

## Amputee and Prosthetic Rehabilitation – Standards and Guidelines

(2<sup>nd</sup> Edition)

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

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Chair: Dr Rajiv Hanspal

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# Amputee and Prosthetic Rehabilitation Standards and Guidelines (2nd Edition)

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#### **Acknowledgements**

The members of the working party are very pleased with the high response rate and are extremely grateful to all participants in the consultation process, without whom it would not have been possible to develop these standards and guidelines.

Particular thanks must go to Professor Lynne Turner-Stokes, Chair of the BSRM Research and Clinical Standards Sub-Committee for her advice especially on the procedure involved in their development and Mr Sam Gallop CBE, Chair of emPOWER for his help not only as a valuable member of the working party but also for enabling the launch of the Report at the Annual emPOWER Conference.

The working party are also very grateful to the wider group of consultees listed in Appendix 1 and acknowledge the help and co-operation of several other colleagues not listed but who helped towards the publication of this report.

We are grateful for the indefatigable assistance of both Anne Costelloe and Wendy Hope in producing/editing the manuscript.

#### Launch of the Report

The Society has always worked closely with the User Organisations, now often represented under the single umbrella of emPOWER. It is therefore particularly encouraging that the report is being launched at the Annual emPOWER Conference on the 21st October 2003.

#### **WELCOME**

As a wearer of artificial limbs, and a user of a wheelchair, I cordially and gratefully welcome this superb  $2^{nd}$  Edition of Amputee and Prosthetic Rehabilitation – Standards and Guidelines. They build on the firm foundations laid by the excellent  $1^{st}$  Edition produced in September 1992.

There are 5 "C"s vital to the independence of the limbless individual: Choice, Comfort, Capability, Caring and Cosmesis.

John Hutton was the first Health Minister to recognise the importance of Cosmesis, and thereby further to extend the opportunities available to healthcare staff with users to practice the holistic approach to Rehabilitation reflected in these Standards and Guidelines.

In the "new" National Health Service there must be continual changes if we are to create and benefit from innovation – innovation for independence. These Standards and Guidelines will help provide secure and sound and well-lit pathways along which individuals who have lost their limbs can proceed with confidence and renewed hope for their full inclusion into society and with equal opportunities.

On behalf of all amputees I express our gratitude to all who, on our journeys from Hospital to Disablement Service Centre and beyond, restore our self-esteem and make our lives worth living. Thank you.

#### Sam Gallop CBE

Life President empower, and Chair – The Limbless Association

#### FOREWORD TO 1ST EDITION

I am proud to have been asked to write a Foreword to this important publication by the Amputee Medical Rehabilitation Society.

The Society contains within its membership a wealth of knowledge, skill and experience in Prosthetic Rehabilitation that is unique in Britain, perhaps in Europe and the world.

As the service develops in the Regions after three and a half years of nurture by the Disablement Services Authority, it is essential for those who use it, that standards should be jealously guarded by the new Authorities responsible for its management.

I believe that the "Recommended Standards and Guidelines", now published by that Society, can be of enormous help both to purchasers and providers in the maintenance and, indeed, the improvement of those standards.

It is impossible to exaggerate the importance, very naturally attached to these standards of men and women who depend on the Prosthetic Service.

#### **Holderness**

October 1992

Lord Holderness, Chairman, Advisory Group on Rehabilitation, Department of Health, and Past Chairman of The Disablement Services Authority

#### **FOREWORD**

I feel honoured to be invited to write the Foreword to these important Standards and Guidelines. Honoured because of the admiration and regard that I share for all the skilled and caring staff who bring the benefits of Rehabilitation to limbless people of all ages.

Rehabilitation brings independence.

Rehabilitation for limbless individuals is life-long. Coupled with their own determination, Rehabilitation can enable someone to be independent in all aspects of their daily living – education, employment, sport recreation, leisure etc – the list is life long.

Since the publication of the 1<sup>st</sup> Edition of the Standards and Guidelines in September 1992, there have been many exciting new developments in the services for limbless persons – including wheelchairs as well as artificial limbs. These new developments have also brought new challenges – to accept change and to innovate. I express my appreciation of the numerous ways in which these challenges have, and are, being met.

The "new" NHS is infused by the following values: user-centred, valuing people, recognition of individual needs, partnership working, respect, responsiveness, independence, and social inclusion. I am confident that these values will be sustained and enhanced by the overall objective of these Standards and Guidelines, which is "to establish a basis for the provision of a service of excellence".

I congratulate Dr Rajiv Hanspal and his colleagues on the editorial Working Party, and wish them and their colleagues in all the services involved, with Users, every success in the future.

Rt. Hon. John Hutton MP Minister of State Department of Health

#### **TABLE OF CONTENTS**

#### PART I - AMPUTEE AND PROSTHETIC REHABILITATION

1.	INTRODUCTION	7
	SCOPE AND PURPOSE	7
	DEVELOPMENT	8
2.	HISTORY	11
3.	EPIDEMIOLOGY	13
4.	SERVICES FOR LIMBLESS PEOPLE	15
	SPECIFICATIONS OF PARCs	16
	PROSTHETIC AND AMPUTEE REHABILITATION CENTRES (PARCs)	17
	CARE PATHWAY FOR AMPUTEE REHABILITATION	22
5.	LOWER LIMB AMPUTATION	25
•	PRE-AMPUTATION	25
	AMPUTATION	25
	POST AMPUTATION PHASE	26
	PRIMARY PROSTHETIC REHABILITATION.	27
	PROSTHETIC REVIEW & MAINTENANCE	29
6.	UPPER LIMB AMPUTATION	35
••	REHABILITATION	35
	PRE-AMPUTATION	35
	AMPUTATION	36
	POST AMPUTATION PHASE	36
	PROSTHETIC PHASE	37
	REVIEW AND MAINTENANCE PHASE	38
7.	CONGENITAL LIMB DEFICIENCY	41
. •	ROLE OF DISTRICT GENERAL HOSPITAL	41
	ROLE OF THE LIMB DEFICIENCY CLINIC (at PARC)	42
	OTHER SPECIALISTS INVOLVED AT SPECIALIST LEVEL	43
	PROSTHETIC TREATMENT	43
	EDUCATION	44
	ADOLESCENCE	44
	ADULT LIFE	44
8.	MISCELLANEOUS TOPICS	47
	8.1 COUNSELLING	47
	8.2 OUTCOME MEASURES	49
	8.3 COSMESIS	53
	8.4 LIMBS FOR LEISURE	56
	8.5 WATER ACTIVITY LIMBS	58
PA	RT II - STANDARDS AND GUIDELINES IN AMPUTEE AND PROSTHETIC	
	REHABILITATION	
9.	STANDARDS AND GUIDELINES IN AMPUTEE AND PROSTHETIC REHABILITATION	61
		-
	APPENDICES	69
	APPENDIX 1 - MEMBERSHIP OF THE WORKING PARTY	69
	APPENDIX 2 - RESULTS OF NATIONAL CONSENSUS ON STANDARDS & GUIDELINES	73
	APPENDIX 3 - TRAINING IN AMPUTEE AND PROSTHETIC REHABILITATION FOR	
	SPECIALIST REGISTRARS IN REHABILITATION MEDICINE	75
	APPENDIX 4 - GLOSSARY OF TERMS	77
	APPENDIX 5 - USEFUL ADDRESSES	79

#### 1. INTRODUCTION

- 1.1 The Amputee Medical Rehabilitation Society (AMRS) published its first report 'Amputee Rehabilitation Recommended Standards and Guidelines' in 1992. This report, and the later 'Congenital Limb Deficiency, Recommended Standards of Care', were well received by clinicians in the field. However, there have been many developments in both Prosthetics and Rehabilitation over the last ten years, necessitating revision of this report.
- 1.2 The Special Interest Group in Amputee Medicine (SIGAM), which was formed when the AMRS integrated with the British Society of Rehabilitation Medicine (BSRM) as a special interest group of the BRSM, established a working party in 2000 to undertake this revision.
- 1.3 In the meantime, the BSRM when publishing standards and guidelines for specialist In-patient Rehabilitation<sup>3</sup> and Community Rehabilitation<sup>4</sup>, made it clear that certain areas of service, including Prosthetics and Amputee Rehabilitation, would require their own specific standard sets<sup>5</sup>.

#### Scope and purpose

#### Overall objective of the report including standards and guidelines

- 1.4 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 with equity of access throughout the UK.
- 1.5 It also aims to assist clinical governance and service development with standards presented in a format easily accessible for audit purposes.

#### **Target Audience**

- 1.6 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 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

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

#### Stakeholder Involvement

- 1.8 The working party has a multi-disciplinary membership including four Rehabilitation physicians, a prosthetist, physiotherapist, occupational therapist, Centre manager and two users. Three of the Rehabilitation physicians were authors of the first report published in 1992<sup>1</sup>. Other disciplines consulted include surgery, clinical psychology, counselling, nursing and rehabilitation engineering. Further professionals were consulted because of their knowledge and expertise in specific areas. A list of the participants is included in Appendix 1.
- 1.9 The consultation process involved multi-disciplinary feedback from the full membership (36) of SIGAM with 32 responses, representing 29 Centres in the UK.

1.10 The standards and guidelines have been piloted in seven major Centres to audit current practice against the recommendations.

#### Development

#### Evidence to support standards and guidelines

- 1.11 The guidelines are based on evidence so far as resources allow. Extensive use was made of preexisting reviews especially previously published guidelines and standards and their supportive evidence.
- 1.12 A Medline search alone for key words 'amputation, prosthetics and rehabilitation' showed over 22,000 references in the last 15 years. Despite this, one of the major problems in Rehabilitation is the paucity of level 1 and 2 evidence<sup>5</sup>. Our literature search therefore consisted of a hand search of relevant peer reviewed specialist journals (25 years for Prosthetic journals and 10 to 15 years for various Rehabilitation journals); good quality consensus based reviews and reports, especially in Amputee and Prosthetic Rehabilitation; and generic standards and guidelines for Rehabilitation. In addition to this, a specialist targeted and detailed search was done in selected and topical areas, where required.
- 1.13 The working party decided not to label each standard with a formal level of evidence tag because of the recognised problems<sup>5</sup> of these levels of evidence for standards in Rehabilitation
- 1.14 However the working party felt that it was essential to follow the BRSM guidelines of achieving consensus as supportive evidence (expert opinion). This consultation process was carried out as recommended<sup>5</sup> in three stages.
  - (1) The standards and guidelines were extracted from the revised and updated draft of the previous report and presented for consultation at workshops held at the Annual Scientific Meeting of the SIGAM in November 2001.
  - (2) The revised standards and guidelines were sent in the form of a questionnaire to all full members of the SIGAM ie all those who had a definitive appointment in Prosthetic Rehabilitation. The questionnaire was designed to permit members to respond, in consultation with their clinical teams, on a multidisciplinary basis. They were asked to state whether they agreed or disagreed with each of the recommendations and provided the opportunity to make comments. The results of this questionnaire were reviewed by a small sub-group of the main working party and necessary changes made to the standards in the light of any specific comments received.
  - (3) The final questionnaire was then sent to the same 36 full members of SIGAM for similar review. An extremely high level of agreement was received. Details of the response to this questionnaire are in Appendix 2. The comments with the responses were all given careful consideration by the working party and where appropriate have been incorporated in the final version of the proposed standards and guidelines.
- 1.15 The process followed is similar to the procedure followed by the BSRM when developing their standards for specialist Inpatient<sup>3</sup> and Community Rehabilitation<sup>4</sup>. Because of the very high level of agreement, further rounds of consultation were considered unnecessary.
- 1.16 The process of consultation allowed the working party to classify the level of recommendation of each standard, based on the Kings Fund Organisational Standard Audit Tool<sup>6</sup>.

#### **Updating and Review**

1.17 These standards and guidelines, once published, will facilitate the introduction of an audit tool to conduct a national survey of the current level of service provision. It is planned to review and update the standards and guidelines in 5 years, subject to availability of funding.

#### **Clarity and Presentation**

- 1.18 The Report is essentially in two parts. Part I consists of general information, including background information and recommendations on Amputee and Prosthetic Rehabilitation. Part II consists of the recommended standards and guidelines, based on national consensus.
- 1.19 The working party recognised that Amputee and Prosthetic Rehabilitation is a specialised field with high levels of expertise amongst its health care professionals, but with limited awareness of the service amongst professionals without specific post-graduate training in Amputee Rehabilitation who may be called upon, at times, to manage these patients in clinical practice. It was therefore felt that a comprehensive section on background information should be included in the report. This comprises Part I of the document. This also includes the different options for management with supportive reasons and evidence.
- 1.20 The key recommendations were extracted as standards and guidelines and form part II of the report. The format of presentation, including the sectional numbers are identical to the two sets of previously published BSRM standards <sup>3, 4</sup>.

#### **Applicability**

- 1.21 The review of the standards and guidelines is particularly apposite at a time of change in the health care system, with the formation of Primary Care Trusts (PCTs). Whilst certain aspects of prosthetic services, eg upper limb prosthetics, are still commissioned as a Specialist Service in some areas, there is increasing fragmentation in several parts of the country where commissioners and providers need to be supported with information and guidance in best practice.
- 1.22 Standards are presented in a format easily accessible to the development of an audit tool, which is available on the BSRM website (www.bsrm.co.uk).
- 1.23 A report of this nature cannot be directive and it is not within the remit of the report to designate the status of any provider unit. However it presents recommendations for the criteria that Centres should fulfil to provide any particular level of service.

#### **Terminology**

- 1.24 Similarly, the report has no intention of recommending any specific name, eg Disablement Services Centres (DSCs), for such Centres. For the purpose of this report we have preferred the term PARC (Prosthetic and Amputee Rehabilitation Centre), though a few alternative names like PARS (S= services), Amputee Rehabilitation Units or Limbless Clinics have been suggested.
- 1.25 Specialist terminology/acronyms are listed in Appendix 4.

#### **Editorial Independence**

- 1.26 This report is funded by the Special Interest Group in Amputee Medicine of the BSRM whose aims and objectives are similar to the objectives of this report. No funding was obtained from any commercial organisation.
- 1.27 The standards and guidelines are the conclusions of the multi-disciplinary working party, including users, and based on extensive deliberation, including the previously mentioned national consensus.

#### **Conflict of Interest**

1.28 Most of the members of the working party are senior professionals employed in the NHS. The details of their appointments are listed in Appendix 1. Those who work for a private organisation have signed a form declaring any potential conflict of interest with the standards and guidelines. These individuals refrained from any discussion where this could represent a source of conflict.

#### References:

- 1. Amputee Medical Rehabilitation Society. *Amputee Rehabilitation Recommended Standards and Guidelines*. London: AMRS, 1992. (Available from British Society of Rehabilitation Medicine).
- 2. Amputee Medical Rehabilitation Society. *Congenital Limb Deficiency: Recommended Standards of Care*. London: AMRS 1997. (Available from British Society of Rehabilitation Medicine).
- 3. Turner-Stokes L, Williams H, Abraham R, Ducket S. Clinical Standards for Specialist Inpatient Rehabilitation Services in the UK. *Clin Rehabil* 2000; **14**(5): 468-480.
- 4. Turner-Stokes L, Williams H, Abraham R.. Standards for Specialist Community Rehabilitation Standards in the UK. *Clin Rehabil* 2001; **15**: 611-623.
- 5. Turner-Stokes L. National guidelines and standards . Clin Rehabil 2002; 16 (Suppl1):13-20.
- 6. Kings Fund. Kings Fund Hospital Accreditation Programme Organisational Standards and Criteria 1995; 1:63.

#### 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 started 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 & Social Services (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 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 Report<sup>1</sup> recommended further improvements and encouraged the adoption of a holistic approach to Rehabilitation.
- 2.5 In response to the 'McColl' Report<sup>2</sup> published in1986, the management of the Artificial Limb and Appliance Service was transferred to the Disablement Services Authority, a special health authority set up to run the service until March 1991 and with the responsibility to oversee the transfer of the ALAC services to the National Health Service Regions by 1st 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 visiting services<sup>3</sup>. 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 Prosthetic 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 in 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 OTTO (Occupational Therapist in Trauma and Orthopaedics).

- 2.10 There is also a National Forum for Amputee Rehabilitation Counsellors (NFARC) and a Nurses Amputee Network and Special Interest Group (NAN).
- 2.11 The Rehabilitation Engineers have the Prosthetics and Othotics 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. The Procurement and Supplies Agency (PASA) of the Department of Health and User Representatives are invited to both meetings.
- 2.13 All stakeholders including users, BHTA, clinical groups, manager and commissioner representatives have been brought together under the auspices of the Prosthetic Strategic Supply Group chaired by PASA. This has a clinical sub-group – The Amputee Rehabilitation Clinical Forum which is currently looking to recommend outcome measures and prescription guidelines for national use.

#### References:

- 1. The Scottish Home and Health Department. *The future of the artificial limb service in Scotland. Report of a working party set up by the Secretary of State for Scotland.* (Chair Denny M) 1970.
- 2. McColl I. *Review of Artificial Limb and Appliance Services* Department of Health & Social Security. HMSO, 1986.
- 3. Prosthetic Advisory Group to Minister for the Disabled. A Report of the Working Party (Chair Carter-Jones, L). College of Occupational Therapists; 1994

#### 3. EPIDEMIOLOGY

- 3.1 National statistics on amputations were previously available through the Department of Health and Social Security. The collective compilation of data temporarily ceased following the transfer of services to the National Health Service, but has been resurrected by the creation of the National Amputee Statistical Database (NASDAB) Steering Group, supported by the Amputee Medical Rehabilitation Society (now SIGAM), the Disablement Services Centres, The British Healthcare Trades Association and the NHS Purchasing and Supplies Agency (PASA).
- 3.2 A minimum set of data from referrals nationwide to all the Disablement Services Centres (DSC) are collected quarterly and updates are published in an Annual Report by the Information and Statistics Division, NHS Scotland on behalf of the NASDAB. The validity of the data is becoming increasingly reliable due to the co-operation of all responsible for good record keeping.
- 3.3 Not all patients with amputations are referred for limb fitting. At present nearly 63,500 patient records remain open in the DSCs with almost 6000 new patients being referred annually. There is significant variation in the referral patterns between the health regions and Centres. Each region receives between 100-600 (average 425) new patients and each Centre between 30-300 (average 128) per year. There are 44 Centres in the UK.
- 3.4 The recently published annual report for 2000-01<sup>1</sup> showed a total of 5767 new referrals to prosthetic services in the UK for the year ending 31<sup>st</sup> March 2001, a 6% increase since 1999-00. Lower limb amputations accounted for 92% of total amputations. One quarter of the males and two-fifths of the females are over the age of 75 years at the time of referral and the commonest cause (72%) of amputation is vascular disease, nearly half of these with diabetes mellitus. Trauma accounts for 10% of all amputations, and tumours for 3%; most patients in these categories are of a younger age.
- 3.5 Upper limb amputations accounted for nearly 5% of the total amputations and the commonest cause (56%) was trauma. Referrals with congenital limb deficiency accounted for just over 2%.
- 3.6 Patients with multiple (more than two) amputations though very rare, only 17 cases in 2000-01, absorb a significant amount of resources.
- 3.7 The improvement in data recording and maintenance within Centres, and collection and analysis on a national basis, are continually being reviewed by the National Amputee Statistical Database (NASDAB) Steering Group. There are proposals currently being considered to include data relating to trends in prosthetic prescription and functional outcomes.

#### References:

1. NASDAB (National Amputee Statistical Database). *The Amputee statistical database for the United Kingdom 2000-2001*. Information and Statistics Division, NHS Scotland 2003 on behalf of NASDAB. 2003.

#### 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:
  - 1. Department of Health. *A First Class Service: Quality In the New NHS*. London: HSC. 1998<sup>1</sup>.
  - 2. Departmnt of Health. *The NHS Plan A plan for investment. A plan for reform.* The Stationery Office London: 2000<sup>2</sup>.
  - 3. HSC 1998/198 Commissioning in the New NHS<sup>3</sup>.
  - 4. Amputee Medical Rehabilitation Society. *Amputee Rehabilitation Recommended Standards and Guidelines*. London: 1992<sup>4</sup>.
  - 5. Amputee Medical Rehabilitation Society. *Congenital Limb Deficiency; Recommended Standards of Care.* London: 1997<sup>5</sup>.
  - 6. Department of Health Procurement and Supplies Agency. *Amputee Care Guidelines for Commissioners*. Prosthetic Strategic Supply Group: 2001<sup>6</sup>.
  - 7. Department of Health. Specialised Service Definitions to supplement HSC 1998/198. Department of Health supported December 2001<sup>7</sup>.
  - 8. Royal College of Physicians. *Medical Rehabilitation for people with physical and complex disabilities*. A report from the Royal College of Physicians' Committee on Rehabilitation Medicine. London 2000<sup>8</sup>.
  - 9. Audit Commission. Fully Equipped the provision of disability equipment services to older or disabled people by the NHS and social services in England and Wales. Audit Commission. London; 2000<sup>9</sup>.
  - 10. Audit Commission. Fully Equipped 2002. Audit Commission. London; 2002<sup>10</sup>.
- 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)<sup>11</sup>, commissioned at a level above that practicable by the Primary Care Trust (PCT); generally for an area of population larger than the newly formed Strategic Health Authorities. This is for a number of reasons:
  - The number of amputees is relatively small, a number likely to be on average less than 25-30 new amputees per year for each PCT.
  - 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. The clinical expertise needed does not form part of the undergraduate education of any of the professional groups involved, with the exception of prosthetists.
  - A 'critical mass' of patient population through specialist services is essential for achieving and maintaining high standards and cost-effectiveness.
- 4.3 Two of the publications (5 and 10 above) 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 and should be commissioned collaboratively by consortia of Strategic Health Authorities, or equivalent.

4.4 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.

#### SPECIFICATIONS OF PARCS

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

#### 1. TERTIARY REFERRAL PARC

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 must 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).

A Tertiary Referral PARC must have designated facilities for children, equipped to allow for their assessment appropriate to their age.

Tertiary Referral Centres should hold specialist clinics, in conjunction with surgeons and/or Paediatricians, for:

- Congenital limb deficiency
- Children
- Complex limb loss

Tertiary Referral Centres must be preserved to ensure specialist expertise in the future, both for rare and expensive conditions and for teaching, education and research<sup>12</sup>.

#### 2. THE PARC

The standard PARC provides a service for:

- All lower limb amputees
- Straightforward upper limb amputees and cases of congenital limb loss provided that Staff with appropriate expertise are available
- More complex cases whose conditions are stable

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 cases.

#### 3. THE LOWER LIMB PARC

A Consultant led service with experienced Prosthetists, Physiotherapists, Occupational Therapists and Nursing support, providing facilities only for lower limb Rehabilitation. These Centres will be affiliated to a Tertiary Referral Centre on a 'hub and spoke' basis.

4.6 It may also be appropriate for any Centre to hold Visiting Clinics, dependent on local need and arrangements.

4.7 All users of these services should 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)

- 4.8 Prosthetic & 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.
- 4.9 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.
- 4.10 An inflexible transport system is often quoted as being a limiting factor to a good clinical service (Audit Commission, 2000)<sup>9</sup>. 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.
- 4.11 The PARC should be part of, or closely linked to, a more general Supra-PCT (or Strategic Health Authority) Rehabilitation Unit.
- 4.12 The prosthetic workshop should have facilities for the adjustment repair, and assembly of prostheses, with the proviso that the manufacture of prostheses may by agreement be located elsewhere, subject to local arrangements, providing time-scales are appropriate and quality control effective.
- 4.13 The specialist Amputee Rehabilitation team should have access to prompt radiology 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, clinical psychology and social work.
- 4.14 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 3 areas, crossing organisational barriers, is vital<sup>13</sup>. 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-Guidelines<sup>6</sup> and the expected involvement of service users in the NHS Plan.

#### Composition of the Team

- 4.15 The clinical team based at the referring hospital should consist of the following:
  - The **Surgeon** must be suitably trained and experienced in amputation surgery<sup>14,15,16</sup> and have a practical knowledge of current basic Prosthetic and Rehabilitation principles, so that the most suitable amputation stump 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).
- **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 stump 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<sup>17,18</sup>. Nursing staff should be aware of the services available from/at their local PARC and the appropriate referral pathways.
- **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 stump oedema. The Physiotherapists should use the relevant evidence-based clinical guidelines<sup>19</sup> 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<sup>20</sup>, and help in improving liaison with the PARC.
- All amputees must have access to an **Occupational Therapist**, 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 Occupational Therapist should where indicated, undertake a home visit with the new Amputee and make appropriate recommendations prior to a safe discharge home.
- 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.
- 4.16 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 the Physicians in Geriatric Medicine, bearing in mind that some of these patients will benefit from active Rehabilitation, while others will require long-term care. Community hospitals also play an important role for some of these patients.
- 4.17 It is the responsibility of the Consultant Surgeon (or in some cases the Consultant Physician) to refer appropriate patients to the PARC. This decision should be made following discussion with the members of the local Rehabilitation team, the patient and their relatives and be informed by a knowledge of services provided by the PARC. A study of referrals in Leeds<sup>21,22</sup> showed only 7% inappropriate referrals, indicating that in general, referrals may be deemed to be satisfactory. It may not be appropriate to refer all amputees to the PARC, but neither should referrals be restricted only to those who will obviously benefit from a prosthesis. Some Centres provide services appropriate to all amputees, whilst others which are focussed to achieving Prosthetic Rehabilitation may not be appropriate for all referrals. Local policies and improved service networks will help improve the appropriateness of referrals.
- 4.18 If the amputation is not required urgently, and particularly if amputation is a treatment option rather than a necessity, the patient should be offered a consultation with the specialist team prior to amputation.
- 4.19 The specialist team at the Prosthetic and Amputee Rehabilitation Centre should include the following:
  - A 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<sup>23</sup>. The role of the Consultant in Rehabilitation Medicine is well described in the Royal College of Physicians' Report, Medical Rehabilitation for People with Physical and Complex Disabities (2000)<sup>8</sup> and the Clinical Governance Supplement of Clinical Rehabilitation<sup>24</sup>. Supporting medical staff may include an Associate Specialist, Staff Grade doctor or a Clinical Assistant 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 CCST in Rehabilitation Medicine includes 3 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<sup>25</sup>. A check list of the minimum training requirement proposed in the form of a log sheet by SIGAM is in Appendix 3. The additional training required for consultants at Tertiary Centres are being reviewed by a subgroup of SIGAM.

- **Prosthetists** are all registered Allied Health Professionals with the Health Professions Council and have undertaken an accredited training period of 4 years or equivalent. Prosthetists should be conversant with the guidelines published by the British Association of Prosthetists and Orthotists (BAPO, 2000)<sup>26</sup> 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** 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<sup>19</sup>. They should be able to liase 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 undertake prosthetic limb training for patients with upper limb amputation or congenital deficiency, including training in one-handed activities where relevant<sup>27</sup>. 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 (CNS) are nurses trained in the holistic care of amputees. They should have undertaken a training in tissue viability and wound management and have a good understanding of prosthetics and Amputee Rehabilitation. Many will have undertaken counselling courses to enable them to assist patients to deal with the emotional effects of their amputation. The role of the CNS in rural areas incorporates the maintenance of close links between hospitals and the PARCs.
- A Counselling Service must be provided by **Clinical Counsellors** who have experience of working in a Rehabilitation setting. 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 qualified Clinical Counsellor<sup>28,29</sup>. The Counsellor should also be available to see relatives or carers of the amputee.

- A Clinical Psychologist with experience in dealing with the particular problems of patients with physical disabilities should be readily available to see selected patients<sup>30</sup>.
- A **Rehabilitation Engineer** should be available to advise on technical matters related to the quality, risk management, maintenance, assessment and prescription (eg gait analysis) procurement and disposal of prosthetic devices. Rehabilitation Engineers can be either Clinical Scientists or Clinical Technologists. The former are registered under the Health Professions Council (HPC), the latter are expected to be registered in early 2005, transferring from the current register coordinated by the Institute of Physics and Engineering in Medicine (IPEM).
- A **Podiatrist** should be available, particularly to provide care for the remaining foot in unilateral lower limb diabetic or dysvascular amputees, or appropriate links with local podiatric services must be established<sup>31</sup>.
- Employment Advisory Service/Vocational Rehabilitation: 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<sup>32,33</sup>. There is a higher incidence of amputees returning to work in mainland Europe where Vocational Rehabilitation is better established<sup>34,35</sup>.
- 4.20 The Centre must provide adequate information regarding the services it supplies, the equipment provided and care for equipment<sup>36</sup>. 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.
- 4.21 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.
- 4.22 **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. 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

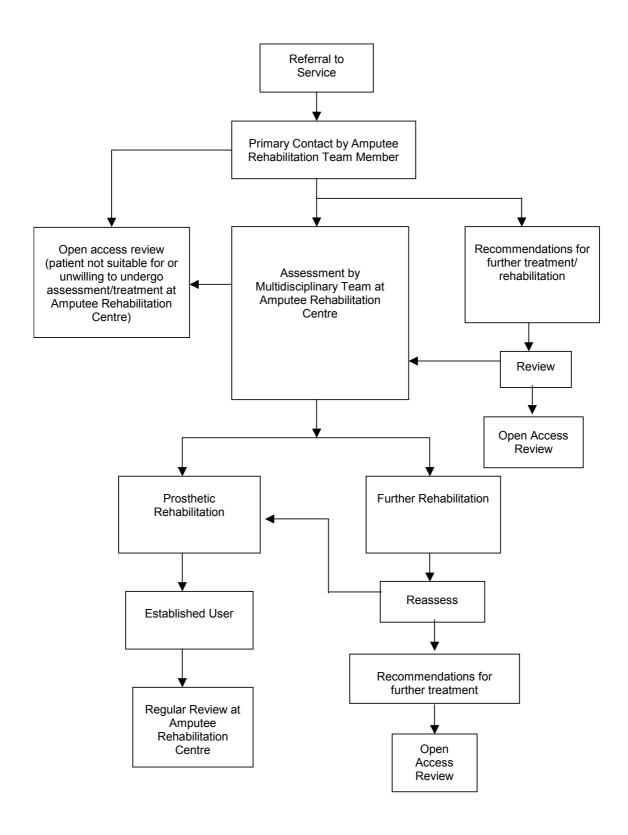
- 4.23 It is important that there are close links between the specialist team at the Prosthetic Rehabilitation Centre and the support services in the community, which include
  - General practitioner
  - Community physiotherapist
  - Community occupational therapist
  - Community nurse
  - Social worker
  - Local Authority social services
  - Relevant Voluntary Organisations

#### Clinics

4.24 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 Prosthetic Rehabilitation Centre should be under the care of a named consultant and prosthetist.

- 4.25 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.
- 4.26 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.
  - Children's Clinic. At Tertiary Referral Centres a clinic for children, including those with acquired amputations and those with congenital limb deficiency should be held, 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.
  - **Joint 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 Vascular Surgeon, 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.
  - **Joint 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<sup>37</sup> sometimes bearing a relationship to pre-amputation pain<sup>38</sup> and for a notable subset, pain may be quite disabling. Pain after amputation should be viewed from a broad perspective that combines anatomic as well as the impact of functioning<sup>39</sup>. 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 inadquate<sup>40</sup>.
  - Visiting Clinics. Visits by the Consultant in Rehabilitation and/or a prosthetist and other team members to referring hospitals which carry out relatively large numbers of amputations can be very useful in improving liaison, may save patients travelling, and are particularly useful for seeing new amputees<sup>13</sup>. However, it must be recognised that the facilities for assessing and advising these patients are likely to be less comprehensive at a Visiting Clinic than they would be at a Prosthetic and Amputee Rehabilitation Centre. In certain localities, it may also be helpful to have Visiting Clinics for established amputees, for example, to carry out minor repairs to prostheses. Again, it is important to recognise that there are major limitations as to what maintenance work can safely be undertaken without full workshop facilities.
- 4.27 **The Care Pathway** for an amputee from referral is shown in the following algorithm.

#### CARE PATHWAY FOR AMPUTEE REHABILITATION



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#### 5. LOWER LIMB AMPUTATION

- 5.1 The management and Rehabilitation of lower limb amputation should be multi-disciplinary and the benefits of an organised service are recognised<sup>1,2</sup>. It should be considered in the following phases:
  - Pre-Amputation
  - Amputation
  - Post Amputation
  - Primary Prosthetic Rehabilitation
  - Prosthetic Review and Maintenance

#### PRE-AMPUTATION

- This phase starts when amputation becomes a clinical option in the patient's management. 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, Rehabilitation and prosthetic review & maintenance programme, prosthetic options and projected outcomes. Realistic Rehabilitation goals should be defined. A therapy programme should be started pre-operatively to establish a basis for post-operative Rehabilitation and to introduce the patient to the physiotherapist who may be a local focus for information. Pre-operative pain control should be adequate and may include pre-operative epidural anaesthesia<sup>3,4</sup>; the evidence for the benefit of epidural analgesia in reducing subsequent phantom pain, however, is not conclusive. If necessary and if time permits, a **pre-amputation consultation** with a Consultant in Rehabilitation Medicine specialising in prosthetics, or the most appropriate member of the PARC Multidisciplinary Team, should be arranged, especially
  - when the patient requests more information than the local hospital team can provide
  - when further clinical advice about amputation and patient management is required, particularly when congenital limb deficiency or deformity are involved
  - when an elective amputation is planned
- 5.3 Peer group support from a suitable, established amputee can be very helpful.

#### **AMPUTATION**

- 5.4 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<sup>5</sup>.
- 5.5 The amputation should be performed by a surgeon experienced in appropriate techniques<sup>6,7,8</sup> in a setting where there is adequate access to Prosthetic and Amputee Rehabilitation services. Surgery should follow a recognised operative technique<sup>9</sup> and be planned to optimise future Rehabilitation potential including prosthetic limb use<sup>10,11,12</sup>. The aim of surgery should be to form a stump or 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<sup>13</sup>, or the long posterior flap<sup>14</sup> in trans-tibial amputations and lateral myodesis in trans-femoral amputations<sup>15</sup> 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. A knee disarticulation, generally not favoured by prosthetists may be appropriate for non-ambulatory patients<sup>16</sup>. If Prosthetic Rehabilitation is

planned the knee joint should be preserved, if at all possible <sup>17,18,19</sup>. 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<sup>18</sup>. A shorter below-knee stump (8cm), if necessary to assist wound healing is acceptable because the stump length in trans-tibial amputees has no relationship to the relative outcome in unilateral below-knee amputees for peripheral vascular disease<sup>19</sup>.

5.6 It is advisable that each Health District should have a designated vascular or orthopaedic surgeon whose strategic responsibility includes amputation. This responsibility should extend to establishing and maintaining links with the appropriate Prosthetic Rehabilitation Centre or Centres and to act as a member of the local team.

#### POST AMPUTATION PHASE

- 5.7 This consists of the post-operative period, which blends with the pre-prosthetic and prosthetic phases. Barsby and Lumley (1987)<sup>20</sup> published a useful check list which covers all these phases.
- 5.8 Good post-operative analysis is essential to control ongoing phantom limb pain and allow the patient actively to participate in their post-operative Rehabilitation as soon as possible.
- 5.9 The choice for post-operative dressing is left to the operating surgeon. Post operative rigid dressing may be beneficial for trans-tibial amputations in a specialised unit, but may require more than one change and adequate support and awareness from the nursing team in the ward is essential to avoid complications. In other circumstances a soft tissue dressing is preferable.
- 5.10 After removal of the dressings originally applied in the operating theatre, stump support should initially be gentle and can be provided by the correct use of lightly elasticated tubular support (eg Tubifast <sup>TM</sup>) but not Tubigrip <sup>TM</sup> which is too tight. Once healing is established, a formal shaped elasticated stump sock (eg Juzo<sup>TM</sup>) will improve comfort and reduce oedema. The general use of stump bandages<sup>12</sup> for this purpose is not recommended.
- 5.11 All amputees should have access to adequate therapy services; physiotherapy, occupational therapy and psychological support from a clinical 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. This includes EWAs, and stump oedema control equipment. Units with a significant number of amputees for Rehabilitation should have a variety of early walking aids for assessment as appropriate 21,22,23,24. They should also carry stocks of stump supports such as stump shrinkers/socks to facilitate the reduction of stump oedema. A wheelchair and suitable stump support for trans-tibial amputees must be provided in the early post-operative phase.
- 5.12 All amputees should be considered for Rehabilitation with a prosthetic limb and have a multi-disciplinary<sup>1,2</sup> assessment by suitably experienced staff. The assessment may take place at the patient's local hospital or at the Prosthetic & Amputee Rehabilitation Centre 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 the healing of the amputation in isolation.
- 5.13 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 Clinical Psychology colleagues. The new amputees and relatives and carers should be informed about their local and national support groups and amputee organisations eg Limbless Association, BLESMA (British Limbless Ex-Serviceman'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<sup>26</sup>.

- 5.14 Hospitals should have referral forms for the appropriate PARC available. The form should record all information relevant to decisions about Prosthetic 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 Prosthetic Rehabilitation.
- 5.15 All amputees should be offered referral to the Centre as in some cases the objective of Rehabilitation is to enable the patient to be independent without a prosthesis. Many elderly dysvascular amputees in particular will not benefit from a prosthesis<sup>27</sup>.
- 5.16 Life expectancy of a vascular amputee is short<sup>28,29</sup> and in the elderly is associated with a considerable morbidity and deterioration of functional and residential status<sup>30</sup>. Amputees with extensive co-morbidity are less likely to walk<sup>31,32,33</sup>, though many still use their prosthesis daily for help with transfers and cosmetic purposes, especially those with associated musculo-skeletal impairment eg rheumatoid arthritis<sup>34</sup>. Similarly, Prosthetic Rehabilitation can be successful in patients with prior stroke, especially in terms of independence, life style and self-respect <sup>35</sup>. 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 unlikely to benefit from a prosthesis<sup>36,37,38</sup>. Other factors that are significantly related to less prosthetic use are age, female gender, possession of wheelchair, level of physical disability, poor compliance<sup>39</sup> and self perception and the amputee's dissatisfaction<sup>40</sup>. The majority of elderly amputees currently prescribed a prosthesis do achieve useful function in a prosthesis which justifies the expense of this form of Rehabilitation<sup>41</sup>. 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<sup>42</sup>. All amputees should have access to an appropriate wheelchair<sup>43,28</sup>.
- 5.17 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.
  - The patient is safe and functionally independent, if necessary from a wheelchair.
  - If undergoing Prosthetic 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 and essential adaptations are in place and that the appropriate arrangements have been made for further adaptations.
- 5.18 If any of the above are lacking, adequate alternative support must be provided.

#### PRIMARY PROSTHETIC REHABILITATION.

- 5.19 This phase starts with the decision that Rehabilitation with a functional prosthesis is appropriate, and 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.
- 5.20 The aim of Prosthetic 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<sup>44</sup>.

- 5.21 At the PARC, the amputee should be fully assessed by a physician trained in Prosthetics and Rehabilitation techniques. The physician should have all relevant information from the hospital Amputee Rehabilitation team and where necessary, liaise with other members of the team (physiotherapists and prosthetists) when carrying out the full primary assessment.
- 5.22 The patient, relatives and carers, if appropriate, should be informed about the outcome of the assessment. The patient should be informed of 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 levels of outcome in terms of mobility varies for different individuals. They may range from assistance for transfers or limited indoor walking for some independence in personal care, to normal gait and lifestyle including return to work and participation in physical sport and leisure<sup>45</sup>. 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<sup>46</sup>.
- 5.23 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. While 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 47,48,49.
- 5.24 The patient's GP and the referring consultant should be kept informed of the outcome of the assessment, the treatment given and progress.
- 5.25 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 as appropriate, according to local arrangements.
- 5.26 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 physiotherapists is important. Inpatient Rehabilitation programmes for bilateral amputees<sup>50</sup> are likely to prove more satisfactory than prolonged outpatient physiotherapy. Patterns of recovery during the early milestones must be recognised and adequate time given for therapy and Rehabilitation<sup>51</sup>.
- 5.27 Contrary to general belief, the benefits of Computerised Laboratory Gait Analysis in prosthetic fitting and alignment adjustments remains doubtful<sup>52,53</sup> thus limiting its use mainly to research purposes.
- 5.28 Diabetes Mellitus accounts for about 40% of new lower limb amputee referrals<sup>54</sup>. Peripheral vascular disease is a major contributor to pathogenesis of foot ulceration among diabetics<sup>55</sup> and in neuropathic patients, there is a seven-fold risk of foot ulceration<sup>56</sup>. In this situation the quality of life is higher following Amputee Rehabilitation in comparison to people with chronic diabetic foot ulcers<sup>57</sup>. Fifty percent of unilateral diabetic amputees will develop a serious contralateral lesion within 2 years<sup>58</sup>. The team approach to the care of diabetic amputees is strongly recommended<sup>57,59</sup>.
- 5.29 For cases of multiple limb loss<sup>60</sup>, 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. 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.

- 5.30 Multiple limb amputations involving both upper and lower limbs are very 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 their Rehabilitation in a Centre where experienced, specialised staff are available.
- 5.31 Whilst the majority of multiple amputations are due to trauma and would require a closer collaboration with the plastic and orthopaedic surgeons, multiple amputations following septicaemia are commoner among the paediatric and adolescent age group, 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.
- 5.32 A diverse selection of programmes and patient related outcome measures are used. Outcomes could be better compared if all Centres used similar outcome measures<sup>61</sup>. Progress and mobility achieved with a prostheses should be documented, preferably using validated outcome measures<sup>62</sup>. The most commonly used<sup>63,64</sup> outcome measure for prosthetic mobility has been the Harold Wood Stanmore Grades<sup>65</sup>, though the BSRM currently recommends the recently validated SIGAM Grades<sup>66</sup>. Mobility measures like the Rivermead Mobility Index that were originally developed for neurological cases are inappropriate as they do not fulfil Rasch Analysis<sup>67</sup>. In the Rehabilitation of amputees, aspects other than mobility may also need to be measured in the outcome. Various outcome measures that may be useful are described in the 'basket of measures' in chapter 8.2.

#### PROSTHETIC REVIEW & MAINTENANCE

- 5.33 Once the amputation stump has stabilised, the patient has acquired basic skills with their prosthetic limb and achieved the initial goals, the amputee moves on to this phase (established user). 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 support. The need for continued Rehabilitation is recognised<sup>68</sup>.
- 5.34 Skin and soft tissue problems in the residual limb<sup>69</sup> continue to be common and troublesome despite good hygiene and the use of newer socket materials, such as silicone<sup>70</sup>.
- 5.35 Falling and fear of falling are pervasive amongst amputees<sup>71</sup>. Balance confidence is the only variable factor associated with mobility capability and performance in social activity<sup>72</sup> and early education, advice regarding prevention and ongoing intervention is recommended<sup>71,73,74</sup>. The residual limb may be more vulnerable to trauma due to associated osteoporosis<sup>75</sup>.
- 5.36 Patients may need to attend the PARC for the management of symptoms directly, or indirectly associated with their amputation. Cardio-vascular disease is common<sup>76</sup> and should be considered in light of the increased energy requirement for walking with a prosthesis<sup>77</sup>. Back pain or phantom limb pain may also need to be addressed<sup>78</sup>. There is some evidence of increased incidence of secondary degenerative changes in the major joints<sup>75</sup>. 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<sup>79</sup>.
- 5.37 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.

- 5.38 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 and medical staff.
- 5.39 The patient should be educated in their need to attend the PARCs for attention to the limb at suitable intervals for reasons such as:
  - Mechanical maintenance and repair of the prosthesis<sup>80</sup>.
  - 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 higher activity prosthetic componentry, or different socket styles, as they progress. Newer designs of prostheses may have physiological functional benefits<sup>81,82</sup>.
  - Adjustment to fit due to normal or abnormal changes in the patient's stump conformation.
  - The availability of appropriate, newer technology for limb components.
  - The prevention of complications.
  - To maintain mobility, function and independence.
- 5.40 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<sup>83</sup>.
- 5.41 During clinical follow up appropriate referrals to specialist clinics like a Diabetic Foot Clinic, pain management clinic etc may be indicated.
- 5.42 The availability of advanced technology such as computer aided socket design in manufacture within a Centre, if integrated and supported in the clinical environment, offers the prospect of enhanced repeatability of equipment fit and performance and better optimisation of performance for each prescription.

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# 6. UPPER LIMB AMPUTATION

- 6.1 This section deals with the specific differences between the management and Rehabilitation of upper limb and lower limb amputees.
- 6.2 Upper limb amputations are much less frequent (160-200 new amputees per year) than lower limb amputations<sup>1</sup>. The main cause of amputation of the arm remains trauma (56%) followed by tumour (13%). The age group is considerably younger (80% under 60 years of age). There are approximately 11,000 upper limb amputees in England requiring maintenance of their prostheses and follow up. Despite the lower incidence of upper limb amputations, the longer life expectancy of these individuals contributes to the proportionately large prevalence of upper limb amputees in the population.
- 6.3 The need for a 'critical mass' to ensure standards, expertise and satisfactory overall delivery of this specialist service dictates that upper limb prosthetic services be provided predominantly at Tertiary Referral PARCs, (see para 4.5). Standard PARCs may provide a service for straight forward upper limb amputees, if appropriate expertise is available.

#### REHABILITATION

- 6.4 The referring teams from the hospital are likely to be the Orthopaedic or Plastic and Reconstructive surgical teams. At the Prosthetic and Amputee Rehabilitation Centre (PARC), the Rehabilitation consultant and prosthetist should have a good knowledge of upper limb prostheses and appliances in addition to general prosthetic and Rehabilitation techniques.
- 6.5 It should be noted that the occupational therapist has a greater role to play than the physiotherapist. 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.
- 6.6 The amputee must be fully involved in discussions and decisions regarding his or her Rehabilitation at all stages.
- 6.7 The management and Rehabilitation of major upper limb amputation is considered in the following phases:

#### PRE-AMPUTATION

- 6.8 It is recognised that when upper limb amputations are due to trauma, the amputation may have to be done as an emergency procedure. In cases of elective amputation, a pre-operative, pre-amputation consultation with staff from the PARC 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 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
  - 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.

#### **AMPUTATION**

- 6.9 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<sup>2</sup>. If this is not possible, the operating team must obtain appropriate advice.
- 6.10 Joint consultation between the Rehabilitation team and the Surgical team may be necessary to decide on the level of amputation.
- 6.11 The ideal stump should be of optimal length (or as close to that as circumstances allow) and should have a gently tapered shape with no prominent bony points and the cut bone ends bevelled, smooth and covered with the best available soft tissue flaps. This will give increased comfort when using the prosthesis.
- 6.12 In cases where bone growth is still occurring, there is a high tendency of bony overgrowth and spurs, which may require repeated surgery. This is a particular problem with trans-humeral amputation. The incidence may be reduced with a capping of autogenous cartilage or plastic. This is not a problem where a joint has been disarticulated<sup>3</sup>.
- 6.13 The elbow joint should be preserved whenever possible, using skin grafts or free flaps if necessary to achieve this. If a partial hand amputation is needed, as much of the hand as possible should be preserved<sup>2</sup>. Special consideration will apply if there is associated neurological (eg Brachial Plexus) injury.

#### POST-AMPUTATION PHASE

- 6.14 It is recognised that in general upper limb amputations heal more quickly than lower limb amputations.
- 6.15 The incidence of phantom limb sensation and pain is higher following upper, as opposed to lower limb amputations and it is, therefore, especially important to ensure adequate pain relief (before and after amputation). If necessary a regional block or patient controlled analgesia (PCA) by pump may be appropriate.
- 6.16 Stump bandaging is generally not recommended. Tubular elastic support (eg Tubifast <sup>TM</sup>) is preferred and should be used night and day until the artificial limb is fitted. Unlike the lower limb, suitable ready-made elasticated stump socks may not be available, but can be custom made. Stump 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 Flotron <sup>TM</sup>.
- 6.17 Psychological support, either from a counsellor or clinical psychologist in the local hospital or PARC, may be indicated and should be arranged if appropriate. A greater need has been identified in upper limb amputees<sup>4</sup>.
- 6.18 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.

6.19 An occupational therapist should see the amputee to advise on personal independence and activities of daily living, including driving<sup>5</sup> and ensure that adequate referrals to Social Services are made<sup>6</sup>.

#### PROSTHETIC PHASE

- 6.20 Ideally, the patient will 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 in the proximal joint. Therapy for personal care and activities of daily living are required as is an holistic approach to pain relief. At the PARC the amputee should see the Consultant in Rehabilitation Medicine, a prosthetist, physiotherapist and the occupational therapist, and the patient should be included in discussions about their future Rehabilitation programme, including prosthetic prescription. The need for counselling is greater at 6 to 18 months after limb loss<sup>4</sup>.
- 6.21 The result of the assessment and the Rehabilitation programme including the limitations of prostheses should be explained to the patient and documented<sup>7</sup>. The appropriate time scale for prosthetic delivery will be based on the patient's identified needs. The first prosthesis is usually fitted before the stump is stable so that 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 stump is stable, it may be appropriate to progress to a myo-electric or other type of electric powered arm, provided the amputee shows some aptitude with the body powered prosthesis. If the amputee is not competent with these, the heavier powered prosthesis may not be suitable<sup>8</sup>.
- 6.22 It should be recognised that the use of functional prostheses for more proximal amputations is difficult<sup>9</sup>. In a study by Jones and Davidson<sup>10</sup> 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<sup>9,11</sup>. Many individuals may only need a cosmetic prosthesis. Cosmetic arms do have some function<sup>12</sup> as they are used for back-up, steadying and supporting use and may be better termed 'passive function prostheses'<sup>13</sup>.
- 6.23 There is a wide range of terminal devices available for use with artificial limbs<sup>14</sup> and these can be interchanged. It is usually recommended that the amputee starts with a split hook which is best for basic training, plus either a mechanical or cosmetic hand. Future additions or changes depend upon the individual's lifestyle, occupation and leisure activities. The advantages and disadvantages of the different prostheses, especially the myo-electric prostheses should be explained to the patient<sup>15</sup>. Adequate and appropriate attention should be given to the appearance and cosmetic finish of the prosthesis<sup>16</sup>.
- 6.24 Whilst occupational therapy is best given at the PARC, frequent outpatient therapy sessions at Centres may not be practicable for all clients. Therefore, some sessions may need to be undertaken at the local hospital. Thus, it is essential that close liaison exists between the district hospital and the PARC.
- 6.25 Admission as an in-patient for around 5 days to the specialist Rehabilitation Centre may sometimes be required as often sufficiently specialised occupational therapy is not available at the local hospital for upper limb prosthetic training.
- 6.26 Upper limb amputation need not be a barrier to employment<sup>17</sup> and while Millstein et al<sup>18</sup> 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<sup>19</sup>.

6.27 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 Section 8.4).

#### REVIEW AND MAINTENANCE PHASE

- 6.28 All upper limb amputees using a prosthesis need to be followed up at a PARC for mechanical repairs, renewal or change of prosthesis or appliance to facilitate changes in lifestyle, occupation or recreational activities.
- 6.29 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 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 contralateral limbs <sup>9,20</sup>. This may require appropriate therapy, and education should be available.
- 6.30 A change in the prosthetic prescription (eg to myo-electric) may require further training sessions with the occupational therapist<sup>13</sup>.
- 6.31 Children who have not reached skeletal maturity need a 3-4 monthly review to accommodate growth and changes in development/requirements. This is addressed in greater detail in the next section as many children have a congenital upper limb deficiency rather than an acquired amputation.

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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.

  Provided other life threatening congenital abnormalities are absent, these children are expected to develop normally in the early months and until they are much older and start to compare themselves with their peers, they will not have the sense of loss associated with acquired limb deficiency. 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<sup>2</sup>. It is made considerably more complex if more than one limb is deficient. In the early stages, 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 percent<sup>3</sup>.

#### ROLE OF DISTRICT GENERAL 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 an orthopaedic surgeon (preferably 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. 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 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, 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<sup>4</sup>. 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<sup>5</sup>. Ideally therefore, the care of these children should be concentrated at the larger Tertiary Referral PARC, at least initially. However, to take into account patients' wishes, problems of travelling and access etc, some of the more established patients, particularly those with relatively straightforward needs, may be seen at the local Prosthetic and Amputee Rehabilitation Centres, provided good clinical links are maintained with the larger Centre.
- 7.11 The clinical team at the Limb Deficiency Clinic should be led by a consultant who is 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 6 months). The limb deficiency should be classified using the ISO system<sup>6</sup>. 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<sup>7</sup>. 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.
- 7.12 Patients with major limb deficiencies should remain under the care of the named consultant at the Clinic indefinitely, and 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).
- 7.13 Involvement of a specialist occupational therapist at an early stage is essential for children with upper limb deficiency. The occupational therapist will initially advise the parents, and will subsequently supervise prosthetic training (if appropriate) together with one and two-handed activities, and 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<sup>9,10</sup>, 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.

#### OTHER SPECIALISTS INVOLVED AT SPECIALIST LEVEL

- 7.15 **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 offspring of the affected child.
- 7.16 **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.
- 7.17 **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 6 months of life, as more surgical options may be available at a younger age<sup>11</sup>. 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.
- 7.18 It is recommended that the Prosthetic and Amputee Rehabilitation Centre should have well established links with these specialist surgeons, and joint clinics are an excellent way of bringing this about.

#### PROSTHETIC TREATMENT

- 7.19 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 a prosthesis, should start using a simple cosmetic arm. Limb fitting should be undertaken when independent sitting balance is achieved at about 6 months<sup>12,13</sup>. 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<sup>12,14</sup>.
- 7.20 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 occupational therapist based at the PARCs. This occupational therapist will also advise on the use of other appliances, aids or 'gadgets' and one-handed activities.
- 7.21 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<sup>15,16</sup>. 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.
- 7.22 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, 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.
- 7.23 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 Limbless Rehabilitation Centre.

- 7.24 Children using prostheses should be followed up by the Rehabilitation physician at 3-4 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.
- 7.25 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<sup>12</sup>. Except in cases of very high bilateral deficiency, lower limb prostheses are generally well tolerated and heavily used.

#### **EDUCATION**

7.26 Most children with congenital limb deficiencies are capable of attending a school, and should do so. Often a school visit by the specialist occupational therapist 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 lavatory 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 a Statement of Educational Need.

#### ADOLESCENCE

7.27 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. Specialist advice may be required in terms of considering a suitable career.

#### **ADULT LIFE**

7.28 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.

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# 8. 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.

#### 8.1 COUNSELLING

#### Introduction

8.1.1 Counselling services for people with amputations are relatively new, but are growing fast. Counselling is aimed at enabling clients 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<sup>1</sup>.

## **Evidence from previous studies**

- 8.1.2 Whilst the doctors and prosthetists were perceived by patients as offering an adequate service in most cases<sup>2</sup>, a majority would have valued the opportunity of specialist counselling at some stage during their experience.
- 8.1.3 A recent study<sup>3</sup> 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 24 months following the amputation.
- 8.1.4 The above findings were substantiated by further research, using standardised measures of emotional distress<sup>4</sup>.
- 8.1.5 Livneh<sup>5</sup> recommended that fostering a problem-focussed, rather than emotion-focussed coping strategy leads to better psychological adjustment.
- 8.1.6 The complexity of the psychological factors involved in amputees' acceptance of prostheses, is discussed by Desmond & Maclachlan<sup>6</sup>.

#### Recommendations

- 8.1.7 Every Centre should have a counselling service with readily available access.
- 8.1.8 All patients and relatives of patients who express a wish to see a counsellor should be offered the service.
- 8.1.9 Primary patients should be made aware of the availability of counselling services on their first appointment, or as soon as possible.
- 8.1.10 The service should be audited by adequate record keeping.
- 8.1.11 Strategies should be developed which are most helpful to the clients' problems (eg arranging a meeting with a 'matched' user where requested, supporting a re-housing application where necessary etc).

- 8.1.12 Client satisfaction with the service should be monitored every two years, or sooner if a problem should arise.
- 8.1.13 Pre-amputation counselling should be given in every case of elective amputation unless medical indications pre-empt it.
- 8.1.14 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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#### **8.2 OUTCOME MEASURES**

#### Introduction

8.2.1 The need to use outcome measures in clinical practice of Rehabilitation is well recognised. One of the two proposed RCP standards for the speciality of Rehabilitation Medicine<sup>1</sup> is 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%).

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

8.2.2 Outcome measures should be selected in relation to the individual goals for Rehabilitation and success must be viewed in relation to pre-morbid function<sup>2</sup>. 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 used similar outcome measures<sup>3</sup>. To enable this the working party recommends, between alternatives, the use of outcome measures marked with an asterisk as \*.

#### 8.2.3 Impairment Measures

- ISO Stump Descriptors<sup>4,5,6</sup>. These are the internationally recognised descriptors for various levels of upper and lower limb amputations and congenital limb deficiencies.
- McGill Pain Scores<sup>7</sup> which are well recognised for description of pain.
- Numeral Rating Score or Visual Analogue Score for pain<sup>8</sup> which are widely used for scoring pain.
- Socket Comfort Score<sup>9</sup> is a validated numerical measure for comfort of prosthetic socket fit.
- Laboratory Gait Analysis<sup>10,11</sup>. It is sophisticated, time-consuming and expensive eg kinetics, kinematics, EMG etc. The benefits in prosthetic fitting and alignment adjustments remains doubtful, thus limiting its use mainly to research purposes.

#### 8.2.4 Global Disability/Activity Measures

- \*Barthel Index<sup>12,13,14</sup>. This still remains the most commonly use global disability measure.
- UK FIM. This is not useful in isolation in Prosthetic Rehabilitation 15.

#### 8.2.5 Mobility Disability/Activity Measures

- \*SIGAM Grades<sup>16</sup>. This is a recently validated 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.
- Harold-Wood Stanmore Mobility Grades<sup>17</sup>. This remains the most commonly used disabilty measure for mobility<sup>18,19</sup> and validated with high inter-rater reliability and repeatability.
- \*Locomotor Capabilities Index (LCI)<sup>20</sup>. 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, now 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<sup>21</sup>.

- Volpicelli Grades<sup>22</sup>. Not validated, but often used in studies.
- \*Various Timed Walking Tests<sup>14,23,24,25,26</sup>. A simple objective measure that appears to correlate well to functional mobility in both neurological disability and amputees.
- Amputee Activity Score<sup>27</sup>, 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<sup>28</sup>.
- Prosthetic Profile of the Amputee Questionnaire <sup>29,30,31</sup>. 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. It's use is recommended for data base accumulation, programme outcome/discharge summary and research studies.

#### 8.2.6 Handicap/Participation Score

- \*London Handicap Scale<sup>32</sup>, originally developed for people with neurological disability.
- ICIDH Handicap Score<sup>33</sup>/ICF (International Classification of Function).
- AMRS Handicap Scale. A handicap score for the amputee based on the ICIDH and recently validated<sup>34</sup>.
- Quality of Life Measure eg Prosthesis Evaluation Questionnaire<sup>35</sup>.
- 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<sup>36</sup>. It may be useful in research for predicting prosthetic wear and use of prostheses.
- TAPES<sup>37</sup> (Trinity Amputation and Prosthetic Scales) is a small 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.

#### 8.2.7 **Emotional**

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)<sup>38</sup>.
- General Health Questionnaire (GHQ)<sup>39</sup>. Has been shown to be useful for use in amputees<sup>40</sup>.

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#### 8.3 COSMESIS

#### Introduction

- 8.3.1 There is a close relationship, between body image and prosthesis satisfaction<sup>1</sup>. 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 which is acceptable to the individual patient. Advances in the manufacture and availability of high and low definition silicone cosmeses have given a much more realistic finished appearance. Widespread publicity has rapidly raised users' awareness of, and, demand for, this level of cosmetic effect.
- 8.3.2 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**

- 8.3.3 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<sup>2</sup>.
- 8.3.4 Body image disruption was higher in younger people and those who suffered amputation due to trauma<sup>2</sup>.
- 8.3.5 In a study of spontaneous subjects raised by the patients during counselling sessions, 20% mentioned body image as a particular problem<sup>3</sup>.
- 8.3.6 Breakey<sup>4</sup> 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.
- 8.3.7 An ongoing study<sup>5</sup> on the perceptions of the limb before and after use of off the shelf silicone covers is currently producing mixed results because of other problems with the artificial limb, though the cover itself is generally well accepted.
- 8.3.8 A separate pilot study<sup>6</sup> has shown that patients prefer off the shelf silicone covers (SkinFX<sup>TM</sup> and Skinergy<sup>TM</sup>), in terms of appearance and feel to traditional stockinette 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<sup>5</sup>.
- 8.3.9 Donovan-Hall et al<sup>7</sup> 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**

8.3.10 **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.

- 8.3.11 **Upper Limb:** Partial hand & 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.
- 8.3.12 **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**

- 8.3.13 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.
- 8.3.14 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 cosmeses alone<sup>7</sup>.
- 8.3.15 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).
- 8.3.16 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.
- 8.3.17 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.
- 8.3.18 Only one high definition silicone cosmetic cover should be prescribed (life span is estimated at 18-24 months), but prescription of low definition silicone cosmesis is appropriate as 'back-up'.
- 8.3.19 Audit of outcome is essential to review the clinical effectiveness of silicone cosmesis by reassessment of psychological/life issues with appropriate assessment tools.

#### Relative Contra-indications/Exclusions

8.3.20 **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 2nd/3rd prostheses.
- 8.3.21 **Upper Limb:** Incompatible functional components, overall weight of silicone cosmesis, psychological problems not associated with the prosthesis, unstable stump volume or stump/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.
- 8.3.22 **Lower Limb:** Incompatible functional components, overall weight of silicone cosmesis, unstable stump volume or stump/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.
- 8.3.23 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**

- 8.3.24 Prescription criteria should be based on functional need and be non-discriminatory.
- 8.3.25 The Rehabilitation team should have appropriate training in assessment methods and treatment options.
- 8.3.26 Patients should have access to written information about relative contra-indications, restriction of prescription options and limitations of colour matching.
- 8.3.27 Treatment goals/objectives should be agreed and fully documented before commencing manufacture.

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#### 8.4 LIMBS FOR LEISURE

#### Introduction

- 8.4.1 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<sup>1,2</sup>. User groups have emphasised the importance of considering the limbless person's lifestyle and hobbies when making decisions regarding prosthetic prescription.
- 8.4.2 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.
- 8.4.3 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 amputation stump 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.
- 8.4.4 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, which are now available. 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.
- 8.4.5 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<sup>3</sup>. This is considered in more detail in a separate section.

#### **Recommendations on Procedures**

- 8.4.6 Leisure and sport should be considered as part of holistic Rehabilitation for people with limb loss.
- 8.4.7 Where possible, minor changes to the day to day limb should be considered to help patents in sport and leisure.
- 8.4.8 Advice regarding non-prosthetic aids and appliances to help participation in sport and leisure should be discussed with patient.
- 8.4.9 If a dedicated/special sports activity limb is indicated, it should be considered as a second limb (as opposed to prescribing a third limb)<sup>4</sup>.
- 8.4.10 The indication for prosthetic prescription and patient's use of the limb in sport and leisure should be documented.

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#### 8.5 WATER ACTIVITY LIMBS

#### Introduction

- 8.5.1 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.
- 8.5.2 The following are recommended indications and procedures based on a national consensus study<sup>1</sup>.

#### **Indications**

- 8.5.3 Specific water activity sport or leisure, which necessitates the use of a water activity limb eg scuba diving, jet ski etc.
- 8.5.4 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 and
  - 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.
- 8.5.5 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**

- 8.5.6 A referral may come either from the patient/user or a member of the multi-disciplinary team who has identified the need.
- 8.5.7 A consultation is arranged with the Rehabilitation Physician and an appropriate team member if necessary.
- 8.5.8 The need and indications are discussed including an explanation of the limiting factors.
- 8.5.9 The present day-to-day prosthesis should be viewed to see if light modification may serve the specific purpose.
- 8.5.10 A demonstration model of the water activity limb and its uses, mechanics and limitations should be shown if possible.
- 8.5.11 If a water activity limb is prescribed indications should be documented.
- 8.5.12 Follow up should be arranged to identify use and provide appropriate maintenance of prosthesis if necessary.

#### Reference:

1. Hanspal RS, Nieveen R. Water Activity Limbs. Prosthet Orthot Int ,2002; 26: 218-225.

# Amputee and Prosthetic Rehabilitation – Standards and Guidelines

(2<sup>nd</sup> Edition)

# Part II

Amputee and Prosthetic Rehabilitation Standards and Guidelines

# 9. STANDARDS AND GUIDELINES IN AMPUTEE AND PROSTHETIC REHABILITATION

- 9.1 The proposed Standards and Guidelines are based on national consensus. The key recommendations from the background information in chapters 4-8 were initially extracted as Standards and Guidelines. The process of achieving consensus is described in detail in paragraph 1.14.
- 9.2 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<sup>1</sup>. 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.
- 9.3 The standards are in a format identical to the BSRM Standards for Specialist Inpatient Rehabilitation Services<sup>2</sup> and for Community Rehabilitation Services<sup>3</sup>. The Standards marked with an asterisk\* are quoted directly from the previously published BSRM Standards.
- 9.4 The Standards have been prioritised, into three categories, defined in The King's Fund Organizational Audit Tool<sup>4</sup>:

#### **Kings Fund Organisational Audit Categories for Standards:**

Category	Definition
A	Essential Practice If these are not in place then: Legal and/or professional requirements will not be met A risk to patients, staff or visitors will be created The patient's rights, in terms of The Patient's Charter, will be compromised
В	Good Practice Standard good practice expected to be in place in any hospital/Trust across the UK
С	Desirable Practice Good practice which is not yet standard across the UK

9.5 To conform to the above definitions, the term 'must' has been used for all standards in category 'A' and 'should' has been used for standards in categories 'B' and 'C'.

# 9.6 Standards for Amputee and Prosthetic Rehabilitation:

1.	SERVICE PROVISION	A=Essential Practice B=Good Practice C=Desirable Practice
1.1	The Prosthetic and Amputee Rehabilitation Service must be regarded as a 'Specialist Service', as per the national definition of Specialist Services.	(A)
1.2	Every Prosthetic and Amputee Rehabilitation Centre (PARC) must have an agreed and written Operational Policy	(A)
1.3	Each PARC must have an appropriately trained Consultant in Rehabilitation Medicine who will be in charge of the overall care of the patient.	(A)
1.4*	<ul> <li>Service Users within any district should have access to all appropriate Rehabilitation services which aim to maximise physical, psychological and social well-being, including:         <ul> <li>Specialist in-patient Rehabilitation services</li> <li>Out-patient and day Rehabilitation supported by adequate transport systems to ensure reliable attendance</li> <li>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</li> </ul> </li> </ul>	(B)
1.5*	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)	(B)
1.6	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.	(A)
1.7	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.	(A)
1.8*	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.	<b>(B)</b>
1.9	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.	(A)
1.10	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.	(A)
1.11	The Consultant and the Manager should be the official representatives of the PARC in matters relating to the Trust.	<b>(B)</b>
1.12	At all PARCs patients must have adequate access to relevant information in appropriate formats and in a choice of languages.	(A)
1.13	The PARC must have on site, a Prosthetic Workshop equipped to deal with the day to day adjustment or repair and assembly of the majority of prostheses.	(A)
1.14	Centres providing prosthetic services for upper limb loss and congenital limb deficiency must fulfil defined criteria for these services.	(A)
1.15	The number of Consultants at each Centre will depend on the case mix and other commitments, but each Consultant should undertake a minimum of three notional half days (NHD's), including flexible sessions, in Amputee Rehabilitation.	(B)

	SERVICE PROVISION (continued)	A=Essential Practice B=Good Practice C=Desirable Practice
1.16	Each patient must have a named Consultant in Rehabilitation Medicine and a named Prosthetist.	(A)
1.17	Each PARC must have a structure in place to fulfil the requirements of Clinical Governance.	(A)
1.18	Each PARC must have an established complaints procedure.	(A)
1.19	The PARC must provide equity of access for all, irrespective of age or disability(ies).	(A)
1.20	The PARC should ensure provision of appropriate transport for patients as clinical needs dictate.	<b>(B)</b>
1.21	Every PARC should have adequate facilities for the collection of, and should collect, statistical data relating to Amputee Rehabilitation and prosthetics for the National Amputee Statistical Database (NASDAB).	<b>(B)</b>
1.22	Patients and Carers should be involved in the planning and review of Rehabilitation services in their area.	<b>(B)</b>
1.23	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.	(B)
2.	REHABILITATION TEAM	
2.1	Rehabilitation must be carried out by a co-ordinated inter- or multi-disciplinary team(s).	(A)
2.2	At the District General Hospital Each District General Hospital should have at least one Consultant Surgeon with special responsibility for amputation surgery (usually a Vascular Surgeon).	(B)
2.3	The District General Hospital should have a designated and appropriately trained Therapist or other Allied Health Professional to co-ordinate Amputee treatment.	<b>(B)</b>
2.4	The District General Hospital must have an Occupational Therapy service familiar with needs of new amputees or must have access to same.	(A)
2.5	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.	(A)
2.6	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.	(C)
2.7	The District General Hospital must make provision for the Rehabilitation of those amputees not suitable for Prosthetic Rehabilitation after liaison with the PARC.	(A)
2.8	At Prosthetic & Amputee Rehabilitation Centre The Multi-Disciplinary Team at each PARC must include a Rehabilitation Physician, Prosthetists, a Specialist Physiotherapist, and a Specialist Occupational Therapist.	(A)
2.9	When appropriate, patients at all PARCs should have access to an Orthotist, Counsellor, Social Worker, Clinical Psychologist, Rehabilitation Engineer, Podiatrist, Clinical Nurse Specialist and Employment Advisor.	<b>(B)</b>
2.10	The composition of the Multi Disciplinary Team at each Centre must be appropriate to the level of service provided (see paragraphs 4.5, 4.15 and 4.19).	(A)

3.	REFERRAL	A=Essential Practice B=Good Practice C=Desirable Practice
3.1*	Specialist Rehabilitation services should have:  • A defined inclusion criteria and	(B)
3.2*	• A written procedure for referral and for assessment Referral will be accepted from an appropriate agency (with the agreement of the physician or surgeon) in accordance with the written referral procedure.	(B)
3.3*	Where relevant, the funding/contract should be agreed prior to assessment to avoid disappointment.	<b>(B)</b>
3.4	Receipt of referral should be acknowledged promptly with an appointment or relevant information if there is a delay in the appointment.	<b>(B)</b>
4.	START OF REHABILITATION	
4.1	<b>Pre-amputation phase</b> A pre amputation consultation with an appropriate PARC team member, should be arranged where amputation is a treatment option (as opposed to treatment necessity).	(B)
4.2	During pre-amputation consultation, for upper limb amputees, particular emphasis should be placed on the likely function with and without a prosthesis.	(B)
4.3	A meeting with an appropriate established amputee should be considered before every case of elective amputation.	(C)
4.4	Unless clinically contra-indicated a Rehabilitation programme should be started pre-operatively.	<b>(B)</b>
4.5	The Amputation  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.	(A)
4.6	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.	(A)
4.7	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.	(A)
4.8	Surgical team must liaise with the PARC when clinically indicated	(A)
5.	REHABILITATION ASSESSMENT AND PROGRAMME PLANNING PHASE	
5.1	Assessment All amputees, must be offered referral to the PARC.	(A)
5.2*	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.	(A)
5.3	At the PARC the patient should be assessed by the multidisciplinary team, as appropriate.	(A)
5.4	Following assessment, realistic Rehabilitation goals should be set with the agreement of the patient and documented, including reasons for any failure to reach agreement.	(B)
5.5	The patient must be informed about the outcome of the assessment.	(A)
5.6	If Prosthetic Rehabilitation is planned, the prosthesis should be prescribed after consultation with relevant members of the multi-disciplinary team.	<b>(B)</b>

	REHABILITATION ASSESSMENT AND PROGRAMME PLANNING PHASE (continued)	A=Essential Practice B=Good Practice C=Desirable Practice
5.7*	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.	(A)
	Programme Planning Phase	
5.8	For complex cases, an inpatient facility, offering continued Prosthetic Rehabilitation should be available.	(C)
5.9	All patients must be given information about Rehabilitation and lifestyle options as an amputee.	(A)
5.10	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.	(A)
5.11	Experienced clinical counselling and psychological support should be available for all upper limb amputees.	<b>(B)</b>
5.12	All new patients attending the PARC should be made aware of the availability of counselling.	<b>(B)</b>
5.13	All PARCs should have a written and agreed policy for the provision of  Cosmeses	<b>(B)</b>
	Leisure Limbs and	
	Water Activity Limbs	
6.	THE REHABILITATION PROGRAMME	
<u> </u>		
6.1	Prosthetists must follow the manufacturers' instructions and guidelines on risk management and any deviations from standard practice must be fully documented.	(A)
6.2	The completed prosthesis should be delivered satisfactorily within the contractually stated time.	(A)
6.3	The patients should have direct access to team members as appropriate and in accordance with local guidelines	<b>(B)</b>
6.4	The service provided must be responsive to any individual patient's change in lifestyle, occupation or general health.	(A)
6.5	Outcome should be recorded during the Rehabilitation phase, preferably using validated outcome measures.	<b>(B)</b>
6.6	Adequate and appropriate attention must be given to the appearance and the cosmetic finish of the prosthesis.	<b>(B)</b>
6.7	Facilities for design and supply of custom made/one off appliances required for amputees especially for work related activities, should be available.	<b>(B)</b>
6.8	All amputees should have access to Vocational Rehabilitation (including advice on driving)	(C)
6.9	The appropriate follow up arrangements must be documented and appropriately explained to the patient.	(A)
	Congenital Limb Deficiency	
6.10	If a limb deficiency is detected during pregnancy, an antenatal referral to a Limb Deficiency Clinic should be offered.	<b>(B)</b>
6.11	The Paediatrician should refer to the Consultant in Rehabilitation Medicine specialising in Congenital Limb Deficiency at the tertiary PARC within one month of birth.	<b>(B)</b>

	THE REHABILITATION PROGRAMME (continued)	A=Essential Practice B=Good Practice C=Desirable Practice
6.12	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.	(B)
6.13	The child and parents/guardians should be seen in a Specialist Limb Deficiency Clinic within 3 months of birth.	<b>(B)</b>
6.14	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).	(A)
6.15	The multi-disciplinary team must provide ongoing care for the child and parents/guardians with appropriate and documented follow-up plan.	(A)
6.16	At the PARC, designated prosthetists with the appropriate specialist experience should look after all patients with Congenital Limb deficiency.	(A)
6.17	A therapist specialising/experienced in management of limb deficiency must be available to all children with Congenital Limb Deficiency.	(A)
6.18	Expert orthotic advice and treatment should be readily available.	<b>(B)</b>
6.19	Ongoing advice and help must be offered as the children become adolescents and adults	(A)
7.	DISCHARGE	
7.1	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 GP informed.	(A)
8.	FOLLOW-UP	
8.1*	All Rehabilitation facilities must have a written policy and procedure on follow-up.	(A)
8.2	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.	<b>(B)</b>
8.3	During the maintenance phase of established amputees, the service must be responsive to the changing needs of the patient.	(A)
8.4	Feedback to the GP and any other relevant authority should be provided on follow-up, when clinically indicated.	(B)
9.	STAFF DEVELOPMENT	
9.1*	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.	(A)
9.2*	All professional staff should be kept up-to-date, and there should be a written policy on training.	(A)
9.3*	Staff should have local access to up-to-date Rehabilitation textbooks and the major Rehabilitation journals relevant to their service.	<b>(B)</b>
9.4*	Regular training must be available both within and between disciplines, and time must be allocated for training on a regular basis.	(A)
9.5*	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.	(A)
9.6*	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.	(A)
9.7*	All services must undertake audit as a routine part of clinical practice.	(A)

#### A=Essential Practice **STAFF DEVELOPMENT** (continued) **B**=Good Practice C=Desirable Practice 9.8\* Audit should be undertaken as a multi-disciplinary activity. **(B)** 9.9\* Audit sessions should be documented, and where change in practice is **(B)** recommended, a named person should be designated to ensure implementation of those recommendations. 9.10\* 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 & AGENCIES

- 10.1\* 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:
  - Diabetic services
  - Plastic surgery
  - Continence and tissue viability services
  - Wheelchairs and special seating
  - Occupational health etc
- 10.2\* Rehabilitation services should have clearly identified policies or pathways for:

**(C)** 

- Working with general practitioners and primary care teams (generic services)
- Support and specialist Rehabilitation for children and adolescents with disabilities approaching adult life
- Transfer to care of the elderly Rehabilitation services for adults approaching later life
- Representing individuals' interest in community settings, eg decision, making for those with special care needs or communication deficits whose competence to participate in decisions may require representation from a third party
- 10.3\* There should be identified pathways to access and/or work with:

**(C)** 

- 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)

- 1. Turner-Stokes, L. National Guidelines and Standards. Clin Rehabil 2002; 16(Supp1): 13-20.
- 2. Turner-Stokes L, Williams H, Abraham R, Ducket S. Clinical Standards for Inpatient Rehabilitation Services in the UK. *Clin Rehabil* 2000; **14**(5): 468-80
- 3. Turner-Stokes L, Williams H, Abraham R, Clinical Standards for Specialist Community Rehabilitation Services in the UK. *Clin Rehabil* 2001; **15**:611-23)
- 4. King's Fund Hospital Accreditation Programme Organizational Standards and Criteria 1994/5;1: 63

### 10. APPENDICES

#### **APPENDIX 1 - MEMBERSHIP OF THE WORKING PARTY**

## Membership of the Working Party

Dr Rajiv Hanspal (Chair)	Consultant in Rehabilitation Medicine
Di Kajiv Hanspai (Chan)	Alderbourne Rehabilitation Centre
	Hillingdon Hospital, Pield Heath Road, Uxbridge,
	Middlesex UB8 3NN
	Also President of BSRM, Past Chair of ISPO(UK)
	and Past President of AMRS
Dr Annabel Hennessy (Joint Secretary)*	Consultant in Rehabilitation Medicine
	Morriston Hospital, Swansea, West Glamorgan
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Dr Dougall Morrison (Joint Secretary)	Consultant in Rehabilitation Medicine
(11 11 11 ())	Prosthetic Service, Mary Marlborough Centre,
	Nuffield Orthopaedic Centre, Headington, Oxford
	OX3 7LD
	Also Past Honorary Secretary AMRS
Mr Duncan Cotter *	Consultant in Rehabilitation Medicine
	Skipton General Hospital, Skipton, North Yorkshire
	BD23 2RJ
	Also Past President of AMRS
Mrs Judith Davis	Patient Services Manager
	West Midlands Rehabilitation Centre, Selly Oak,
	Birmingham B29 6JF
Dr David Foster	Life Member, Limbless Association
	The Limbless Association, Roehampton
M. C. C. H. CDE	Rehabilitation Centre, London SW15 5PR
Mr Sam Gallop CBE	Chair, emPower and Life President
	The Limbless Association, Roehampton
Mus Laust Vingston	Rehabilitation Centre, London SW15 5PR
Mrs Janet Kingston	<b>Senior Occupational Therapist</b> , Mobility Centre, <i>Nottingham City Hospital, Hucknall Road</i> ,
	Nottingham NG5 1PJ
	Also Honorary Secretary, Scientific Sub-Committee
	ISPO.UKNMS
Dr Lal Landham	Consultant in Rehabilitation Medicine
Di Dai Bananan	West Kent NHS and Social Care Trust, Medway
	Maritime Hospital, Gillingham, Kent ME7 5NY
	Also Member of the Executive Committee,
	ISPO (UK NMS), SIGAM and ARC Forum
Mr Richard Nieveen	Principal Prosthetist
	Blatchfords, Lister Road, Basingstoke, Hampshire
	RG2 24A
	Also Past Member of Executive Committee of
	ISPO(UK NMS), and Education Sub-Committee
	BAPO

<sup>\*</sup> Mr Cotter left the working party in January 2003 due to ill health and was replaced by Dr Annabel Hennessey.

#### **Consultant Advisors**

The following were consulted for advice specifically with reference to their speciality:

Mr Ken Andrew (Prosthetics)	Executive Professional Officer, British Association of Prosthetists and Orthotists, Sir James Clark Building, Abbey Mill Business Centre, Paisley PA1 1TJ
Dr Keren Fisher (Psychology)	Consultant Clinical Psychologist, Clinical Psychology Department, Royal National Orthopaedic Hospital, Brockley Hill, Stanmore, Middlesex HA7 4LP
Ms Mags Miller (Prosthetics)	Training and Personnel Manager, RSL Steeper, Riverside Orthopaedic Centre, 51 Riverside, Medway City Estate, Rochester, Kent ME2 4DP Also Vice Chair ISPO(UKNMS), Past Chair of BAPO, formerly Prosthetics and Orthotics Officer, DoH (AHP Branch)
Ms Marion Price MBE(Counselling and User)	C/o Stanmore DSC, Royal National Orthopaedic Hospital Trust, Brockley Hill, Stanmore, Middlesex HA7 4LP
Professor Kingsley Robinson (Surgery)	Surgical Advisor, Rehabilitation Centre, Queen Mary's University Hospital, Roehampton, London and Visiting Professor, Biomedical Engineering Group, University of Surrey, Guildford
Mrs Kim Roberts (Nursing)	Clinical Nurse Specialist – Amputee Rehabilitation Artificial Limb and Appliance Centre, Morriston Hospital, Swansea SA6 6NL Also, member of Nurses Amputee Network
Colin Dance (Rehabilitation Engineering)	Rehabilitation Engineering Manager, RE Division, Department of Medical Engineering and Physics, Kings College Hospital NHS Trust, Rehabilitation Centre, Bowley Close, London SE19 1SZ Also, Chair of RESMaG (POIG) and PCAG and Member of Executive Committee of ISPO (UK NMS)

#### **Other Contributors**

The following members of the BSRM were consulted on specific matters because of their particular experience and expertise:

Dr Dipak Datta	Consultant and Honorary Senior Clinical Lecturer in Rehabilitation Medicine Mobility & Specialised Rehabilitation Centre, Northern General Hospital, Herries Road, Sheffield S5 7AU Also, Chair ISPO (UK NMS)
Dr Nick Jayawardhana	Consultant Physician Castle Hill Hospital, Cottingham, East Yorkshire HU16 5JQ Also Chair of BSRM Special Interest Group in Amputee Medicine (SIGAM)
Dr Jai Kulkarni	Consultant/Honorary Clinical Lecturer in Rehabilitation Medicine Withington Hospital, Cavendish Road, Manchester M20 8LB
Dr Jeff Lindsay	Consultant in Rehabilitation Medicine West Midlands Rehabilitation Centre, Selly Oak, Birmingham B29 6JF Also, Member SIGAM Sub-Committee
Dr Vera Neumann	Consultant/Senior Lecturer in Rehabilitation Medicine Chapel Allerton Hospital, Chapeltown Road, Leeds LS7 4RB Also President Elect of BSRM
Dr Ernest Van Ross	Consultant in Rehabilitation Medicine Withington Hospital, Cavendish Road, Manchester M20 8LB Also Past President of AMRS/SIGAM

# APPENDIX 2 - RESULTS OF NATIONAL CONSENSUS ON STANDARDS & GUIDELINES

The following are the results of the final round of consultation (n=32) for the recommended standards and guidelines.

No of the	Agree	Disagree
recommended	8	9
standards/guideline		
1.1	32	0
1.2	31	1
1.3	30	2
1.4	32	0
1.5	31	1
1.6	32	0
1.7	32	0
1.8	32	0
1.9	32	0
1.10	32	0
1.11	32	0
1.12	32	0
1.13	32	0
1.14	26	0
1.15*	27	4
1.16	32	0
1.17	31	1
1.17	32	0
1.19	31	1
1.20	30	2
1.21*	29	1
1.22*		
1.22*	29	2
	29	2
2.1	32	0 2
2.2	30	
2.3	31	1
2.4	31	1
2.5	32	0
2.6*	29	2
2.7*	30	1
2.8*	28	3
2.9*	27	2
2.10	31	1
3.1*	30	1
3.2	28	4
3.3*	28	2
3.4*	29	2
4.1	30	2
4.2*	28	1
4.3*	28	3
4.4	31	1
4.5	32	0
4.6*	28	1
4.7*	29	2
4.8	32	0
5.1*	26	4
5.2*	29	1
*not all respondents comme	nted on this stan	dard

*not all respondents	commented on	this standard
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No of the	Agree	Disagree
recommended	rigice	Disagree
standards/guideline		
5.3	32	0
5.4	31	1
5.5	32	0
5.6*	30	1
5.7	32	0
5.8*	30	1
5.9	32	0
5.10*	31	0
5.11*	25	1
5.12	30	2
5.13 *	29	2
6.1	31	1
6.2	31	1
6.3	32	0
6.4*	29	2
6.5	31	1
6.6	30	2
6.7	32	0
6.8	32	0
6.9	32	0
6.10*	27	3
6.11*	28	2
6.12 *	31	0
6.13*	28	3
6.14	32	0
6.15 *	31	0
6.16*	28	3
6.17	32	0
6.18	32	0
6.19	32	0
7.1	32	0
8.1	30	2
8.2	32	0
8.3	31	1
8.4	32	0
9.1*	31	1
9.2*	31	1
9.3	32	0
9.4	32	0
9.5	32	0
9.6	32	0
9.7	32	0
9.8	32	0
9.9	32	0
9.10	32	0
10.1	32	0
10.2*	25	4
10.3*	27	2

# APPENDIX 3 - TRAINING IN AMPUTEE AND PROSTHETIC REHABILITATION FOR SPECIALIST REGISTRARS IN REHABILITATION MEDICINE

**Requirement:** a minimum equivalent of 3 months full-time in Disablement Services Centre to include the following in Amputee and Prosthetic Rehabilitation.

Name of Specialist Registrar:		
Attended:	(Name of Centre)	Disablement Services Centre
from (date)	to	

Session/Subject *		C / R**	Date(s) <sup>†</sup> Comments	Signature
Sessions				
Clinic Sessions	(26)	С		
Clinical Assessment of Primary Amputee	(10)	С		
Delivery and check out procedure of Prosth Lower limb Upper limb Pre-Amputation Consultation	esis: (10) (5) (2)	C C		
Session with Prosthetist to include casting for sockets, fitting, alignment adjustments and workshop	(5) nent	С		
Session with Physiotherapist to include gait re-education	(2)	С		
Session with Occupational Therapist to include arm training	(2)	С		
Session with surgeon to see transtibial amputation and transfemoral amputation	(2)	R R		
Session with Pyschologist/Counsellor to include counselling and psychology of limb loss	(2)	R		
Session with Chiropodist to include footcare	(1)	R		

Session/Subject *	C/R**	Date(s) <sup>†</sup> Comments	Signature
Subjects to be covered in tutorials/clinics	3		
Models of service delivery and organisation	С		
Principles of Prosthetics	С		
Functional Outcome Measures	С		
Principles of amputation surgery and post operative care			
Problems in amputation stump, medical and prosthetic management and stump care	С		
Stump revision and surgical management of problems in amputation stump	С		
Wound care	С		
Diabetic feet and foot care	С		
Congenital Limb Deficiency Upper Limb	С		
Congenital Limb Deficiency Lower Limb	С		
Upper Limb Amputations Transhumeral	С		
Upper Limb Amputations Transradial.Distal	С		
Gait Analysis	С		
Lower Limb Prosthesis Transtibial	С		
Lower Limb Prosthesis Transfemoral & Through Knee	C		
Lower Limb Prosthesis Symes & Through Foot	С		
Lower Limb Prosthesis Hip Disarticulation	С		
Prosthesis with high technical Specifications	С		
Quality control and CE marking	С		
Phantom phenomena and pain	С		
Management with co-existing medical conditions	С		
Others			
BSRM Course on Amputee Rehabilitation	R		
University of Strathclyde courses:			
Lower limb prosthesis	R		
Upper limb prosthesis	R		
Visit to prosthetic manufacturing company	R		
Research project	R <sup>t</sup>		
Audit project	R <sup>t</sup>		
Teaching presentation	R <sup>†</sup>		

*	Number in	hrackets i	s the number	of sessions	required
		ואמנגערואו	> 111C 1111111111111	いしってっついいっ	150000

Name and signature of supervising trainer at DSC

<sup>\*\*</sup> C = compulsory / R = recommended

At least one of these should be compulsory

#### **APPENDIX 4 - 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 for those with limb loss or deficiency.

Association

LLPOT Lower Limb Prosthetic Occupational Therapist.

NAN Nurses Amputee Network and Special Interest Group.

NASDAB National Amputee Statistical Database (see 3.1).

NFARC National Forum for Amputee Rehabilitation Counsellors.
OTTO Occupational Therapist in Orthopaedics and Trauma.

**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.

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 British Society for

Rehabilitation Medicine.

STEPS Association for children with lower limb deficiency.
ULPOT Upper Limb Prosthetic Occupational Therapist.

#### **APPENDIX 5 - USEFUL ADDRESSES**

Organisation	Address	Tel/fax numbers	Email/website
BACPAR	BACPAR, C/o Chartered Society of Physiotherapy, 14 Bedford Row, London WC1R 4ED	tel: (020) 7242 1941	www.bacpar.org.uk
BAPO	British Association of Prosthetists and Orthotists Sir James Clark Building, Abbey Mill Business Centre, Paisley PA1 1TJ	tel: (0141) 561 7217	www.bapo.com
BLESMA	British Limbless Ex- Serviceman's Association Frankland Moore House, 185-187 High Road, Chadwell Heath, Essex RM6 6NA	tel: (020) 8590 1124	www.blesma.org
BSRM	British Society of Rehabilitation Medicine C/o Royal College of Physicians, 11 St Andrews Place, London NW1 4LE	tel: (01992) 638865 fax:: (01992) 638905	admin@bsrm.co.uk www.bsrm.co.uk
College of OT's	College of Occupational Therapists 106-114 Borough High Street, Southwark, London SE1 1LB	tel: (020) 7357 6480 fax: (020) 7450 2299	www.cot.org.uk
emPOWER	Empower Rehabilitation Centre, Roehampton Lane, London SW15 5PR	tel: (020) 8355 2341 fax: (020) 8788 3444	enquiries@empowernet.org www.empowernet.org/
ISPO	International Society for Prosthetists and Orthotists UKNMS, PO Box 2781, Glasgow G61 3YL	tel: (0141) 560 4092 tax: (0141) 560 4092	info@ispo.org.uk www.ispo.org.uk/
Limbless Association	Limbless Association Rehabilitation Centre, Roehampton Lane, London SW15 5PR	tel: (020) 8788 1777	www.limbless-association.org
NAN	Nurses Amputee Network and Special Interest Group C/o West Midlands Rehabilitation Centre, Selly Oak, Birmingham B29 6JF		
REACH	Reach Head Office PO Box 54, Helston, Cornwall TR13 8WD	tel: (0845) 1306225 fax: (01872) 262098	reach@reach.org .uk www.reach.org.uk

Organisation	Address	Tel/fax numbers	Email/website
REBSIG	Rehabilitation Engineering and Biomechanics Special Interest Group Chair of REBSIG Fairmount House 230 Tadcaster Road York YO24 1ES, UK	tel: (01904) 610821 fax: (01904) 612279	office@ipem.org.uk and mark for Chair REBSIG www.ipem.org.uk/sigs/rhsig/r ebsig.html
RESMaG	Rehabilitation Engineering Services Managers Group Dr Colin Gibson (Chair 2003) Head of Rehabilitation Engineering, Rehabilitation Engineering Unit, Rookwood Hospital Llandaff Road, Cardiff CF5 2YN	tel: (0209) 20313931	Colin.Gibson@rehabeng.uhw-tr-wales.nhs.uk
Royal College of Physicians	Royal College of Physicians of London 11 St Andrews Place, Regents Park, London NW1 4LE	tel: (020) 7935 1174	www.rcplondon.ac.uk
SIGAM	Special Interest Group in Amputee Medicine of the BSRM, British Society of Rehabilitation Medicine, C/o Royal College of Physicians, 11 St Andrews Place, London NW1 4LE	tel: (01992) 638865 fax: (01992) 638905	www.bsrm.co.uk
STEPS	Steps, Lymm Court, 11 Eagle Brow, Lymm, Cheshire WA13 OLP	tel: (0871) 717 0045 Fax: (0871) 717 0045	info@steps-charity.org.uk www.steps-charity.org.uk/

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