Specialised Commissioning: Prosthetics Patient Survey Report 2018

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1 Executive summary

NHS England is responsible for planning and buying specialised services for people who need complex disability equipment. This includes all major upper and lower limb amputees and people with congenital limb deficiencies who have the potential to use prostheses to help them mobilise or improve upper limb function.

To inform the ongoing review into how these services are organised and paid for, NHS England launched a survey over three months from August 2018 to better understand patient and carer experience of prosthetics services, and where people feel we could do things differently. This was widely publicised on the NHS England website and sent to all registered stakeholders and prosthetics centres. Patient groups were very helpful in sharing the information on their websites and through social media. People responded to the online version of the survey, as well as paper versions.

We received 855 responses from patients and carers. The majority of people were happy with the care they receive, although around a quarter of patients expressed some dissatisfaction with their care. We heard some very positive feedback about dedicated, compassionate and experienced staff. However it was clear from the feedback received, that one of the main things people want to see is more clarity and fairness around what is available from NHS services.

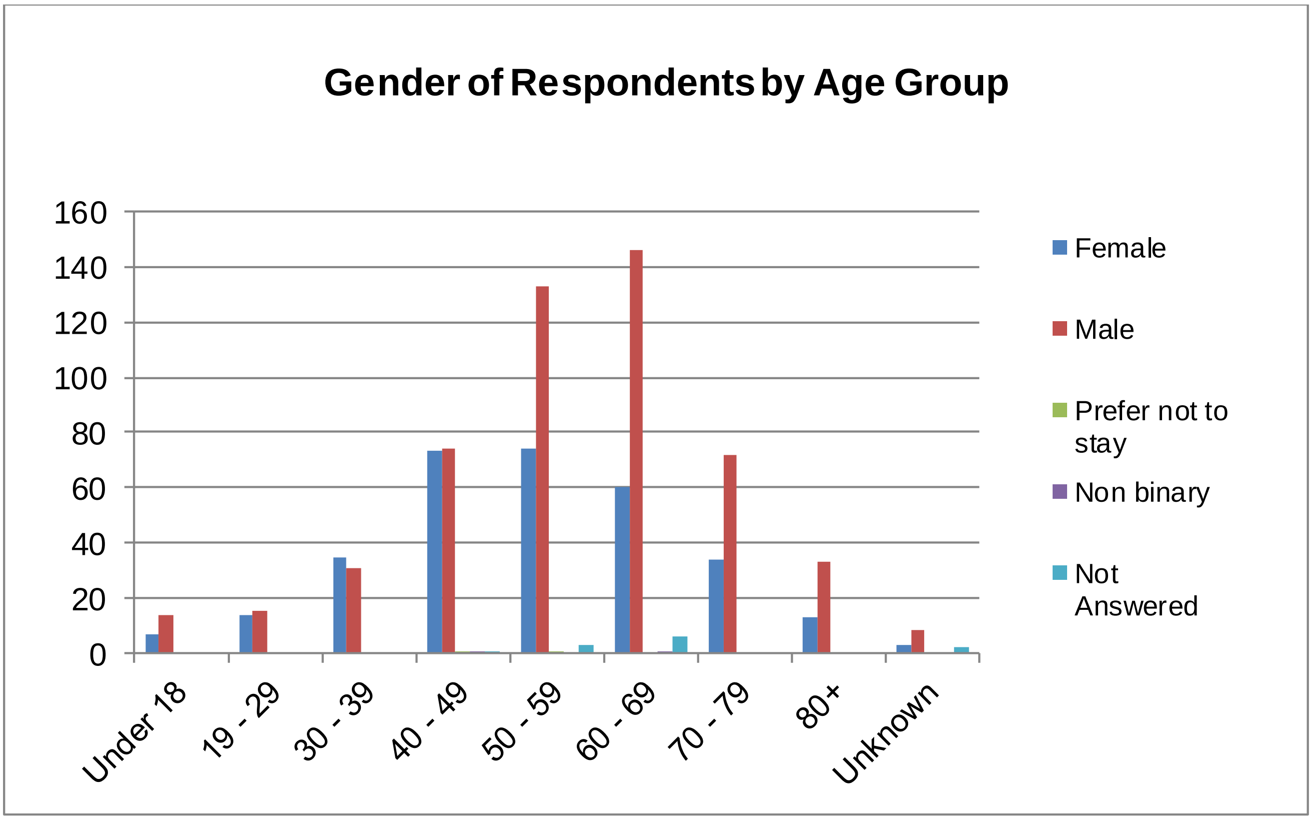
This report sets out the key themes raised by respondents, detailing where people would like to see changes made to the way that prosthetics services are delivered.

2 Survey responses

2.1 Respondents' profile

We received 855 responses from patients and carers. At least one person responded from each of the current 35 centres, and as expected the most responses came from the larger centres. The vast majority of respondents were adult patients (88%) with some responses from children and their parents (6%) and a small number of carers of adult patients (2%) sharing their views.

Demographically the largest number of respondents were in the 50-70 age bracket, with considerably more male than female respondents. There were twice as many male respondents than female aged 50 or over.



Only 6% respondents identified as non-white, which is less than half of the number of people from BME backgrounds than you would expect in the general population.

Around two thirds of respondents had lower limb loss, and one third had upper limb loss, with only a few people (1%) reporting both upper and lower limb loss.

2.2 Current travel times

Over half of the people who responded travel less than 20 miles to their current centre, with only 5% people travelling over 70 miles.

Just over 100 people (around 1 in 8 people) indicated that they do not attend their nearest centre, and these were the main reasons that people gave for visiting other centres:

- Some people expressed surprise at the idea that they could ‘choose’ to travel further, and assumed you could only be treated at your nearest centre, or where originally referred.
- Some choose to travel further following **poor experience at a closer centre**. The most common complaint is inability of centre to provide a comfortable fitting socket. Several patients reported particular incidents where they have been unhappy with approach of clinician or what they’ve been offered.
- **Continuity**. Some people have relocated but choose to continue attending the centre that they are happy with. A few people have followed staff that have taken a job at another centre.
- Some people travel further to access a **better resourced centre** with more specialist expertise – especially for those with complex needs (including upper limb).
- **Convenience.** Some people mentioned that they visit a further centre as they already attend that hospital for other conditions or complications.
- A small number of people have **opted for private treatment** for a more responsive service or equipment not routinely commissioned by the NHS.
- Some centres that are providing **prosthetics for children** can be ill-equipped or have little experience in treating children and young people. Facilities are not designed to be used by children, with limited rehabilitation or inappropriate support.

2.3 Further specialisation within prosthetics services

We asked whether patients and their families would be willing to travel further for more specialised services that affect a smaller number of people, and are therefore difficult to resource effectively in all centres.
The responses we received were inconclusive, with equally divided opinion on whether it would be beneficial to further specialise services for children & young people, upper limb and congenital limb deficiencies.

If these ideas are explored further we would need to discuss this in more depth with patients who may be affected, as this is more complicated than a simple ‘yes or no’ response, and patients would need to understand when and why they may be expected to go to a different centre, and how this could work in practice.

2.4 Satisfaction with current prosthetics services

Over two-thirds of respondents indicated that they were satisfied or very satisfied with the services they receive, however this left 16% indicating that they were dissatisfied or very dissatisfied.
People shared lots of positive comments about the service they receive. Patients appreciate the experience, knowledge, dedication, honesty and friendly attitude of their healthcare team, especially when they feel able to discuss their needs, problems, and suggestions with them.

Very experienced healthcare staff were highly praised, but people did have concerns about the **high turnover of staff** at some centres and a reliance on temporary or junior staff, as building a good relationship with a prosthetist was particularly valued.

For those who are not happy with the service they receive, **socket fit was raised as one of the most common complaints**. Several people commented that there should be an attitude of ‘getting it right first time’ with reported delays, unnecessary multiple appointments and waits before issues were resolved. Delays have meant that by the time the socket is ready, there have already been changes to the stump in the meantime – not uncommon for new amputees or people that are left inactive and gain weight.

Comments from patients included:

“There is a need for a smoother process, such as one day adjustment and repair”.

“A check-socket option before agreeing on a long-term limb is not given to ensure right fit, which means multiple products need to be made before a right fit can be made”.

“Comfortable socket fit is critical, but the approach, equipment and standards vary from centre to centre”.

Concerns were also raised about the **equipment on offer**:

- Reference was made to specific technology that is not currently commissioned by the NHS, for example, osseointegration, bionic hands, genium leg, 3D printed limbs and hands, etc.
- Dissatisfaction with difficulty accessing MPK (microprocessor knees) with some people feeling the rollout has been too slow in some centres or that the criteria for access is too restrictive.
- Queries about whether additional limbs (including shower, activity or spare limbs) should be available to all patients.
- Dissatisfaction with joints that are not moveable, heavy and ‘ugly’.
- Picture-printed limbs are offered for children in some centres but not in others.
- Easier access to prosthetic consumables, such as stump socks and silicone sleeves.

The key theme was that people felt there was **a lack of clarity or consistency** in what is available on the NHS.

“There should be a clear catalogue of available options/limbs/sockets under the NHS, which is the same for all providers in England”.

Many people were aware that the way that services are currently funded means **money doesn’t ‘follow the patient’**, with most centres paid through block contracts that do not necessarily reflect the number of patients seen, or the complexity of their care. This was a very common theme from respondents, who felt that the way prosthetics services are paid for should be changed to ensure that payment is fair and transparent, allowing for maximum patient choice.

“Money should follow the patient with options to easily go to another centre”.

The difference between the level of service and quality of equipment offered to **veterans and civilians** was raised by lots of people. While some people commented that this seems completely reasonable given the fact that veterans were injured serving our country, there were still expressions of frustration at seeing what could be available and some felt that this inequality should be addressed.

Other comments were around a perceived lack of **patient involvement, holistic care and personalisation.** There were comments that the age and activity level of patients is not always taken into account and some people with specific complexities (such as those requiring multiple prostheses) didn’t feel their needs were fully recognised.

There were also comments that some centres are not adequately resourced or skilled to manage the care of children and young people.

“Patients and carers want their consultations to be incorporated into the central decision making about prostheses – there should be more customisation”.

Some issues were focused on the centre itself, with some people reporting **poorly located buildings with run down facilities or décor**. Of note were the multiple comments about shared fitting rooms, with people commenting that these did not afford enough privacy or dignity.

“Some of the buildings and waiting areas need modernising to make them more patient-friendly and provide private rooms for appointments”.

While most centres appear to have some form of **patient participation group**, this is not necessarily the case, and some people commented that all centres should have regular patient groups. These should act as a forum for staff to regularly hear feedback from service users and share ideas about where improvements can be made.

Psychological support and family counselling were cited by many people as being an important part of the prosthetics service, that some felt were not easily accessible in all centres.

“You can’t underestimate the psychological impacts of losing a limb and coming to terms with being an amputee. I found dealing with the phantom limb pain really difficult”.

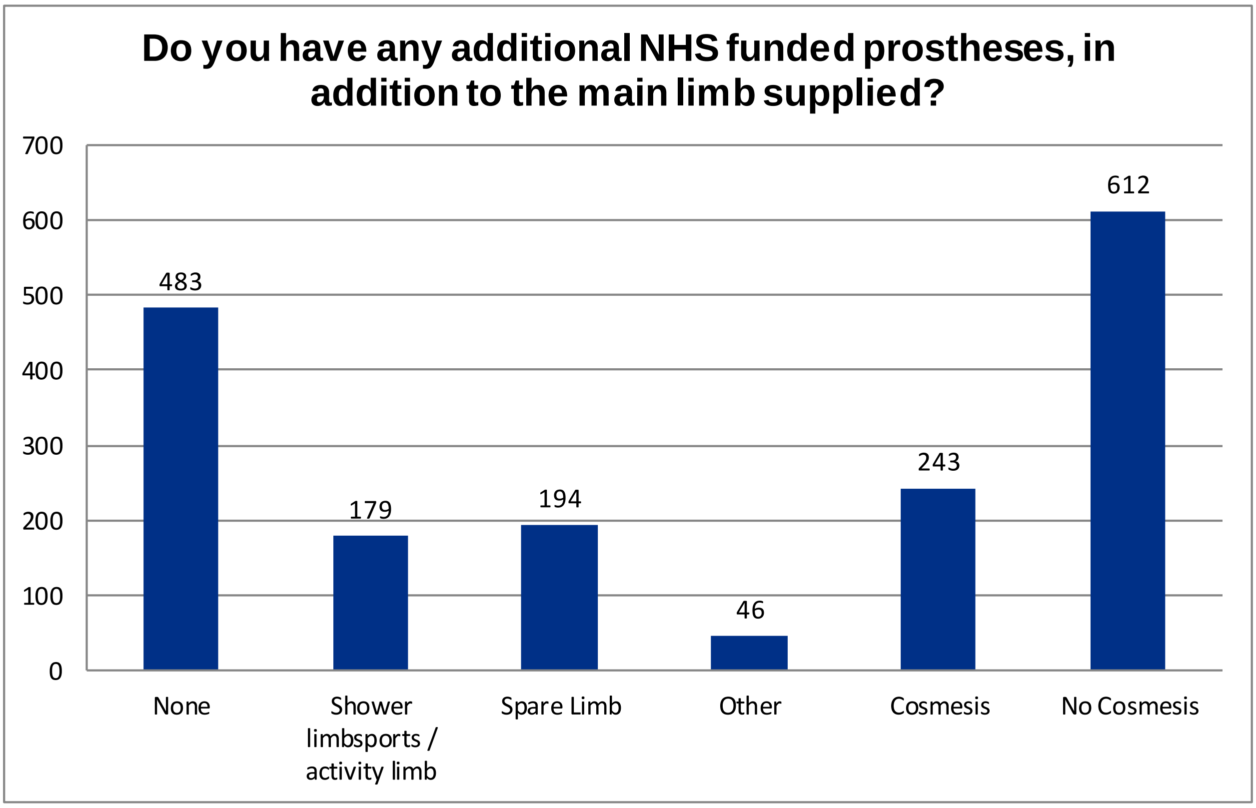
Some of the comments were concerned with **support just before and after an amputation**, and some people felt unsupported through this transition period before they were ready to consider using prosthetics.

Generally people felt there should be more **information for patients**. The majority of these comments centred on the need for reliable, fair and consistent information about what is available on the NHS, although some people wanted to know more about wider issues such as benefits advice and community resources.

2.5 Additional NHS funded limbs

Over half of the respondents (483 people) indicated that they had only been supplied with one limb, with less than a quarter of respondents indicating that they had been supplied with a shower limb and a similar number that had received a spare limb. A further 46 people (5%) reported that they had been supplied with a different type of additional limb, and most commonly this related to specific sports or leisure activities.

Around a third of respondents felt confident that they understood what should be available on the NHS and had access to all the care or equipment required. The inequitable access to additional limbs was commonly cited as a source of tension, with some people commenting that it seemed like only people who are prepared to argue their case are offered 'extras'. Equally just less than a third knew whether their centre had clear policies on access to equipment, including additional limbs, and again many expressed frustration that this seems unfair.



2.6 Cosmeses

Less than a third of respondents had been supplied with a NHS silicone cosmesis, but that could be because it is not required for a specific limb or if the patient preferred not to use a cosmesis. Some people commented that they had bought their own cosmesis as they thought that those available on the NHS were inadequate.

For those who do have a cosmesis, only 6% were unhappy with the match they had been supplied with and the reasons given for dissatisfaction included:

- Not a good match of size or colour, as not enough skin tone options available.
- High definition cosmeses are not routinely commissioned by the NHS, and some respondents are unhappy with this, as they feel these are required to meet their needs.
- Covering does not extend to the full limb.
- There is no benchmark or standard expected from all of providers – some reported poor quality or dirty products.
- The covering is not anatomically correct, for example, nails are not in the correct position, and there is an unnatural ‘plastic feel’.
- Some centres do not offer silicone covers, with only foam covering available.

2.7 What is currently missing from prosthetics services?

The most common themes raised were on equitable access to:

- Counselling and psychological therapies;
- Pain management services, including phantom limb pain;
- Specialist physiotherapy and occupational therapy;
- Access to affordable gyms and sports facilities & equipment;
- Benefits, welfare and job seeking advice; and
- Social support or peer support.

“There’s significant scope to improve rehabilitation and proactively support patients in having an active life. Provide a more person-centred approach to rehabilitation, not just the prosthesis. Some centres have gyms and group sessions but many do not have anything of that sort”.

2.8 What would you like to see change in prosthetics services?

Some of the comments were **concerned with issues about the ways that centres operate** – for example, how appointments or patient transport are organised. Some people were concerned by a lack of routine follow up, while others commented that appointment times were too short and that it was difficult getting appointments at short notice when required.

While this is very important feedback, these are changes that would need to be addressed at a local level with individual centres and are unlikely to be directly impacted as a result of the review undertaken by NHS England.

Some of the other common issues that were raised include:

- Clearer guidance for all patients on entitlements and benefits, as well as information on what is available in the prosthetics centre, and how to access other support such as patient groups.
- The money for prosthetics services should be ring-fenced so hospitals cannot use them to fund other services.
- More privacy during fitting – in particular there were several comments about communal fitting rooms which do not support dignity and the personal nature of the discussions.
- More co-ordinated approach to the other key services used by prosthetics patients, including wheelchair services, orthotics etc.
- Improve the speed of prosthetics limb provision and repairs.
- Some people commented that they felt all prosthetics services should be provided by the NHS, and were unhappy that private companies were involved.

2.9 How could centres work better together to offer the best service for patients?

For many people this was not a question that they felt they could answer, as they only visit one centre and don't have a sense about how centres could work more closely together or how that could benefit patients.

Several people commented that they felt patients should be able to **choose and go to any centre of their choice,** and that centres should work together to enable that to happen smoothly.

Some people were able to share examples where they had seen the benefits of a **collaborative approach between the prosthetics centre and a local hospital**, as well as between larger prosthetics centre and smaller units. One respondent shared how they had benefitted from a joint MDT (multidisciplinary team) approach where rehabilitation staff, prosthetic technicians and surgeons from different hospitals meet together to discuss patient care. It was suggested that this type of collaboration could be a requirement.

"There should be formal requirements for centres to work jointly and share best practice, education, jointly provide smooth access to specialist services and fast and effective referrals of patients to the best place for their condition and link with the community services".

Support and development networks could support staff - where professionals from different centres in a region share regular training and good practice, and can easily ask for advice from colleagues in other centres.

The **difficulties of information sharing** were raised, and some respondents queried why all centres that care for a patient don't currently have shared access to their case notes.

Regular **patient satisfaction surveys** and benchmarking information should be available to all patients **-** so that they can make informed choices and NHS England can manage the service improvements.

Good quality services should be as close as possible to patients so their needs are looked after locally, but there should be **clear referral policies to specialist centres** for more complex needs.

Treatment plans and goals should be agreed with patients and revisited regularly, and these should be shared with all the centres/units who are looking after the patient.

2.10 ‘Top-ups’ to NHS services.

Several respondents queried whether services could provide a **mixture of NHS and private services,** so that people could ‘trade up’ their NHS provided care or equipment.

“Patients should be given an option to take over budget that they can spend where they choose so that they could attend private prosthetic centres and ‘top up’ with own money. Patients should be able to be referred to a private centre where the NHS provider is unable to meet their complex needs, or the patient should be given an option to top up the NHS cost to get a more advanced limb rather than go privately and pay the full price”.

This is not an option that could be considered for prosthetics services as this contravenes the basic NHS constitution principle that the NHS must be ‘free at the point of delivery’. There are very few exemptions to this, for example the cost of wheelchairs and spectacles, and this would require a legislative change. We are not aware of any Government plans to consider such a change at this time.