OPUS

Prosthetic Review Meeting with NHS England

2pm - 4pm

Wednesday 14th November 2018

Summary of meeting

Sandra welcomed everyone to the meeting, she introduced OPUS and Carolyn, the representative from NHS England. There was no agenda the floor was opened to the users who had attended. A summary of concerns and user statements had been sent out previously to all those who had registered an interest with OPUS.

The meeting kicked off with a question about the veterans and the difference in the service between veterans and non-veterans.

It was acknowledged that there is a big discrepancy in the service provided and the components available for veterans and non-veterans. Carolyn said that NHS England has nothing to do with the funding of the veteran's prosthetics, they are paid for by the fines paid by the banks to the government and the government used some of this money to pay for veterans' prosthetic treatment. It was pointed out that all amputees deserve a good service no matter the cause of amputation; from a congenital defect, illness, trauma, elective or an NHS mistake. Just like the veterans all amputees had no choice in becoming disabled. Carolyn said they were trying to address the gap between the veterans and the NHS. It was agreed that the socket fit which is most important should be no different than that of a Veteran.

A question was raised about the inequality across the centres; it was noted that there is an inequality across England and that it is a postcode lottery if the service is good, bad or exceptional. The service should be a good service and the same service should be offered across all the 35 centres. Carolyn said that this reviews aim is to raise all centres up to the highest standards and centres are to be made accountable for the service given to users. At present it is very difficult to compare figures as all centres report statistics in a different format. It was noted that if a good socket fit is not achieved at the first stage then it becomes costly, having a good fit first time round means that it is less man hours and resources therefore the aim is to try to have a good socket fit first time. This is also beneficial for the user. All centres have been consulted to offer their feedback on ways this can be achieved. Carolyn said that we can learn a lot from the veterans and the service they provide.

She said that the veterans no longer use CADCAM, it was agreed around the room that CADCAM was not the way forward. Carolyn confirmed that NHS England would not be asking centres to use CADCAM.

Socket fit and quality are the two most important areas; no amount of expensive components can replace or compensate for good socket fit. Socket fit needs to be priority in the review as this is both key to keeping cost down and providing the user with a good usable prosthesis.

Carolyn stressed that one of the main aims of the review is to make the service standard throughout all 35 centres in England. All centres need to work to the highest of standards. We asked Carolyn about funding and how they proposed to address the fact that funding does not follow patients. She explained that at present funding given to each centre was set around the amount of patients that each centre had in the 1990's and that this figure has not changed even though the amount of patients has changed dramatically, she also explained that when a patient asks for a second opinion that the centre giving the second opinion does not receive any extra funding for this. This is an area that needs changing. The centres are being asked to submit a report each month stating how many users they have seen. It was also pointed out that more complex cases and multiple amputations should be taken into account when working out funding.
Carolyn spoke about possibly having larger centres of excellence (Hubs) with smaller regional centres under their supervision which would mean that most cases could be seen in the smaller centres that were more local to the patient's home address but specialised cases would be seen in the larger centres. It would also mean that all users would have access to a multi disciplinary team. Concern was given to this idea. Would this mean we had a two-tier system, this is what the review was trying to avoid. Who decides who attends what centre? Would the prosthetists be content working in the smaller centres as they may see them as inferior, already there is a lack of quality, experienced prosthetists, many go to work in the private sector after receiving training in the NHS centres. There needs to be a lot of consultation around this idea. Could having a 'hub and spoke' system' cause more inequality?

It was noted how important this review is and how this is our chance to have our say in a service that is being overhauled. Once the review is completed and the implementations are in place there will be no other chances for change for a long time. It is of upmost importance to get this right so that our service is improved. Carolyn said this is your opportunity to shape the service you wish to be offered.

Paediatric days would be held in the larger centres to allow children and their parents to mix. This is proven to be very successful are these days are already held in Stanmore. It was acknowledged by both Carolyn and the Stanmore patients that Stanmore has a solid multidisciplinary team lead by the wonderful Dr Sedki. The continued support of OPUS from all the staff at RNOH staff should be acknowledged.

Carolyn said that as contracts ended, NHS England would be involved with the tendering of new contracts. All contracts for centres are different which is adding to the postcode lottery. When contracts come to an end NHS England will make sure that all contract stipulate the same guidelines. This will make it easier to see which centres are doing well and which need to make improvements. This will standardise the centres.

It was also pointed out and acknowledged by Carolyn that the funding must follow the patient and that complex cases and multiple amputations need to be counted.

Two users spoke about having joint replacements and how this is more complex in a patient with an amputation. Surgeons need to be educated to consult with the prosthetic consultants before surgery to give the best outcome for the patient. It was suggested that prosthetics should have a longer rotation within all surgeons training.

Carolyn confirmed that it was not their intention to lose any of the 35 centres across England. All 35 centres will remain open.

Carolyn said that what they are trying to achieve is to bring prosthetics in line within the main NHS service. She said that at present that prosthetics are not running as part of the NHS and all centres are not standardised.

It was noted that patients are being better informed of services with the help of user groups like OPUS, Step Up and RLUG to name just a few. It is important for users to get to know their options around leg components and be able to start a dialogue with their prosthetist and be able to discuss options.

One user said that after her amputation she had been sent to Lambert Rehabilitation Centre as an inpatient. She expressed how helpful it was. She received intensive physio and was seen by a prosthetist and occupational therapist and that she was able to walk out of the centre on her new limb and did not need a wheelchair. Due to this she was able to return to work earlier and her mental health issues due to the loss of the limb were reduced. She also mentioned the help it was to all the patients as they were all recovering at different stages and able to offer each other emotional peer support. This type of intensive residential rehab may be cost effective in the long run.

The provision of two or more limbs was discussed. A user who is a congenital amputee said that she had been issued with 2 limbs plus a swim leg while she was growing up. She said that she climbs and swims. Funding does not allow her to receive a climbing limb she would need to ask to be funded by a charity. She mentioned the effect on mental health if you cannot participate in your chosen sport. The NHS do not provide any sports legs for amputees. Swim legs can be called shower legs. It was mentioned that due to this there are now many ‘go fund me’ and ‘just giving’ posts on social media.

Another user stated that only having one limb can increase the chance of skin damage. He

explained that if you can alternate your limb the pressure points on the residual limb will be different for different sockets. This was backed up by several other users who likened having one limb to having one pair of shoes and how if a pair of shoes were rubbing you can change them not to cause more damage. It was also pointed out that if you only have one limb then you will not have any backup should the limb have a breakage of any sort and be unwearable. This renders the patient wheelchair bound, if they have a wheelchair, not all amputees have a wheelchair. It was strongly felt within the room that two limbs plus a shower leg would be needed by most active amputees. Many users expressed that sometimes limbs will not be fixed in a day and that on these occasions a secondary limb is vital.

Carolyn stated that it was being proposed that in the new service amputees would be entitled to one main leg plus one other, that would be a secondary leg. It was acknowledged around the room that this was not what was required, and most users felt that two limbs plus a shower leg was the minimum.

A user said how she had been prescribed a hydraulic ankle and that it had changed her life. She was far more mobile with this ankle. Another user stated that she had been an amputee four years and did not know what foot she had and what her entitlement is.

Re use of components was discussed. At present components cannot be reused as the NHS consider components to be of single use under the policies and guidelines of the manufacturers. Carolyn stated that this policy is being investigated. The re use of products even refurbished components are something that is still to be decided by the review. A user suggested the NHS could refurbish the components.

In Stanmore all the used legs get sent abroad as is the case by most centres.

The time that we are at appointments was discussed. It was noted that many users can expect to be in the centre all day and often the limb needs to stay in the centre to be worked on. In these cases a secondary leg is critical as the patient will be wheelchair bound without their leg.

The NHS do not fund sports legs for adults but funds them for all children. We discussed how this will work when these children become 18 and are no longer entitled to sports legs. The psychological affect on these children when they turn 18 and can no longer be issued with a sports leg on the NHS is worrying and this needs to be considered.

Carolyn explained that the government fund the children's sports legs not the NHS and therefore when they become 18 the government will no longer fund a leg and the resulting problems are yet to come to light.

It was mentioned about the need to possibly being able to top up a NHS leg with privately purchased components or covers and the issues this can cause.

Carolyn explained that at present each centre is ordering components individually and therefore not receiving the benefit of the bulk purchasing. There is also no standardised

pricing system across centres. Carolyn confirmed that they will NOT be reducing the range of components that the centres may buy from but will have a standardised price pre-contracted by the NHS for all NHS centres. This means that all products will be the same price for all centres which is not the case at present.

Carolyn said that it was proposed that the review will be completed and implemented by April 2020.

All centres will be brought up to the same standard and when each contract comes to an end a new NHS contract will be enforced. All contracts will be the same across all 35 centres.

It is proposed that:

NHS England will have control of funding, quality, contracts and purchasing.

Everything will be open and transparent.

All contracts to be standardised.

All centres will be paid for the patients it supports and funding will follow patients

The amount of money the hospital Trust can charge from the service will be investigated

Funds will be available to help innovation especially research into good fitting sockets

Carolyn said NHS England valued the input of users and that they had received 890 responses from the survey available on line on the NHS website.

It was again put forward that users should be more involved in this process and that although the review committee involved charities, users had a non-biased input that should be taken into account also. OPUS offered to be involved in the review process.

Carolyn was asked to attend our Big Meet Up on Saturday 24th November at the Battleaxes, Elstree and she agreed to come along to speak individually with users.

Meeting was brought to a close and Carolyn stayed and chatted to many of the users who had attended the meeting.