual limb as a matter of urgency.
- 6.21 A specialist amputee occupational therapist should see the amputee to advise on personal independence and activities of daily living, including driving⁷ and ensure that adequate referrals to Social Services are made.⁸

Prosthetic phase (if applicable)

- 6.22 The patient should have been to the PARC for pre-amputation consultation. Although prosthetic fitting may be deferred for four to six weeks after the amputation, it is advantageous for the patient to attend the PARC in the early post-operative phase for therapy to maintain muscle tone, posture and adequate range of movement of all joints.
- 6.23 Therapy for personal care and activities of daily living are required as is a holistic approach to pain relief.
- 6.24 At the PARC the potential multi disciplinary team (MDT) should consist of:
 - The [Consultant in Rehabilitation Medicine](#) to manage the surgical wound, scar, residual limb pain, phantom limb pain, associated medical conditions and to manage and plan the overall amputee rehabilitation.

- The **Prosthetist** works on the design and provision of the artificial limbs, this includes cosmetic and functional limbs, body powered and myoelectric limbs and orthotic devices. The prosthetist will work very closely with the occupational therapist especially during the training phases and different prosthetic trials.
- The **Occupational Therapist (OT)**, who should be involved in the decision-making process regarding prescription. The OT is essential for assisting the patient in learning to use assistive devices, training the patient in utilisation of prosthetics and orthotics, teaching regarding the management of activities required, especially with regards to vocation and employment and with attention to best methodology for the specific tasks. The OT should engage the patient in client centred goal setting to assist with the prescription decision, train the patient and oversee trials of different prosthetics (if applicable) that are necessary before the appropriate type of prosthesis is provided. This is most pertinent to myoelectric prostheses where technological advancement has seen a huge shift in terms of functionality and cost.
- The **Practitioner Psychologist** to offer counselling sessions as needed by the patient during adjustment, this needs to be offered from preamputation if possible, but the need has been shown to be greater at 6 to 24 months after limb loss.⁷
- The **Physiotherapist** to demonstrate appropriate exercises to maintain range of motion of the residual limb from the point of operation (pre-operatively if possible) and strength training after wound healing has taken place and the musculature incorporated in the flap has appropriately healed.

6.25 The result of the assessment and the rehabilitation programme including the limitations of prostheses should be explained to the patient and documented.⁸ The appropriate time scale for prosthetic delivery will be based on the patient's identified needs. The first prosthesis is usually fitted before the residual limb is stable and one or more refits will be necessary. At this stage it is usual to provide a cosmetic or working body powered arm, which is easy to adjust and use. This enables the wearer to develop skills and become accustomed to limb wearing. Once the residual limb is stable, it may be appropriate to progress to a myoelectric or other type of electric powered arm, provided the amputee has demonstrated tolerance of the limb wearing with regards to the pressure and weight of the limb. Appropriate training and trialling of myoelectric prostheses is essential to ensure appropriate provision of prosthetics and utilisation of resource based on competency evidenced by subjective and objective outcome measures.

6.26 It should be recognised that the use of functional prostheses for more proximal amputations is difficult.⁹ In a study by Jones and Davidson¹⁰ only 37% of upper limb amputees used their prosthesis regularly in the long term with 19% being occasional users. There is a higher rate of rejection of prosthesis in proximal amputations.^{11,12} Many individuals may only need a cosmetic prosthesis. Cosmetic arms do have some function¹³ as they are used for back up, steadying and supporting use and may be better termed 'passive function prostheses'.¹⁴

6.27 There is a wide range of terminal devices available for use with artificial limbs¹⁵ and these can be interchanged. It is usually recommended that the amputee start with an active functional terminal device to commence early prosthetic training. Provision of a passive cosmetic hand may also be appropriate at this stage. Future additions or changes depend upon the individual's lifestyle, occupation and leisure activities. The advantages and disadvantages of the different prostheses, especially the myoelectric prostheses should be explained to the patient.¹⁶ Adequate and appropriate attention should be given to the appearance and cosmetic finish of the prosthesis.¹⁷

6.28 Intense occupational therapy where the patient has multiple appointments through the week for a week or more at the Specialist Rehabilitation Centre may sometimes be required as most often sufficiently specialised occupational therapy is not available at the local hospital for upper limb prosthetic training.

6.29 Upper limb amputation need not be a barrier to employment¹⁸ and while Millstein et al¹⁹ showed a high incidence of return to work, amputees typically needed to change jobs and retrain. Vocational Rehabilitation, targeted for the amputee, increases the chance of return to work, and should be encouraged and arranged if possible. This may include work place assessment and advice on career choice or occupational alternatives.^{18,19}

6.30 Facilities for design and manufacture of one-off custom-made terminal devices for work related activities are useful. Leisure and recreational activities should also be considered, (see paragraphs 10.69-10.79).

- 6.31 It must also be recognised that digit and partial hand amputees often require access to the services for management of residual limb and phantom limb pain, psychological assistance and provision of prosthetics in the form of high definition prosthetics. The latter are often essential to the patient both from a physical, functional, but above this, a psychological perspective.
- 6.32 High definition limbs are often requested by upper limb amputees as the hands are almost constantly exposed and as such appropriate provision and education regarding the limitations of these should be available.

Review and maintenance phase

- 6.33 All upper limb amputees using prosthesis need to be followed up at a PARC for mechanical repairs, renewal or change of prosthesis or appliance and to facilitate changes in lifestyle, occupation or recreational activities.
- 6.34 Routine follow up appointments may not be necessary for established adult amputees, but they must have open access to a PARC. Indications for an appointment may include management of residual limb or phantom limb pain, a change in need secondary to occupational or leisure activities requiring a change in prosthetic prescription, or development of clinical symptoms in the residual or contra-lateral limb. It is recognised that over 50% of unilateral upper limb amputees will develop musculo-skeletal symptoms in the contra-lateral limbs.^{8,20} This may require appropriate therapy, and education should be available.
- 6.35 A change in the prosthetic prescription (eg to myoelectric) may require further training sessions with the OT.¹³
- 6.36 Children who have not reached skeletal maturity may require routine reviews to accommodate growth and changes in development/requirements. Children with acquired amputation will require more frequent reviews due to the unequal growth due to physal damage. This is addressed in greater detail in the next section as many children have a congenital upper limb deficiency rather than an acquired amputation.
- 6.37 In recent years, researchers and clinicians have become increasingly interested in functional outcome measures in users of upper limb prostheses. Evaluation remains difficult. There are a few outcome measures with proven psychometric quality for use in evaluation of upper limb prosthesis users. Different measures cover different aspects of health and the use of a different mixture of outcome measures would give a better picture of the outcome of this group of patients. Lindner et al²¹ recommend ACMC²²⁻²⁵ and PUF²⁶⁻²⁹ for children and ACMC²²⁻²⁵ and selected parts of OPUS^{30,31} and TAPES^{32,33} for adults in addition to SHAP³⁴. They also believe that measures that focus on the social interaction in paediatric users are required.
- 6.38 Ritchie et al³⁵ attempted to review the perceptions of cosmesis and function in adults with upper limb prostheses and found that the received studies mostly examine functionality and cosmesis as separate constructs and found that their conclusions were limited due to the disparity of the user groups studied. Biddiss & Chau (2007)³⁶ surveyed upper limb prosthetic use and abandonment over 25 years and found mean rejection rates of 45% for body powered and 35% for myoelectric prosthesis in children compared to 26% for body powered and 23% for myoelectric prostheses in adults. The wide variance ranged from 0 to 75% and was almost certainly due to the heterogeneous sample and the different practise and service structure in different parts of the world. This also confirmed the difficulty in comparing the outcome across different populations and highlighting that the rehabilitation and outcome remains very individual.

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7. Congenital limb deficiency

- 7.1 The birth of a child with congenital abnormalities of the limbs is a cause of great anxiety to the parents and family. They require an adequate explanation, reassurance that experts are available to give them detailed advice regarding these rare conditions, practical assistance and counselling.¹ Provided other life threatening congenital abnormalities are absent, these children are expected to develop normally in the early months. They will not have the sense of loss associated with acquired limb deficiency until they are much older and start to compare themselves with their peers. Such children instinctively tend to use the limbs they have to interact with the environment and to mobilise.
- 7.2 The management of these patients is effectively from birth throughout the individual's life and involves various professional disciplines at different stages.² It is made considerably more complex if more than one limb is deficient. In the early stages, starting ante-natally if the diagnosis is known at that stage,³ it is primarily the parents who are being supported, with the emphasis shifting progressively to the child as he or she becomes older. Unfortunately, the non-registration rate for adults with congenital upper limb deficiency could be as high as 64%.⁴

Role of the local hospital

- 7.3 The infant should be seen in the neo-natal period by the paediatrician to recognise the limb deficiency, exclude other congenital anomalies, and give initial advice and information to the parents. It is often helpful for a locally based paediatrician to take on responsibility for the longer-term follow-up of the child.
- 7.4 Those infants with lower limb abnormalities where major joint involvement is present or suspected, must be seen at an early stage by a paediatric orthopaedic surgeon in particular to test the hip joints for subluxation or dislocation. In certain cases, for example proximal femoral focal deficiency, a paediatric orthopaedic surgeon should keep the child under long-term review. For most cases of congenital limb deficiency, early surgery on the extremity should be avoided (within the first two years). It is important to give time to see how the individual child develops, and for the parents to understand the benefits and limitations of surgery. Even in the minority of cases where there is an indication for surgery, it will usually be a treatment option, rather than a necessity.
- 7.5 A designated social worker or health visitor (or, depending on local arrangements, another designated individual such as a therapist) should assist the family from an early stage, to provide general support and counselling, and to advise on benefit entitlements and the relevant voluntary support organisations. These comprise REACH for children with upper limb deficiency, and STEPS for children with lower limb deficiency.
- 7.6 The Consultant Paediatrician (or by local arrangement a designated consultant from another discipline) should refer the child to the appropriate Limb Deficiency Clinic as early as practicable, and ideally within the first month of life (unless this is inappropriate due to other life-threatening problems). This is not because early treatment is usually necessary, but to ensure that the parents receive detailed and accurate specialist advice.
- 7.7 Although routine ultrasound scans still sometimes miss these abnormalities, results of ultrasound scans are improving and if a limb deficiency is detected during pregnancy, the parents should be referred ante-natally to the appropriate Limb Deficiency Clinic.
- 7.8 Good liaison between the paediatric service, Limb Deficiency Clinic and orthopaedic surgeons is vital. It should be borne in mind that the management of almost all children with transverse limb deficiencies is by provision of a prosthesis or advice, and surgery is rarely indicated. Children with longitudinal limb deficiencies may require both a prosthesis and surgery.

Role of the Limb Deficiency Clinic (at PARC)

- 7.9 Depending upon the type of deficiency, the family may require only an advisory service. Various aids or 'gadgets' may be suggested, or a prosthesis or simpler custom-made appliance may be indicated. A minority will be helped by surgery. The optimal timing of prosthetic fitting and/or surgery should be discussed.

- 7.10 Ideally, the family should be seen at a special Limb Deficiency Clinic, where all the necessary expertise can be concentrated, and this will help to ensure that there is a critical mass of such patients to ensure optimal levels of care.⁵ This Clinic also provides parents with an opportunity to meet other families with similarly affected children. Because many of these patients will require prostheses or similar appliances, a Tertiary Referral PARC is a suitable base for the Limb Deficiency Clinic. These conditions are rare, thus smaller PARCs are unlikely to have sufficient numbers of such patients mentioned above.⁶ Ideally, therefore, the care of these children should be concentrated at the larger Tertiary Referral PARC, at least initially. This is supported in the current Service Specifications for Specialised Prosthetic Services of NHS England.⁷ However, to take into account patients' wishes, problems of travelling and access etc, some of the more established patients, particularly those with relatively straight forward needs, may be seen at the local PARCs, provided good clinical links are maintained with the larger Centre.
- 7.11 The clinical team at the Limb Deficiency Clinic (LDC) should be led by a Consultant in Rehabilitation Medicine, who should be a specialist with expertise in congenital limb deficiency, prosthetics, and rehabilitation. Ideally the consultant should see the infant with his or her parents by about one month of age (certainly before six months). The limb deficiency should be classified preferably using the ISO system.⁸ This will allow the parents to be given more specialist advice on the prognosis for their child, and on the options available for suitable short and long-term management and rehabilitation. The consultant at this clinic should also be able to advise the parents and surgeons regarding possible reconstructive surgery, including the optimal timing of such surgery, if indicated, from the point of view of the child's overall development. For example, Syme's amputation for a major longitudinal deficiency of the fibula is often appropriate shortly after the child is old enough to walk, and this would allow early fitting of an end bearing prosthesis.⁹ However, close liaison with a Specialist Paediatric Orthopaedic Surgeon with experience of these uncommon children's conditions is vital, particularly in cases of rarer and more variable types of deficiency, such as proximal femoral focal deficiency.¹⁰ (Likewise, for children with upper limb deficiency, either a Plastic Surgeon or Paediatric Upper Limb Surgeon should be involved in the management.)
- 7.12 Patients with major limb deficiencies should remain under the care of the named consultant at the LDC indefinitely. After the initial medical referral, the family should be able to seek appointments at the clinic directly (ie without having to be referred each time by their General Practitioner), on a six-monthly basis.
- 7.13 Involvement of a specialist occupational therapist (OT) at an early stage is essential for children with upper limb deficiency. The OT will initially advise the parents and will subsequently supervise prosthetic training (if appropriate) together with one and two-handed activities as well as provide advice and support when the child is starting at school.
- 7.14 Although most children with congenital lower limb deficiency, even those with secondary complications, will use their prosthesis for daily activities,^{11,12} and learn to walk on their own (with or without a prosthesis), those with more proximal loss or more complex disabilities will need the help of a specialist physiotherapist and, in all cases, parents should have access to one. Parents should have the option of seeing a counsellor with special experience of patients with limb deficiency and should be given the names and addresses of voluntary organisations. Children with lower limb congenital deficiency should be assessed by an OT to ensure that they are able to participate in age appropriate personal care, educational and leisure activities.

Other specialists

- 7.15 Other specialists involved include:
- **Medical Genetics** - Parents should be offered an appointment with a Consultant in Medical Genetics, to advise on the risk of congenital abnormalities in any future pregnancy, and in the future offspring of the affected child. Clinical features that might predict the discovery of a genetic cause include a bilateral malformation, positive family history, and having increasing numbers of limbs affected.¹³

- **Orthopaedic Surgeon** - As mentioned above, close liaison with a specialist Paediatric Orthopaedic Surgeon is important in many of these cases. This is particularly important in cases where hip instability is present or suspected, and where either limb lengthening or amputation are options in treatment. Joint consultations with surgeons help establish appropriate management plans in the early stage and at appropriate times subsequently, when required. The attached algorithm (Figure 7.1)¹⁴ summarises the possible clinical management options as appropriate. Congenital Limb Deficiency is rare and the experience of most orthopaedic surgeons of their management will be small.¹⁵ The suggestion of the establishment of special limb deficiency clinics seems a sensible way of collecting the necessary expertise together in one place to advise patients on the long- term management, throughout life, of their problems.
- **Plastic Surgeon/Hand Surgeon** - For patients with partial deficiency of the hand, the advice of a hand or plastic surgeon should be sought within the first six months of life, as more surgical options may be available at a younger age.¹⁶ This is particularly relevant in cases of syndactyly where this may require separation, or where for example pollicisation of an index finger or digital transfer, require consideration.

7.16 It is recommended that the PARC should have well established links with these specialist surgeons, and combined clinics are recommended.

Prosthetic treatment

- 7.17 Children who have an upper limb deficiency (such as a transverse deficiency of the radius and ulna partial), which is likely to be helped in later life by prostheses, should start using a simple cosmetic arm. Limb fitting should be undertaken when independent sitting balance is achieved at about six months.^{17,18} A functional body or electrically powered limb would generally be introduced at about 18 months of age, once the child is well established with walking, with more complicated control mechanisms being added later.^{17,19}
- 7.18 Patients requiring an upper limb prosthesis are a small group, and supervision of training in the use of artificial arms should be by a specialist OT based at a PARC. This OT will also advise on the use of other appliances, aids or gadgets/devices and one-handed activities.
- 7.19 Early fitting of the first upper limb below elbow prosthesis has a limited impact on prosthesis use and rejection rates during later stages of life.²⁰ Early fitting does not guarantee better satisfaction or improved functional use in the long term.²¹ Prosthetic prescription for upper limb congenital deficiency should instead be aimed to achieve targeted functional activities when and as required.
- 7.20 Children with lower limb deficiency should commence prosthetic fitting (and training) when they show signs of being ready to walk. Unilateral lower limb deficient children at any level and those with bilateral loss from below the knee are ready for prosthetic fitting when they pull to stand between 9 to 12 months.^{22,23} Unless an early amputation is appropriate, an extension prosthesis may be required, either of below knee end weight bearing or ischial bearing type, depending upon the degree of stability at the knee and hip joints. Many users of extension prostheses prefer to retain the extension prostheses despite the poorer cosmeses,²⁴ though others request a surgical intervention if inconvenienced by the cumbersome extension prostheses or if the prosthetic fitting becomes increasingly difficult.
- 7.21 Where possible, all children with either congenital or acquired limb loss should be treated by the same team of doctors, nurses, therapists, and prosthetists, to retain continuity, to ensure a high level of expertise, and to provide an opportunity for families with similarly affected children to meet. New prostheses (or new sockets) should be delivered within two weeks. To facilitate this and to maximise the prosthetist's control over the manufacturing process, all prostheses should be fabricated at the PARCs. Delay in obtaining component parts for the prosthesis is liable to delay production; if such components are not rapidly and reliably available from the manufacturer or importer, then adequate stocks should be held. Ideally the prosthetists dealing with this group of patients should also be proficient in related orthotic treatment; failing that, ready access to a suitably experienced orthotist is essential. This could be by means of a joint clinic.

- 7.22 Some children will benefit from in-patient treatment at particular times, and facilities should be available to admit the child with a parent close to the PARC.
- 7.23 Children using prostheses should be followed up by the prosthetist at three monthly intervals, and the rehabilitation physician at four-six monthly intervals to allow alterations required by growth and changing needs to be made. Other patients should be able to make appointments easily and quickly when required.
- 7.24 The acceptance and usefulness of upper limb prostheses varies considerably between apparently similar individuals or levels of deficiency. The main disadvantage of a prosthesis is that it lacks sensation, which is a crucial part of normal hand function. Some individuals become very skilled in the use of their feet for prehension and should not be discouraged from doing so. Children should, however, be given the opportunity to try artificial arms.¹⁷ Except in cases of very high bilateral deficiency, lower limb prostheses are generally well tolerated and heavily used.
- 7.25 Current research has so far detected no significant differences in outcomes between children with upper limb congenital limb deficiencies who use prostheses and those who do not. This is in relation to a broad spectrum of outcomes including participation in sports, happiness and global function²⁵ or quality of life.²⁶
- 7.26 There appears to be an increase in joint hypermobility (laxity) in individuals born with congenital limb deficiencies compared with the prevalence of this condition in the general population. As joint hypermobility may predispose individuals to low back pain, joint effusion, recurrent joint dislocation and ligament rupture, it is useful to identify those individuals with hypermobility.²⁷

Education

- 7.27 Most children with congenital limb deficiencies are capable of attending a school and should do so. Often a school visit by the Specialist OT shortly before the child starts school, with a follow-up shortly thereafter, is very helpful in ensuring that the school staff understand, and can therefore best help the child, with or without a prosthesis. Children with more severe deficiencies may require some physical help (eg with negotiating stairs, use of the toilet etc) but such assistance should be kept to the minimum and be as unobtrusive as possible. Some will require use of a wheelchair, which may pose problems of access. PARC staff may need to participate in preparing An Education, Health and Care Plan (EHCP), which replaces the Statement of Education Needs.

Adolescence

- 7.28 Adolescents require particularly sensitive empathy as they become more concerned with their body image and relationships, and different strategies may need to be adopted for coping with everyday difficulties; for example, a child may always have had help from a parent with washing and dressing, but this may no longer be acceptable to a teenager. Many children who abandoned prosthetic use may require the use of cosmetic passive function prosthesis as adolescents. Specialist advice may be required in terms of considering a suitable career.

Adult life

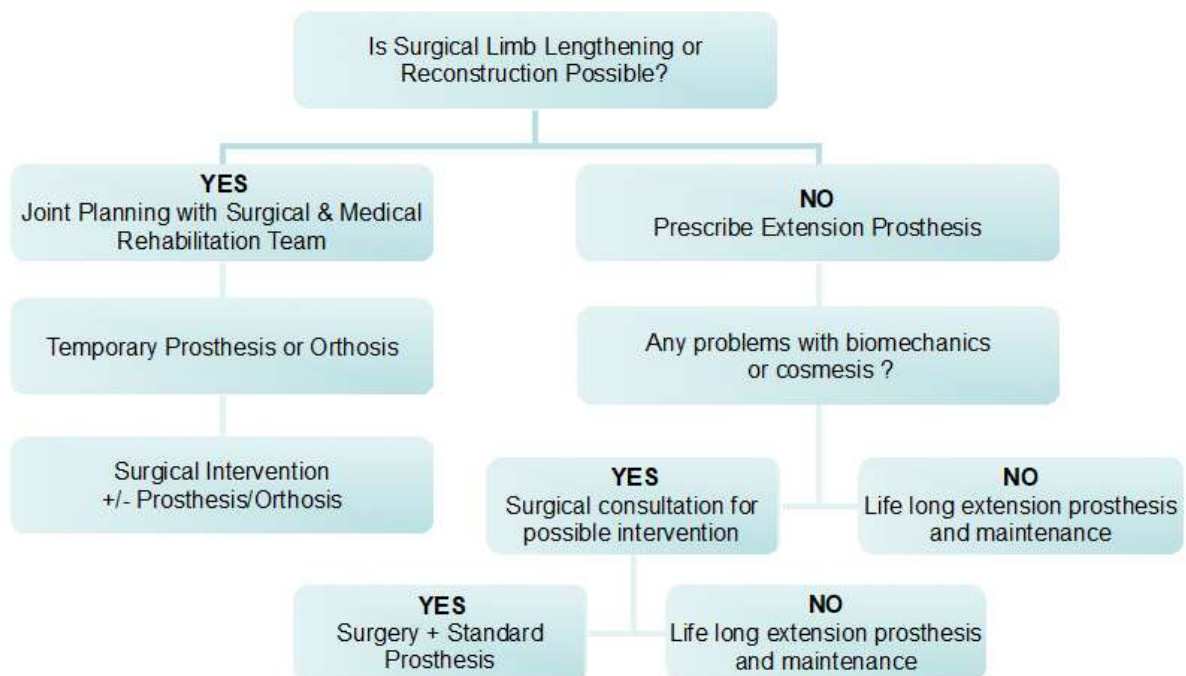
- 7.29 In adult life, the prosthetic needs of many patients with congenital limb deficiency will continue to be more complex than those of people with acquired amputation, and they will continue to require the assistance of a specialist medical and prosthetic team. The vast majority of people with congenital limb deficiency have a normal life expectancy, but they may develop increased difficulties as they become older. For example, those with a lower limb deficiency may develop back pain due to premature secondary degenerative changes, and those with bilateral upper limb deficiencies who have used their feet for prehension may develop problems in the joints of their lower limbs as they become older.

Phantom sensations and pain

- 7.30 It is widely believed that children born with congenital limb deficiencies or amputations early in life do not experience phantoms. However, several research studies have demonstrated a number of children reporting phantoms felt in the missing limbs²⁸ and a small percentage reported phantom pains. The loss of a limb due to early surgery is associated with an increase in the likelihood of experiencing these phenomena.²⁹

Figure 7.1 - Algorithm for Management of Congenital Limb Deficiency

From: Calder P & Hanspal R S. *Management of the Limb Deficient Child*. Oxford Text Book of Trauma & Orthopaedics, 2nd Ed. Oxford University Press, 2011.



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8. Rehabilitation following traumatic limb loss

- 8.1 In 2008, the Department of Health in England accepted the NHS Clinical Advisory Group (CAG) recommendations on Major Trauma Care (Trauma CAG) to establish Major Trauma Networks to provide coordinated pathways of care.^{1,2}
- 8.2 Twenty-six Major Trauma Centres (MTC) were initially established across England, each linked with number of supporting Trauma Units (TU).
- 8.3 Some patients require amputation either as a lifesaving procedure, failure of limb salvage procedure or as late complications of trauma and many are expected to have complex, early and long-term rehabilitation needs.
- 8.4 The Trauma CAG recommends the appointment of a Clinical Lead for Acute Trauma Rehabilitation Services (Consultant in Rehabilitation Medicine) in every MTC. This is included in the service specification.

The role of Rehabilitation Medicine following traumatic limb loss

- 8.5 In severe traumatic limb injuries, where amputation is considered, the role of the Consultant in Rehabilitation Medicine with experience in amputee medicine and prosthetics is highly recommended for:
- Advice on level of amputation as a tailored decision for each individual taking into account other co-trauma and co-morbidities
 - Anticipation and prevention of physical, psychological and social complications, based on knowledge of a condition's natural history and prognosis
 - Evaluation of rehabilitation potential and prognosis for recovery
 - Defining rehabilitation needs and directing patients to appropriate rehabilitation services
 - Coordinating care and collaborating with other medical, therapy and community teams
 - Communicating with patients and families to provide information, support and manage expectations.

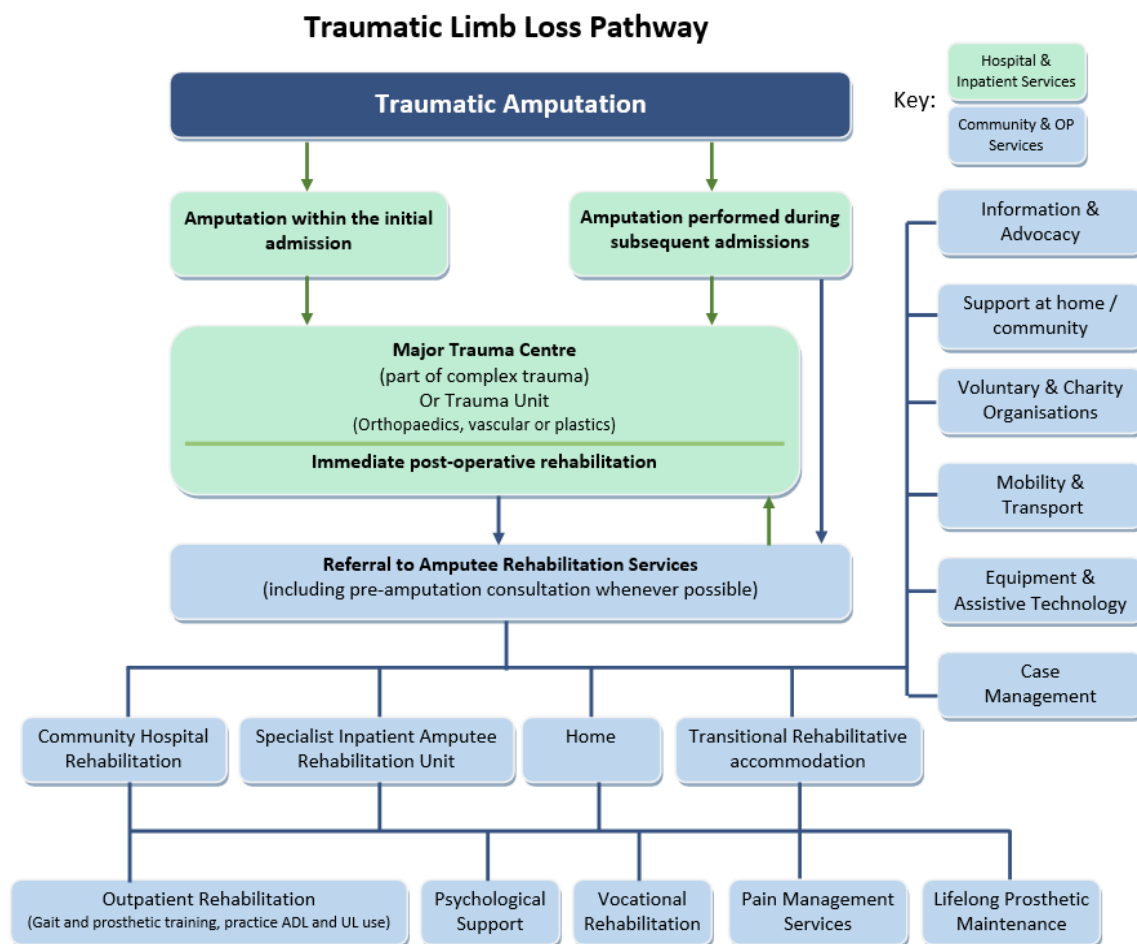
Guidance following traumatic limb loss

- 8.6 Working with the Trauma Audit and Research Network (TARN), the Trauma CAG has developed guidance for completion of the Rehabilitation Prescription (RP), as part of the requirement for the Best Practice Tariff in Major Trauma Centres, (see below).

The Rehabilitation Prescription (RP)

- 8.7 The Rehabilitation Prescription (RP)³ lays down a process for identification of patients with complex needs for rehabilitation, their Specialist Rehabilitation Prescription and the process for referral to Specialist Rehabilitation. This ensures seamless transfer of care and that the individual's care/rehabilitation needs are met throughout the pathway.
- 8.8 The RP is used to document the rehabilitation needs of severely injured patients (Injury Severity Score ISS ≥ 9) and identify how they will be addressed.
- 8.9 It also requires the completion of the TARN minimum dataset (four items only).
- 8.10 A basic RP pro forma has already been produced. This may be completed by a suitably qualified member of staff.

Figure 8.1 - Example pathway for traumatic limb loss, currently implemented in the East of England trauma network



- 8.11 The majority of trauma patients will progress rapidly down the Recovery, Re-enablement and Rehabilitation pathway. An example pathway is shown in Figure 8.1. Their rehabilitation needs can be met within their local general rehabilitation services - Standard Prosthetic Rehabilitation Unit (PRU) or The Lower Limb PRU pathway. This initial RP will also be their actual prescription for on-going rehabilitation at discharge from the MTC.

Coordinated care and interdisciplinary working

- 8.12 Vascular injury⁴ is present in 4.4% of general trauma admissions whilst one third of these concern the extremity vessels. Patients with vascular injury have a higher overall mortality rate (between 18-26%). Most amputations are performed on patients with mangled extremities where limb revascularisation is not possible.
- 8.13 In those that undergo revascularisation, the limb salvage rate is 85%.
- 8.14 In special cases, the early provision of prosthesis might facilitate the start of early rehabilitation even while patients still require further inpatient stay at the trauma centre.
- 8.15 Upper limb traumatic amputation needs an early coordinated approach between plastic surgery, amputee rehabilitation, hand therapy and counselling service.
- 8.16 Children with traumatic amputation need an early coordinated approach between the paediatric team, plastic surgery, amputee rehabilitation, counselling service, primary care, occupational therapy and differing community services including social services and school service.

- 8.17 Counselling should be made available to patients' families from the early stages following trauma.
- 8.18 Careful selection and identification of patients who will require referral to a complex rehabilitation unit is important to start early goal setting and facilitate discharge planning by the relevant rehabilitation centre.

Prosthetic limb prescription

- 8.19 All patients will require rehabilitation input following limb loss. However, not all amputees will be suitable for rehabilitation with a prosthetic limb.

Amputation as a result of an old trauma

- 8.20 For patients who require amputation at a late stage, the BSRM highly recommends pre-amputation consultation with the rehabilitation multidisciplinary team led by a Consultant in Rehabilitation Medicine for the same reasons mentioned above. This is to ensure the best outcome in terms of function, prognosis, amputation level, functional prosthetic rehabilitation and psychological acceptance of the amputation as a treatment.

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9. Care for Veterans with amputations

- 9.1 'A better deal for military amputees' was written by Dr Andrew Murrison MD MP and published in June 2011.¹ The recommendations of the report aim to support military amputees in the transition from the Defence Services Medical Rehabilitation Centre (DMRC) to the National Health Service and their ongoing care including that of ex-servicemen with service attributable amputations or injury leading to amputation.
- 9.2 The report recognised the differential in both funding and rehabilitation services between these health care providers. The cost of rehabilitation in the Army is at an average of £20,000 per annum compared to the £900 in the NHS.¹ The rehabilitation services at the DMRC are inpatient services initiating with the transfer from an acute hospital. The services can be accessed instantly compared to scheduled appointments in the NHS.
- 9.3 The recommendations of the report have the overall aim of supporting amputee veterans (with a War Pension and or Armed Forces Compensation Scheme, AFCS) in both a safe transition and long-term management within the NHS.
- 9.4 The report also states that there should be overall benefits to the wider NHS amputee population as a result of the implementation, including the development of NICE guidelines which have yet to be produced.¹
- 9.5 The report concluded that £15 million over three years should be set aside for the implementation of its recommendations.
- 9.6 It is important to recognise that:
- Most amputees transferring to the NHS have concluded their initial amputee rehabilitation and are deemed established patients. However, there has been a small cohort not completing rehabilitation and continuing their primary rehabilitation in the NHS.
 - The amputees should be maintained on established limbs that were provided in the DMRC, however access to new technology should be made available and funded separately as outlined below.
 - Regular follow up is essential.
 - When established limbs become beyond economic repair, review of appropriate replacements must be supported via full clinical assessment including the outcome measures used for initial provision.
 - For the purposes of this report, 'Veterans' are those who's amputation is directly related to injuries sustained whilst in service.
 - Receiving centres (Enhanced Centres for Veteran Care) must be experienced in the prosthetics of the patient being referred.

Recommendations and scope of provision of prosthetics for ex-servicemen with service attributable injury

- 9.7 The Armed Forces Covenant ensures that ex-servicemen are given priority access to services.
- 9.8 'Veterans receive their healthcare from the NHS, and should receive priority treatment where it relates to a condition which results from their service in the Armed Forces, subject to clinical need' Armed Forces Covenant.²
- 9.9 This Service is focused on maintaining and enhancing mobility, independence and function including the continuation of existing prosthetic prescriptions or the clinically-appropriate upgrade. Consequently, orthotics should be provided if required for mobilisation with a prosthesis. Special consideration should be made for amputees with wheelchair and special seating needs.

- 9.10 Close integration with other services such as pain management and mental health are essential. However, in the case of the latter, it should be noted that almost every former NHS Strategic Health Authority (SHA) region has a version of a Veterans' Mental Health Service in operation, as a response to Dr Murrison's first report entitled 'Fighting Fit: A Mental Health Plan for Servicemen and Veterans'.³
- 9.11 Despite the number of co-morbid health issues that are often associated with these types of amputation injuries, support in these areas should also continue to be provided through existing acute clinical pathways using local NHS resources.

Eligibility

- 9.12 This Interim Service (and further development of the service) is for all veterans who have experienced limb-loss due to 'Service-attributable injury'.
- 9.13 This eligibility should already have been established through the Service Personnel and Veterans Agency (SPVA). NHS staff are therefore not required to establish eligibility, or express a view on the apparent worthiness of a particular case because of knowledge about their military service, beyond confirmation that one of these schemes applies.
- 9.14 The amputee should be able to provide sufficient evidence of their eligibility under this scheme; however, any doubts should be discussed with the BLESMA representative (British Limbless Ex-Serviceman Association) or SPVA in the presence of the patient.

Transfer protocol

- 9.15 Comprehensive documentation should precede the patient transfer from the Defences Medical Rehabilitation Centre (DMRC) to ensure smooth transition and preparation for the arrival of the patient.
- 9.16 The information should be in the form of written reports outlined below:
- Medical discharge summary
 - Patient details
 - Full medical history
 - Current Multidisciplinary Team reports
 - Full history of prosthetic limbs
 - Current prescription of all limbs
 - Other current rehabilitation equipment: wheelchair, orthotics.
- 9.17 It is expected that the primary assessment would be arranged two-four weeks after receiving the transfer documentation. This is to ensure full multidisciplinary assessment is carried out at the Centre.
- 9.18 Current Service personnel who are attending the DMRC may be expected to attend any Centre if access to DMRC is limited at that time or urgent/emergency assessment or treatment is required.
- 9.19 Preparing the patient for transfer is an important aspect of the transition.

Physical activity and fitness

- 9.20 The DMRC emphasises the physical training element to rehabilitation. Large gymnasias and dedicated sports facilities, such as a swimming pool, staffed by physical training instructors has allowed amputees to reach peak physical fitness and strength in addition to ability prior to discharge.
- 9.21 This work needs to be continued in the Enhanced Centres for Veterans Care (ECVC) ideally under the supervision of fitness instructors. This is achieved with a focus on the following:
- Baseline assessment of physical fitness and strength at primary assessment
 - Regular assessments of fitness and recording progress against desired goals
 - Maintaining fitness needs at appropriate levels relating to prosthetic provision to meet agreed goals/vocation requirements/recreational requirements

- Regular MDT follow up appointments
- Jointly arranged appointments between physiotherapists, fitness instructors and patient.

BLESMA officer

- 9.22 The role of the BLESMA Support Officer is key in supporting the patient both in their transition and once settled into civilian life. The BLESMA Officer should have ready access to the Centre and MDT.

Table 9.1 - Recommendations of the Murrison Report (2011)

	Recommendation	Accepted?
1.	National commissioning of specialist prosthetic & rehab services through a small number of multi-disciplinary centres	✓
2.	Work effectively with Devolved Administrations	✓
3.	Veterans to access mainstream services through a PARC of their choice	✓
4.	BLESMA support officer in each Centre	✓
5.	Improve and expedite work on the transition from military to NHS services	✓
6.	Produce NICE guidelines	✓
7.	Prospective study of long-term outcomes	✓
8.	Support relocation of Headley Court to National Centre (DNRC), integrated better with the NHS	✓
9.	Military/civilian exchange of healthcare professionals	✓
10.	Extending arrangements for claiming travel expenses	✓
11.	Access to equivalent services if living abroad	✗
12.	Funding audit after 5 years	✓

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10. Miscellaneous topics

The following topics are of specific interest because of the current developments in the service due to recent advances in Prosthetics and Prosthetic Rehabilitation.

Counselling

Introduction

- 10.1 Counselling services for people with amputations are relatively new but are growing fast. Counselling is aimed at enabling patients to understand more about themselves, to use their own strengths to come to terms with their feelings and so to cope with problems. It is not an advice-giving service. Professional practice in prosthetics and orthotics may not require an in-depth knowledge of associated psychological disorders, but professionals should be aware of psychological issues, which may influence the rehabilitation. This knowledge may facilitate appropriate referrals and enhance multi-disciplinary teamwork.¹

Evidence from previous studies

- 10.2 Whilst Consultants in Rehabilitation Medicine and prosthetists were perceived by patients as offering an adequate service in most cases,² a majority would have valued the opportunity of specialist counselling at some stage during their experience.
- 10.3 A recent study³ showed that 75% of patients had emotional problems. Patients with amputation due to trauma and upper limb amputees were more vulnerable to emotional distress. The likely time for people to seek counselling was between six and twenty-four months following the amputation.
- 10.4 The above findings were substantiated by further research, using standardised measures of emotional distress.⁴
- 10.5 Livneh⁵ recommended that fostering a problem-focussed, rather than emotion-focussed coping strategy leads to better psychological adjustment.
- 10.6 The complexity of the psychological factors involved in amputees' acceptance of prostheses, is discussed by Desmond and Maclachlan.⁶

Recommendations

- 10.7 Every Centre should have a counselling service with readily available access.
- 10.8 All patients and relatives of patients who express a wish to see a counsellor should be offered the service.
- 10.9 Primary patients should be made aware of the availability of counselling services on their first appointment, or as soon as possible.
- 10.10 The service should be audited by adequate record keeping.
- 10.11 Strategies should be developed which are most helpful to the clients' problems (eg arranging a meeting with a 'matched' user where requested, social work support for a re-housing application where necessary etc).
- 10.12 Client satisfaction with the service should be monitored every two years, or sooner if a problem should arise.
- 10.13 Pre-amputation counselling should be given in every case of elective amputation unless medical indications pre-empt it.
- 10.14 All patients at risk of increased emotional distress (eg amputation sustained through trauma, upper limb patients) should be offered counselling and if they decline, their refusal should be documented in the medical notes.

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Outcome measures

Introduction

- 10.15 The need to use outcome measures in the clinical practice of rehabilitation is well recognised. One of the two proposed RCP standards for the speciality of Rehabilitation Medicine¹ was that:

All patients enrolled in a Rehabilitation programme should have at least one agreed outcome measure assessed on admission and discharge from the programme (Target 75%).

- 10.16 The outcome measure used will depend on the patient's condition and disability, their rehabilitation needs, and the nature of their programme and, validated outcome measures should be used wherever possible.

Recommendation

- 10.17 Outcome measures should be selected in relation to the individual goals for Rehabilitation and success must be viewed in relation to pre-morbid function.² In Amputee and Prosthetic Rehabilitation, the following outcome measures may be appropriate depending upon the needs and may therefore be considered as 'the Basket of Measures'. Outcomes are better compared if all Centres use similar outcome measures.³ To enable this the working party recommends, between alternatives, the use of outcome measures marked with an [asterisk](#).

Impairment measures

- 10.18 ISO Residual limb descriptors.^{4,5,6} These are the internationally recognised descriptors for various levels of upper and lower limb amputations and congenital limb deficiencies.
- 10.19 McGill Pain Scores⁷ which are well recognised for description of pain.
- 10.20 Numeral Rating Score or Visual Analogue Score for pain⁸ which are widely used for scoring pain.
- 10.21 Socket Comfort Score⁹ is a validated numerical measure for comfort of prosthetic socket fit.
- 10.22 Laboratory Gait Analysis^{10,11} is sophisticated, time-consuming and expensive eg kinetics, kinematics, EMG etc. The benefits in prosthetic fitting and alignment adjustments remains doubtful, however good quality data is vital for supporting the efficacy of new prosthetic components.
- 10.23 Southampton Hand Assessment Procedure (SHAP): the SHAP is a hand function test which was originally developed to assess the effectiveness of upper limb prosthesis.¹²
- 10.24 The Assessment of Capacity for Myoelectric Control (ACMC): is a 30-item standardised clinical assessment designed for the upper limb prosthesis group. It measures the quality of prosthetic hand movement performed by the prosthesis user during a self-chosen, two-handed functional task.¹³⁻¹⁶

Global disability/activity measures

10.25 *Barthel Index.¹⁷⁻¹⁹ This remains the most commonly used global disability measure.

10.26 UK FIM. This is not useful in isolation in Prosthetic Rehabilitation.²⁰

Mobility disability/activity measures

10.27 *SIGAM Grades.²¹ This is a disability measure for mobility and the measure recommended by the BSRM for routine clinical practice. It is also validated for self-completion by the patient and for use over the telephone.

10.28 *Locomotor Capabilities Index (LCI).²² The LCI is a 14 item sub-scale within the Prosthetic Profile of the Amputee Questionnaire (PPA), scored according to whether an individual can perform a particular activity while wearing a prosthesis. It is a valid and reliable tool, widely used by some physiotherapists, who would find it particularly useful as it measures the activities specifically targeted during early post prosthetic physiotherapy programmes. It can also be used for goal setting and be displayed in a polygram.²³

10.29 Volpicelli Grades.²⁴ Not validated, but often used in studies.

10.30 *Various Timed Walking Tests.^{19,25-28} A simple objective measure that appears to correlate well to functional mobility in both neurological disability and amputees.

10.31 Amputee Activity Score,²⁹ which is a measure of disability developed for outpatients with a prosthetic limb. It is validated using a step counter and shown to have retest reliability. It takes 20 to 25 minutes to complete and is most appropriate at the time of discharge.³⁰

10.32 Prosthetic Profile of the Amputee Questionnaire.³¹⁻³³ The Prosthetic Profile of Amputee (PPA) is a very informative questionnaire that yields good quality information relating to prosthetic use, functioning with a prosthesis and factors that may influence this. It is rather a qualitative instrument and because of its length, it is not suitable for daily use. Its use is recommended for data base accumulation, programme outcome/discharge summary and research studies.

10.33 The Amputee Mobility Predictor AMPPro,³⁴ is a predictive tool to assess the ambulatory potential of lower limb amputees, and it can also be used as an evaluative tool to measure function during or after rehabilitation.

10.34 Quality of Life Measure eg Prosthesis Evaluation Questionnaire³⁵ which is a self-reported measure that consists of 54 items grouped into nine domain scales.

10.35 Child Amputee Prosthesis - Prosthesis Satisfaction Inventory (CAPP-PSI) is a promising, brief, parent administered inventory for assessment of prosthetic satisfaction in children with limb deficiency.³⁶ It may be useful in research for predicting prosthetic wear and use of prostheses.

10.36 TAPES³⁷ (Trinity Amputation and Prosthetic Scales) is a multi-dimensional self-report instrument to better understand the experience of amputation and adjustment to a lower limb prosthesis and may be applied as a clinical and research tool.

10.37 Houghton Scale.³⁸ The Houghton Scale measures function of lower limb amputees fitted with a prosthesis in terms of wear and use of the prosthesis. It consists of four items: the amount of time the prosthesis is used, the manner in which it is used, whether an assistive device is used outside, and the individual's perception of stability while walking outside on a variety of terrain and is recommended for routine clinical use.

10.38 Attitude to Artificial Limb Questionnaire (AALQ)³⁹ is specifically designed to measure quality of life of lower limb amputees fitted with a prosthesis. It contains 10 items measuring satisfaction with prosthesis, walking ability, attitude of others to them, and restoration of body image.

10.39 Canadian Occupational Performance Measure (COPM): is an evidence-based outcome measure designed to capture a client's self-perception of performance in everyday living over time.⁴⁰

Emotional

10.40 The assessment of emotional status requires specialist expertise, but the following may be used for screening before referral to a psychologist:

- *Hospital Anxiety and Depression Scale (HAD Scale).⁴¹
- EQ-5D has been shown to be useful for use in amputees.⁴²

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Cosmesis

Introduction

10.41 There is a close relationship between body image and prosthesis satisfaction.¹ Artificial limbs, in replacing a body part, aim to restore both body image and function. To achieve this successfully, the artificial limb must have a cosmetic appearance that is acceptable to the individual patient. Advances in the manufacture and availability of high and low definition silicone cosmesis have given a much more realistic finished appearance. Widespread publicity has rapidly raised users' awareness of, and, demand for, this level of cosmetic effect.

10.42 In January 2001, John Hutton (Minister for Health) announced that (in England only):

"In cases in which silicone cosmesis is clinically appropriate, we wish to see equitable access across the country. In 2001-02 and recurrently, funding will therefore be provided for the NHS to increase existing provision of high to low definition cosmesis which, in future, will be available through a new contract from the NHS Purchasing and Supply Agency."

Evidence of need for improved cosmetic appearance

10.43 Although the attitude to the artificial limb was generally positive, of those who specified ways in which the prosthesis could be improved, 40% specifically mentioned appearance.²

10.44 Body image disruption was higher in younger people and those who suffered amputation due to trauma.²

10.45 In a study of spontaneous subjects raised by patients during counselling sessions, 20% mentioned body image as a particular problem.³

10.46 Breakey⁴ reports that body image and psychosocial well-being and life satisfaction are related. More attention to enhancement of the body image of the amputee is recommended.

10.47 A separate pilot study⁵ has shown that patients prefer off the shelf silicone covers (Skinergy™), in terms of appearance and feel to traditional stockinet and PVC, though the main satisfaction came from the choice given to them. However, in clinical practice, the use of these covers is associated with inherent problems due to the limitation imposed on adjustment of components eg heel height adjustment, and durability.⁶

10.48 Donovan-Hall et al⁷ have shown, in a self-selected group, that participation in activities that involve exposure of body parts is greater for those people with high definition silicone covers.

Recommended indications

10.49 **General** - Recommendations for prescription of Silicone cosmesis should avoid discrimination and be clinically based. Primarily, these will reflect psychosocial well-being and lifestyle issues eg body image disruption, avoidance of inter-personal contact, social isolation/agoraphobia due to the amputation, and the effects of societal reaction to the patient. Certain occupations/professions may require appropriate cosmesis.

10.50 **Upper Limb** - Partial hand and digit amputations (including hand reconstruction/grafting procedures) - there is no other effective, alternative prescription for this level of amputation. Otherwise, silicone cosmesis is generally only appropriate for passive upper limb prostheses.

10.51 **Lower Limb** - Partial foot amputation - Silicone foot prosthesis is already part of normal prescription practice. Otherwise, silicone cosmesis is generally only appropriate for below knee prostheses or the below-knee section of prostheses for other amputation levels, except cosmetic prostheses associated with wheelchair use.

Procedures and assessment

10.52 The basis for prescription should be decided locally, according to local policies/budgets/ prescription priorities (as with any other prescription protocols). For a single amputee the colour of the artificial limb should match the colour of the good limb, and for a multiple amputee especially, as far as

possible, the face. Recent advances in colour matching have permitted this, and the necessary matching funding should follow the patient. A waiting list is acceptable if there are genuine budgetary constraints - openness is paramount and local user groups should be involved in policy decisions.

- 10.53 The reaction to amputation and issues related to body image/cosmesis should be automatically assessed at routine clinical review. Further detailed/specific assessment should be undertaken by relevant members of the Multidisciplinary Rehabilitation Team. The underlying problem may be somatisation of other psychological issues that cannot be solved by cosmesis alone.⁷
- 10.54 Local assessment is mandatory to permit a holistic approach to the management of psychosocial well-being. The option of a prescription of silicone cosmesis should be seen as part of a patient's overall management, not a substitute for other treatments. Organisation of services or supply may necessitate referral to a larger centre, but initial 'ground work' should be done by the local team. Onward referrals or requests for a second opinion should outline the basis of assessment, reasons for referral, and provide all relevant information (routine referral to a Tertiary Manufacturing Centre for initial assessment is not appropriate).
- 10.55 Prescription of a high definition silicone cosmesis should not be viewed as a reward system conditional upon certain behaviours. Low definition silicone cosmesis should be prescribed initially – if there is no improvement in psychological status then there is unlikely to be any benefit from high definition silicone cosmesis.
- 10.56 Patients should be made fully aware of problems of subsequent colour change of the natural skin and agree appropriate colour match for prescription before starting manufacture. Patients who are prescribed silicone cosmesis should be fully aware of the risks of damage, understand the financial implications of prescription, and have joint responsibility with the prescribing clinician. In the event of damage, a reassessment is advisable rather than automatic re-prescription. It is an opportunity to note effectiveness.
- 10.57 Only one high definition silicone cosmetic cover should be prescribed (life span is estimated at three years), but prescription of low definition silicone cosmesis is appropriate as 'back-up'.
- 10.58 Audit of outcome is essential to review the clinical effectiveness of silicone cosmesis by re-assessment of psychological/life issues with appropriate assessment tools.

Relative contra-indications/exclusions

- 10.59 **General** - There are risks of damage from heat, oil, and certain activities and occupations. Beach Activity limbs are susceptible to damage from sharp sand and pebbles. These are not necessarily specific exclusions but the risks of damage may be too high. Patients must be fully aware of environmental constraints, but may prefer to use a prosthesis for 'best'. This has implications for local policies on duplicate or even second/third prostheses.
- 10.60 **Upper Limb** - Incompatible functional components, overall weight of silicone cosmesis, psychological problems not associated with the prosthesis, unstable residual limb volume or residual limb/socket interface, and excessive skin colour change should be considered. Similarly picking up or holding hot objects, cutting sharp objects, general DIY/gardening, and certain sports activities are likely to cause excessive wear and tear.
- 10.61 The appearance, movement and usefulness of a prosthesis will have a large bearing on patients' satisfaction, use and acceptance or abandonment of the prosthesis, as well as impact on the psychosocial well-being and adjustment of the amputee. The most fundamental question of what is perceived as 'cosmetic' by prosthetic upper limb users is still not well defined.⁸
- 10.62 **Lower Limb** - Incompatible functional components, overall weight of silicone cosmesis, need to shorten toe springs affecting performance of prosthetic components, inability to bridge the knee in transfemoral prostheses, unstable residual limb volume or residual limb/socket interface, certain occupations where risk of damage to silicone cosmesis is unacceptably high (crawling/kneeling etc), and high activity or contact sports are relative contra-indications.
- 10.63 All the above contra-indications/exclusions to prescription of high definition silicone cosmesis may reasonably be managed by prescription of a low definition silicone cosmesis as an alternative option.

Summary of recommendations

- 10.64 Prescription criteria should be based on functional need and be non-discriminatory.
- 10.65 The Rehabilitation team should have appropriate training in assessment methods and treatment options.
- 10.66 Patients should have access to written information about relative contra-indications, restriction of prescription options and limitations of colour matching.
- 10.67 Treatment goals/objectives should be agreed and fully documented before commencing manufacture.
- 10.68 Premature replacement of a damaged high definition silicone cosmesis should be justified and documented. The replacement protocol should be pre-agreed with the patient before prescription.

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Limbs for leisure

Introduction

- 10.69 The aim of the Prosthetic Rehabilitation Service should be not only to restore basic mobility to those with lower limb loss, or the ability to carry out basic activities of daily living for those with upper limb loss, but, where possible and relevant, to facilitate the individual's return to work and recreational pursuits.^{1,2} User groups have emphasised the importance of considering the limbless person's lifestyle and hobbies when making decisions regarding prosthetic prescription.
- 10.70 If possible, the prosthesis prescribed for every-day use should also be suitable for the proposed recreational (or occupational) activities of the user. In some cases, however, an additional, more specialised, prosthesis may be required.
- 10.71 Lower limb amputees participate in a variety of activities, and each person requires an individual assessment of their needs. This should consider the impact level of the activity and prosthesis use.³
- 10.72 For users of upper limb prostheses, in many cases a suitable terminal device for the proposed sport or hobby, which can be directly attached to the existing prosthesis, may be available commercially, or may need to be custom made. Sometimes a custom-made appliance, to be attached directly to the residual limb or deficient limb, may be more appropriate than a full prosthesis. For example, there are commercially available terminal appliances for holding a variety of workshop and gardening tools, or for holding golf clubs or other sporting equipment. However, a custom-made appliance

might be required for someone with a congenital limb deficiency to enable him or her to hold a musical instrument. Because the number of patients with upper limb deficiency or loss is relatively small, generally speaking the provision of specialised or extra equipment for recreational use will not cause major budgetary problems.

- 10.73** In the case of lower limb prostheses, the distinction between ‘everyday’ and ‘sports’ prostheses is less clear than it once was, due to the much broader range of feet and knee units, and indeed sockets now available. Furthermore, the same socket can be used for several ‘limbs’ using a Ferrier coupling, thus minimising cost. Because of the greater number of lower limb patients, and because of the disproportionately high cost of some knee and foot units, the prescriber must take due account not only of the clinical need, but also of the budgetary implications, when deciding the most appropriate prescription for any individual.
- 10.74** Swimming is a particularly beneficial and suitable form of exercise for many people with lower limb loss, and some (but not all) may benefit from a specialised prosthesis to facilitate swimming or other water activities.^{3,4} This is considered in more detail in paragraphs 10.83-10.92.

Recommendations on procedures

- 10.75** Leisure and sport should be considered as part of holistic rehabilitation for people with limb loss, in line with current NHS funding agreements.
- 10.76** Where possible, minor changes to the day to day limb should be considered to help patients in sport and leisure.
- 10.77** Advice regarding non-prosthetic aids and appliances to help participation in sport and leisure should be discussed with the patient.
- 10.78** The indication for prosthetic prescription and patient’s use of the limb in sport and leisure should be documented.
- 10.79** A prosthesis for leisure or sports activities should be considered when the residual limb volume and condition fluctuations are no longer an issue affecting socket fit.

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Water Activity Limbs

Introduction

- 10.80** There is increasing availability in the range of special limbs that can be used in wet conditions at work, for sport or leisure and for personal care activities. These are increasingly being requested and often need to be considered as part of the holistic rehabilitation of the individual.
- 10.81** Entry and exit from water should be performed carefully. Walking on the pool deck without the prosthesis should be performed using crutches with tips designed for wet surfaces. Hopping can lead to unforeseen slips and falls resulting in injury. A simple water-resistant prosthesis can be an asset to open water training when the amputee must negotiate the beach and other less stable

terrains.¹ Water activity prostheses need to be carefully constructed so as not to adversely affect buoyancy.

10.82 The following are recommended indications and procedures based on a national consensus study.²

Indications

10.83 Specific water activity sport or leisure, which necessitates the use of a water activity limb eg scuba diving, jet skiing etc.

10.84 Where risk analysis identifies that participation in an activity or leisure pastime presents a health and safety risk as a major issue and a water activity limb can significantly reduce these risks. They may be either due to:

- An associated medical or physical condition, eg concurrent injury or disease
- Social or occupational reasons eg parent of toddlers managing children in and around a swimming pool area
- or occupational, like therapists working in hydrotherapy pool.

10.85 Where other measures to address disability or handicap are impossible or impractical eg where adaptations like fitting appropriate sitting shower facility is impractical or inadvisable.

Recommendations on procedures

10.86 A referral may come either from the patient/user or a member of the multi-disciplinary team who has identified the need.

10.87 A consultation is arranged with the Consultant in Rehabilitation Medicine and an appropriate team member if necessary.

10.88 The need and indications are discussed including an explanation of the limiting factors.

10.89 The present day-to-day prosthesis should be viewed to see if slight modification may serve the specific purpose. This is increasingly possible because of recent developments of newer high tech prosthetic feet and other components that could be used in wet environmental conditions.

10.90 A demonstration model of the water activity limb and its uses, mechanics and limitations should be shown if possible.

10.91 If a water activity limb is prescribed indications should be documented.

10.92 Follow up should be arranged to identify use and provide appropriate maintenance of prosthesis if necessary.

References

1. Gailey R, Harsch P. Introduction to triathlon for the lower limb amputee triathlete. *Prosthet Orthot Int*, 2009; 33(3):242-255.
2. Hanspal RS, Nieveen R. Water Activity Limbs. *Prosthet Orthot Int*, 2002; 26:218-225.

11. Standards for Amputee and Prosthetic Rehabilitation (3rd Edition)

- 11.1 The following Standards and Guidelines are based on national consensus. The key recommendations from the background information in chapters 4-10 were initially extracted as Standards and Guidelines. The process of achieving consensus is described in paragraph 1.13.
- 11.2 Guidelines are lists of recommendations that guide clinicians in the management of individual patients with a particular condition or problem while Standards are recommendations which apply to services or populations, against which audit may be conducted. The statements in Section 4 and 5 are, for the most part, more properly to be considered as Guidelines as they follow individual patient pathways, whereas all other statements relate to service delivery and should therefore be regarded as Standards.
- 11.3 The Standards are in a format identical to the BSRM Standards for Specialist Inpatient Rehabilitation Services and for Community Rehabilitation Services.
- 11.4 Standards marked with an asterisk (*) may not relate to all PARCs but represent desirable practice, which should be evident at all major (Tertiary) Centres.

1.	SERVICE PROVISION
S1.1	The Prosthetic and Amputee Rehabilitation Service must be regarded as a 'Specialist Service', as per the national definition of Specialist Services.
S1.2	Every Prosthetic and Amputee Rehabilitation Centre (PARC) must have an agreed and written Operational Policy.
S1.3	<p>Service Users within any district should have access to all appropriate Rehabilitation services which aim to maximise physical, psychological and social well-being, including:</p> <ul style="list-style-type: none"> • Specialist in-patient Rehabilitation services • Out-patient and day Rehabilitation supported by adequate transport systems to ensure reliable attendance • Home-based/domiciliary Rehabilitation services which should be available for those unable to travel to a Rehabilitation Centre, or for whom Rehabilitation is more appropriately conducted in the context of their normal home environment.
S1.4	Co-ordinated service planning should ensure that suitable services are available within a reasonable travelling distance. (In rural areas, this may involve the establishment of satellite services or peripatetic teams to reach isolated locations).
S1.5	The senior manager and Consultant responsible for the Rehabilitation Service should be involved in the making of Service Agreements with the commissioners of health care for the catchment population.
S1.6	These Service Agreements must take account of the minority of patients with rare, multiple, or particularly complex needs, who may need to cross the standard geographical boundaries in order to obtain optimal care.
S1.7	Where gaps exist in local service provision, defined systems for referral and funding should be in place to ensure that service users/patients can gain timely access to services which are not available in their locality.
S1.8	The senior manager and the Consultant responsible for the Prosthetic Rehabilitation Service must be involved in the placing and subsequent monitoring of all contracts for the manufacture, provision, fit, delivery, repair and maintenance of Prostheses.
S1.9	These contracts (whether private or in-house) must be selected on the basis of competitive tendering, based on quality as well as price. Subject to suitable safeguards and annual review, such contracts should be for at least five years, with the option to roll on for a further two years or more, as shorter contract periods are extremely disruptive to patient care.
S1.10	The Consultant and the Manager should be the official representatives of the PARC in matters relating to the Trust.
S1.11	At all PARCs patients must have adequate access to relevant information in appropriate formats.
S1.12	The PARC should have on site, a Prosthetic Workshop equipped to deal with the day to day adjustment or repair and assembly of the majority of prostheses.
S1.13	Centres providing prosthetic services for upper limb loss and congenital limb deficiency must fulfil defined criteria for these services.
S1.14	The number of Consultant sessions at each Centre will depend on the case mix and other commitments, but each Consultant should undertake a minimum of two PA's in Amputee Rehabilitation. Major Centres (Tertiary Referral see 4.7-4.9) are likely to require a significantly higher number of PA's - a minimum of 5 sessions in Amputee Rehabilitation.
S1.15	Each patient must have a named Consultant in Rehabilitation Medicine and a named Prosthetist.
S1.16	Each PARC must have a structure in place to fulfil the requirements of Clinical Governance.
S1.17	Each PARC must have an established complaints procedure.
S1.18	The PARC must provide equity of access for all, irrespective of age or disability(ies).
S1.19	The PARC should ensure provision of appropriate transport for patients as clinical needs dictate.
S1.20	Every PARC should have adequate facilities for the collection of, and should collect, statistical data relating to Amputee Rehabilitation and prosthetics.

- S1.21** Patients and Carers should be involved in the planning and review of Rehabilitation services in their area through patient and public engagement (PPE).
- S1.22** Each PARC should have and proactively support a Users' Consultative Committee, made up of a representative sample of users /patients/carers of the Centre in collaboration with appropriate staff.

2. REHABILITATION TEAM

- S2.1** Rehabilitation must be carried out by a co-ordinated inter- or multi-disciplinary team(s).

At the District General Hospital

- S2.2** Each District General Hospital (referring surgical unit) should have at least one Consultant Surgeon with special responsibility for amputation surgery
- S2.3** The District General Hospital should have a designated and appropriately trained Therapist or other Allied Health Professional to co-ordinate Amputee Rehabilitation.
- S2.4** The District General Hospital must have an Occupational Therapy service familiar with needs of new amputees or must have access to same.
- S2.5** The District General Hospital must have a physiotherapist experienced in Amputee Rehabilitation to supervise pre-operative and post-operative physiotherapy management, which includes assessment and treatment, using appropriate early walking aids or have access to same.
- S2.6*** The District General Hospital should have a Social Worker/Care Manager with either suitable experience of the needs of amputees or access to appropriate information.
- S2.7** The District General Hospital must make provision for the Rehabilitation of those amputees not suitable for Prosthetic Rehabilitation after liaison with the PARC.

At the Prosthetic & Amputee Rehabilitation Centre (PARC)

- S2.8** The Multi-Disciplinary Team at each PARC must include a Rehabilitation Physician, Prosthetists, a Specialist Physiotherapist, and a Specialist Occupational Therapist.
- S2.9** Patients at all PARCs, in addition to a comprehensive Rehabilitation team, should have access to an Orthotist, Counsellor, Social Worker, Practitioner Psychologist, Rehabilitation Engineer, Podiatrist, Clinical Nurse Specialist and Employment Advisor.
- S2.10** The composition of the Multi-Disciplinary Team at each Centre must be appropriate to the level of service provided (see paragraphs 4.7, 4.24 and Table 4.2).

3. REFERRAL

- S3.1** Specialist Rehabilitation services should have:
- Defined inclusion criteria and
 - A written procedure for referral and for assessment.
- S3.2** Referral will be accepted from an appropriate agency (hospital teams/general practitioner) in accordance with the written referral procedure.
- S3.3** Where possible, the funding/contract should be agreed prior to assessment to avoid disappointment in cases outside the service agreement. (currently Specialist Commissioning by NHS England)
- S3.4** Receipt of referral should be acknowledged promptly with an appointment or relevant information if there is a delay in the appointment.

4. START OF REHABILITATION

Pre-amputation phase

- S4.1** A pre-amputation consultation with a Consultant Physician and/or appropriate PARC team members, should be arranged where amputation is a treatment option. This is to advise and inform the patient and surgical team of possible treatment, prosthetic options and likely outcome.
- S4.2** During pre-amputation consultation, particular emphasis should be placed on the possible cosmetic and functional outcomes, with and without a prosthesis.
- S4.3*** A meeting with an appropriate established amputee should be considered before elective amputation.

S4.4	Unless clinically contra-indicated, a Rehabilitation programme should be started pre-operatively.
	The amputation
S4.5	The amputation must be performed by a suitably experienced surgeon using currently recognised operative techniques with due consideration of future Rehabilitation potential including prosthetic use, except in cases of extreme urgency.
S4.6	All upper limb amputations must be carried out by an appropriately experienced upper limb surgeon using currently recognised upper limb amputation techniques except in cases of extreme urgency.
S4.7	The surgical team must ensure that the patient has adequate peri-operative pain control, including use of pre-operative techniques like epidural analgesia if indicated.
S4.8	The surgical team must liaise with the PARC when clinically indicated.
5.	REHABILITATION ASSESSMENT AND PROGRAMME PLANNING PHASE
	Assessment
S5.1	All amputees, must be offered referral to the PARC.
S5.2	Relevant clinical information, together with any special needs, is reviewed by the PARC staff and any necessary action or provision is implemented prior to the arrival of the individual.
S5.3	At the PARC the patient should be assessed by the multidisciplinary team, as appropriate.
S5.4	Following assessment, realistic Rehabilitation goals should be set with the agreement of the patient and carers and documented.
S5.5	The patient must be informed about the outcome of the assessment.
S5.6	If Prosthetic Rehabilitation is planned, the prosthesis should be prescribed within agreed prosthetic hardware guidelines, after consultation with relevant members of the multi-disciplinary team.
S5.7	Following assessment, a letter/written summary should be supplied to the referrer, summarising the case and the individuals Rehabilitation needs, with recommendations for management and the intervention plan. This should be copied to the GP and other relevant agencies, including the individual (patient) if appropriate.
	Programme planning phase
S5.8*	For complex or otherwise appropriate cases, access to an inpatient facility, offering continued Amputee and Prosthetic Rehabilitation should be available.
S5.9	All patients must be given information about Rehabilitation and lifestyle options as an amputee.
S5.10	If a prosthesis is not being prescribed, the patient, relatives and carers and referrers should be given reasons for the decision and alternative Rehabilitation plans must be documented and implemented.
S5.11	Experienced clinical counselling and psychological support should be available for all amputees.
S5.12	All new patients attending the PARC should be made aware of the availability of counselling.
S5.13	All PARCs should have a written and agreed policy for the provision of <ul style="list-style-type: none"> • Cosmeses • Leisure Limbs and • Water Activity Limbs.
6.	THE REHABILITATION PROGRAMME
S6.1	Prosthetists must follow the manufacturers' instructions and guidelines on risk management and any deviations from standard practice must be fully documented.
S6.2	The completed prosthesis should be delivered satisfactorily within the contractually stated time.
S6.3	Patients should have direct access to team members as appropriate and in accordance with local guidelines.

S6.4	The service provided must be responsive to any individual patient's change in lifestyle, occupation or general health.
S6.5	Outcomes should be recorded during the Rehabilitation phase, preferably using validated outcome measures.
S6.6	Adequate and appropriate attention should be given to the appearance and the cosmetic finish of the prosthesis.
S6.7	Facilities for design and supply of custom made/one off appliances required for amputees especially for work related activities, should be available.
S6.8*	All amputees should have access to Vocational Rehabilitation (including advice on driving).
S6.9	The appropriate follow up arrangements must be documented and appropriately explained to the patient.
Congenital limb deficiency	
S6.10	If a limb deficiency is detected during pregnancy, an antenatal referral to a Limb Deficiency Clinic should be offered and facilitated.
S6.11	The Paediatrician should refer to the Consultant in Rehabilitation Medicine specialising in Congenital Limb Deficiency at the Tertiary PARC at the earliest possible opportunity.
S6.12	Where appropriate, (for example where there are major joint abnormalities), the Paediatrician/Rehabilitation Consultant should, in consultation with parents/guardians, refer the child to a specialist orthopaedic surgeon, preferably for a joint clinical consultation.
S6.13	The child and parents/guardians should be seen in a Specialist Limb Deficiency Clinic within 3 months of birth.
S6.14	The parents/guardians must be given general and detailed expert advice on all relevant treatment options (including the advisability or otherwise of prosthetic and surgical management).
S6.15	The multi-disciplinary team must provide ongoing care for the child and parents/guardians with appropriate and documented follow-up plan.
S6.16	At the PARC, designated prosthetists with the appropriate specialist experience should look after all patients with Congenital Limb deficiency.
S6.17	A therapist specialising/experienced in management of limb deficiency must be available to all children with Congenital Limb Deficiency.
S6.18	Expert orthotic advice and treatment should be readily available.
S6.19	Ongoing advice and help must be offered as the children become adolescents and adults.
7.	DISCHARGE
S7.1	If a patient is being transferred or discharged from the PARC, a report with an adequate clinical summary must be forwarded as appropriate. When the patient abandons limb use, reasons should be documented and the GP informed.
8.	FOLLOW-UP
S8.1	All Rehabilitation facilities must have a written policy and procedure on follow-up.
S8.2	For established amputees, the follow-up procedure should allow patients to have direct access to team members as appropriate and in accordance with local guidelines.
S8.3	During the maintenance phase of established amputees, the service must be responsive to the changing needs of the patient.
S8.4	Feedback to the GP and any other relevant authority should be provided on follow-up, when clinically appropriate.
9.	STAFF DEVELOPMENT
S9.1	Systems in place in the NHS Trust for quality assurance and clinical governance must apply. There should be a system of regular appraisal for all staff.
S9.2	All professional staff should be kept up-to-date, and there should be a written policy on training.
S9.3	Staff should have local access to up-to-date Rehabilitation textbooks and the major Rehabilitation journals relevant to their service.

S9.4	Regular training must be available both within and between disciplines, and time must be allocated for training on a regular basis.
S9.5	Since in-house training is unlikely to be sufficient to meet all training needs, adequate funding must be available to allow staff to meet their training needs at external meetings, at least some of which should be multi-professional.
S9.6	Staff should be actively encouraged to attend national conferences, which will afford the opportunity to network with other colleagues both within and outside their own discipline.
S9.7	All services must undertake audit as a routine part of clinical practice.
S9.8	Audit sessions should be documented, and where change in practice is recommended, a named person should be designated to ensure implementation of the recommendations.
S9.9*	Every opportunity should be sought for multi-disciplinary and inter-agency education and training, including the involvement of patients in management of disability and raising disability awareness.
10. LIAISON WITH OTHER HEALTH CARE SERVICES AND AGENCIES	
S10.1	There should be access to an appropriate range of specialist health care services in acute, mental health and community sectors beyond those provided directly by the Rehabilitation and multi-disciplinary team. These may include: <ul style="list-style-type: none"> • Diabetic services • Plastic surgery • Continence and tissue viability services • Wheelchairs and special seating • Occupational health.
S10.2*	Rehabilitation services should have clearly identified policies or pathways for: <ul style="list-style-type: none"> • Working with general practitioners and primary care teams (generic services) • Support and specialist Rehabilitation for children and adolescents with disabilities approaching adult life.
S10.3*	There should be identified pathways to access and/or work with: <ul style="list-style-type: none"> • Social Services • Housing • Care agencies (including training for care staff for patients with complex needs) • Private sector agencies eg nursing homes • Education and further education including special needs and out-of area provision • Disability employment advisory services and facilities for preparation for work • Financial advice (Benefits Agency, Citizens Advise Bureau, Public Trust Office) • Legal advice (for patients and their families and carers) • Advocacy services - representing the individual's interest for those whose competence to participate in decisions about their care and their future is restricted • Charities, self-help groups and voluntary agencies • Driving ability assessment centre(s).
11. REFERRALS FROM MAJOR TRAUMA CENTRES	
S11.1	Specialist rehabilitation is a critical component of the Trauma Care Pathway, and should be led by a consultant trained and accredited in Rehabilitation Medicine.
S11.2	Trauma centres should identify and organise patients who will require amputee rehabilitation intervention to the relevant PARC.
S11.3	Referral for pre-amputation consultations should be facilitated when medically possible to allow patients to make an informed decision regarding their future management.
S11.4	The rehabilitation multi-disciplinary team should be involved at the early post-operative stage to help prevent and manage possible complications of amputation.
S11.5	Early assessments by an outreach multi-disciplinary team should be arranged for selected patients to enable the early start of rehabilitation while patients are still in the acute site following trauma related limb loss.

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- S11.6** Counselling should be made available to patient's families from the early stages following trauma related limb loss.
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- S11.7** Careful selection and identification of patients who will require inpatient rehabilitation is important to start early goal setting and facilitate discharge planning by relevant PARC centres.
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** These standards may not relate to all PARCs but represent desirable practice, which should be evident at all major (Tertiary) Centres.*

APPENDICES

Appendix 1 – Membership of the Working Party

Dr Imad Sedki (Co-Chair)	Consultant in Rehabilitation Medicine & Past Chair of BSRM Special Interest Group for Amputee Medicine Royal National Orthopaedic Hospital Trust, Brockley Hill, Stanmore HA7 4LP Imad.sedki@nhs.net
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Dr Lorraine Graham	Consultant in Rehabilitation Medicine and Chair of the BSRM Special Interest Group for Amputee Medicine Regional Disablement Service, Musgrave Park Hospital Belfast B9 7JB lorraine.graham@belfasttrust.hscni.net
Dr Fergus Jepson	Consultant in Rehabilitation Medicine Specialist Mobility Rehabilitation Centre Preston Business Centre, Watling Street Road, Fulwood, Preston PR2 8DY fergus.jepson@lthtr.nhs.uk
Professor Jai Kulkarni	Consultant in Rehabilitation Medicine Manchester University Foundation Trust, Specialised Ability Centre, Ability House, Altrincham Road, Manchester M22 4NY Jai.Kulkarni@mft.nhs.uk

Other contributors/consultees

Ms Laura Burgess	Physiotherapist
Dr Keren Fisher	Clinical Psychologist
Mr Steve McNeice	Multiple limb loss patient and NHS England Clinical Reference Group Patient Representative
Dr Alan Mistlin	Consultant in Rehabilitation Medicine, Defences Medical Rehabilitation Centre
Mr John Sullivan	Prosthetist
Ms Clare Tamsitt	Manager
Ms Carolyn Young	Commissioner
Professor Sir Saeed Zahedi OBE	ISPO
Ms Melissa Jacobs	Occupational Therapist

Appendix 2 – Glossary of terms

ADL	Activities of Daily Living.
ALAC	Artificial Limb and Appliance Centre. Old name for PARC (qv) when the Centres were run directly by the DHSS up to 1987.
AMRS	Amputee Medical Rehabilitation Society. Society for Rehabilitation Physicians specialising in the care of those with limb deficiency, and in Prosthetic Rehabilitation. Originally affiliated to BSRM, and was incorporated into the BSRM as a Special Interest Group, SIGAM (qv).
APO	Association of Prosthetists and Orthotists
ARCForum	Amputee Rehabilitation Clinical Forum
BACPAR	British Association of Chartered Physiotherapists in Amputee Rehabilitation.
BAPO	British Association of Prosthetists and Orthotists (see 2.8).
BHTA	British Health Trade Association.
BIST	British Institute of Surgical Technicians.
BLESMA	British Limbless Ex-Servicemen's Association.
BSRM	British Society of Rehabilitation Medicine. A society for all doctors involved in Rehabilitation Medicine.
CNS	Clinical Nurse Specialist.
DSC	Name applied to Prosthetic Rehabilitation Centres when run by the Special Health Authority, the Disablement Services Authority, for 1987-1990 and still used by many such Centres.
EWA	Early Walking Aids. Adjustable supportive multi-use devices, used in the physiotherapy department under supervision as a preliminary to prosthetic fitting. Useful for both assessment and initial walking training (see 5.11).
EmPOWER	'Umbrella' Association linking many voluntary groups connected with different aspects of disability and enablement.
HPC	Health Professionals Council.
IPEM	Institute of Physics and Engineering in Medicine.
Limbless Association	Association for those with limb loss or deficiency.
LLPOT	Lower Limb Prosthetic Occupational Therapist.
NASDAB	National Amputee Statistical Database (see 3.1).
NFARC	National Forum for Amputee Rehabilitation Counsellors.
OTTO	Occupational Therapist in Orthopaedics and Trauma.
PAs	Programmed Activities
PARC	Prosthetic and Amputee Rehabilitation Centre. The name used in this report for the specialised Centres caring for people with acquired and congenital limb deficiency, and which provide Prosthetic Rehabilitation.
PASA	Procurement and Supplies Agency (NHS).
PCT	Primary Care Trust.
POIG	Prosthetics and Orthotics Interest Group (for Rehabilitation Engineers).
Prosthesis	In this document, an artificial limb (plural prostheses). A prosthesis replaces an absent part, whereas an orthosis supports a weak or deficient part, or corrects a deformity.
REACH	Association for children with hand and upper limb deficiency.
RESMaG	Rehabilitation Engineers Management Group.
REBSIG	Rehabilitation Engineering and Biomechanics Special Interest Group
SIGAM	Special Interest Group in Amputee Medicine of the BSRM.
STEPS	Association for children with lower limb deficiency.
ULPOT	Upper Limb Prosthetic Occupational Therapist.

Appendix 3 - Useful addresses

Organisation	Address	Tel no./email	Email/website
BACPAR	BACPAR, C/o Chartered Society of Physiotherapy, 14 Bedford Row, London WC1R 4ED	enquiries@csp.org.uk	http://.bacpar.csp.org.uk
BAPO	British Association of Prosthetists and Orthotists Unit 3010, Abbey Mill Business Centre, Paisley PA1 1TJ	(0141) 561 7217 enquiries@bapo.com	www.bapo.com
BLESMA	BLESMA, The Limbless Veterans, Frankland Moore House, 185-187 High Road, Chadwell Heath, Essex RM6 6NA	(020) 8590 1124 ChadwellHeath@blesma.org	https://.blesma.org
BSRM	British Society of Rehabilitation Medicine C/o Royal College of Physicians, 11 St Andrews Place, London NW1 4LE	(01992) 638865 admin@bsrm.co.uk	www.bsrm.org.uk
College of OT's	Royal College of Occupational Therapists 106-114 Borough High Street, Southwark, London SE1 1LB	(020) 7357 6480	www.cot.org.uk
ISPO	International Society for Prosthetists and Orthotists UKNMS, PO Box 7225 Pitlochry, Perthshire PH16 9AH	(01796) 473556 www.ispo.org.uk	info@ispo.org.uk
Limbless Association	Limbless Association Unit 10, Waterhouse Business Centre, 2 Cromer Way, Chelmsford, Essex CM1 2QE	(01245) 216670 enquiries@limbless-association.org	www.limbless-association.org
REACH	Reach Charity Ltd Pearl Assurance House Brook Street, Tavistock Devon PL19 0BN	(0845) 1306225 reach@reach.org.uk	http://reach.org.uk

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