ISPO UK MS
Multidisciplinary Special Interest Group

Upper Limb Difference & Acquired Amputation

Report of the 2nd meeting of the Group held on Friday 30th April 2021

On Friday 30th April, the second meeting of the ISPO UK Multidisciplinary Special Interest Group for Upper Limb Difference & Acquired Amputation was held via Zoom. The meeting was extremely well attended with in excess of 50 participants representing a cross section of stakeholders. The group continues to grow with further signups following the last meeting. ISPO UK offer a free introductory meeting following which membership of ISPO is required to participate. Membership of ISPO UK does of course provide access to all ISPO UK activities at either no cost or preferential rates. We would like to encourage greater involvement and participation from technicians and need to consider how this can be achieved.

ISPO is a community and we are keen that the Special Interest Group provides a platform to encourage ongoing discussion and joint collaboration. To this end a Slack workspace has been set up for members of the group to continue dialogue between meetings. If you would like to be added to this, please make sure you have joined ISPO (Join ISPO | ISPO UK MS) and the Special Interest Group (www.ispo.org.uk/sig---uldaa---joining-form/). If you think you have already joined the SIG but have not been added to Slack, please contact Irene at info@ispo.org.uk. If you are a member of ISPO International through a different member society (i.e. not ISPO UK) it may be useful if you can send proof of this years membership subscription to Irene to speed up the process of confirming your membership.

The meeting on 30th April began with a summary around the plans for the group. Although this specific meeting was focussed on the development of guidelines, the aims of the Special Interest Group are broader than this. As previously discussed we aim to create a community through which people working in the field can come together to collaborate.

One suggestion for these formal meetings was to include a lightning-talk section. This is where members can share their research or case studies in 3-minute presentation. We plan to take this forward as part of our next meeting in September.

In our first meeting before Christmas, we asked what people wanted out of this group. The key points were very much centred on collaboration, engaging with research and linking up the research and clinical communities. There was also a strong interest in training opportunities.

Hence the decision to focus the second meeting on guidelines as this is a topic with significant interest and the potential for us to work together to enact a useful change at a national level. Very few guidelines are available in relation to upper limb difference and existing guidelines are usually single profession based.

We asked our members to let us know about the guidelines they were aware of:

- ICRC Manufacturing guidelines
- VA/DoD Clinical practice guideline for the management of upper extremity amputation
- College of Occupational Therapists Upper limb prosthetic rehabilitation guidelines
- New York Upper-limb prosthetics manual – including prosthetists' supplement
- BSRM Amputee and prosthetic rehabilitation standards and guidelines
- 1955 National Academy of Sciences Advisory Committee on artificial limbs
- UCLA Fabrication and fitting prosthetic principles for upper extremity amputations
- Atlas of Limb Prosthetics: Surgical and Prosthetic Principles
- Atlas of Amputations and Limb Deficiencies
- Prosthetic Restoration and Rehabilitation of the Upper and Lower Extremity
- Several service guidelines produced/collated by BAPO

We invited three speakers to share their personal experience

Rachel Humpherson: Rachel is a physiotherapist working at Össur and is also the guidelines co-ordinator for BACPAR. Previously Rachel worked at Preston prosthetics centre as a sports physio and developed a keen interest in upper-limb prosthetics. Rachel highlighted difficulties in accessing statistics relating to upper-limb absence making it very difficult to understand rejection rates. The evidence base to determine treatment protocols is limited. With reviews underway into the provision of multi-grasp hands this research is much needed. Rachel highlighted the Atlas of Amputations and Limb Deficiencies as a useful resource but this doesn't necessarily cover the process in detail. The VA/DoD guidelines discuss the steps of the rehabilitation process in a more useful way. Physios don't see many upper-limb patients.

They are in a good position to treat patients to avoid overuse injuries but aren't regularly involved in the process.

Edwina Hudspeth-Stevenson: Edwina is a newly practicing Occupational Therapist based at RNOH Stanmore. She trained in Australia and coming into the field fresh has found the guidelines to be fairly limited. With respect to the OT guidelines there is a lot of useful information, but some of the attitudes are a little bit outdated. She has been reliant on the other members of her Multi-Disciplinary Team. This can be problematic if OT's are coming into smaller or less experienced groups. Questions around how frequently patients should be seen were raised and what we mean when we talk about 'guidelines'.

Sarah Day: Sarah is an upper-limb prosthetics lecturer at Strathclyde University. She has practiced clinically in multiple countries including England, Ireland, Australia, Thailand, and Saudi Arabia. As a new graduate she learnt most of her clinical skills by shadowing a senior colleague. When travelling she learnt a lot about the issues with sweating and non-verbal communication (when not able to speak the language). Overseas, the cosmetic aspects of upper-limb rehabilitation were much greater than in the UK, this included a lot of partial hand patients. Additionally, myo was very much in demand due to the visibility on the internet putting pressure on prosthetists as to how to explain that this may not been the best solution. Guidelines could help to back-up some of these points so it doesn't just sound like the opinion of the prosthetist. When teaching P&O time constraints and patient availability mean students are often all crowded around 1 patient. Upper-limb is seen as a lower teaching priority than lower-limb and this can be a challenge. Students gain limited practical experience of the upper-limb (maybe 3 casts) and universities are reliant on clinical services to provide that experience (not all of whom have many cases). It was suggested from the discussions later on that if within the placement, prosthetists get a lot of lower-limb experience, there should therefore possibly be more focus on upper-limb in education as this is the aspect that centres find harder to up-skill their employees on. The documents available aren't necessarily inaccurate as many of the aspects haven't changed but updating is required with a focus on assessment, the correct prescription and socket fitting. We need multi-centre collaborative research on socket design (what are we fitting, what works, what skills do graduates need?). We need clear clinical pathways and reference documents. Sarah also highlighted the benefits of this group in encouraging the clinics to inform research, and to ensure we are feeding research back into the clinic.

We then moved to a discussion with attendees allocated to one of four breakout rooms before coming back together in the wider room.

Feedback Summary:

- How can we inform prescription?
- How do we identify the needs of each individual?
- Definition of ‘function’
- No evidence to support socket design and application
- No big data to understand the population that we treat
- Goal setting is critical, are we doing this well?
- Treatment/prescription should be bespoke and not limited by outdated sequence/practice
- The needs of each patient will change over time. How do we capture this in a meaningful way? Should the service be proactive or reactive?
- Do current available products meet the needs of patients? Who is developing products and devices for patients with upper limb difference?
- Do ISPO have best practice guidelines? Can we access these?
- Organisations will have their own statistics and guidelines, can we be more open and share this information?
- Available guidelines are often profession specific rather than truly holistic
- What do we mean by the term ‘guidelines”, define. Does terminology overlap such as ‘pathways’, ‘algorithms’ and ‘standards’?
- We need to write down what we do – this is required practice in any other profession or organisation
- How do we draw together and share ‘best practice’
- What do we do and when do we do it? Often asked by surgeons i.e. the optimum length of the amputation residuum. This information should be readily available and evidence based.

- Very little available guidance for consultants
- We need to feedback and inform at a national level, for example the Service Specification consultation process – this is a unique group
- Presentation of any work such as guidelines is crucial with an emphasis on capitalising on technology and visualisation
- Current dissemination of knowledge is often based on a culture and practice approach
- Are current outcome measurement tools fit for purpose?
- A gradual reduction of skilled technicians and knowledge drain is worrying
- Shared resources and knowledge. Current silo working means we are often trying to re-invent the wheel
- What should the service look like when a patient presents?
- Specialist dedicated clinics to underpin training, gain experience and create a teaching environment?
- Patients may benefit from meeting other similar patients
- A re-specialisation of this aspect of prosthetics?
- ISO standards are difficult to obtain and require a fee and not accessible for many
- Guidance required for multi limb loss/bilateral users would be of benefit
- If the root of a MSK problem is related to the prosthetic prescription (or lack of) would therapists personally feel able to influence the renegotiation of prescription a) with the patient b) with your broad rehab/prosthetic team, from a basis of evidence?
- Guidance for surgeons is poor unless they are linked to a Rehab centre

Next steps …

In the coming weeks we would like to know from each of our members:

'What would you like a guideline for?

We are keen that information developed by the group will be open source/open access, but we need to look at the exact format any information is disseminated in.

Our next formal meeting will be on **Friday 17th September 13:30-16:00 (Topic TBC)**. To get involved in the conversation in the meantime, please ensure you join the Special Interest Group so that we can get you added to the Slack workspace.