

## **NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE**

### **Interventional procedures**

#### **Patient Organisation Submission**

### **IP692/2 Direct skeletal fixation of limb or digit prostheses using intraosseous transcutaneous implants**

Thank you for agreeing to give us your views on this procedure or operation and how it could be used in the NHS.

When we are developing interventional procedures guidance we are looking at how well a procedure or operation works and how safe it is for patients to have.

Patient and carer organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of having the procedure or operation
- the outcomes of the procedure or operation that are important to patients or carers (which might differ from those measured in clinical studies, and including health-related quality of life)
- the impact of the procedure or operation on patients and carers. (What are the benefits to patients and their families, how does it affect quality of life, and what are the side effects after the procedure or operation.)
- the expectations about the risks and benefits of the procedure or operation.

To help you give your views, we have provided this template, and ask if you would like to attend as a patient expert at the bottom of the form. You do not have to answer every question – they are there as prompts. The text boxes will expand as you type, the length of your response should not normally exceed 10 pages.

**Please note, all submissions will be published on the NICE website alongside all evidence the committee reviewed. Identifiable information will be redacted.**

About you	
1. Your name	<b>Brian Chenier MBE</b>
2. Name of organisation	Blesma. The Limbless Veterans
3. Job title or position	Support Officer (Prosthetics)
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	<p>Blesma, The Limbless Veterans helps all serving and ex-Service men and women who have lost limbs, or lost the use of limbs or eyes, to rebuild their lives by providing rehabilitation activities and welfare support. Our programmes allow Members and their families to face the challenges ahead with renewed confidence and self-belief.</p> <p>We work tirelessly for our Members when the conflicts that have affected their lives are no longer a focal point in the nation's media. Since 1932, we have been the only national Service charity that supports limbless veterans for the duration of their lives. Our Members range from the youngest amputee veterans to those who fought in WWII.</p> <p>Our main source of income is through general fundraising and donations alongside legacy donations and investments. We do receive some grant funding from grant giving bodies. We currently support approx. 2660 Beneficiaries.</p>
5. How did you gather the information about the experiences of patients and carers to help your submission?	<p>(For example, information may have been gathered from one to one discussions with colleagues, patients or carers, telephone helplines, focus groups, online forums, published or unpublished research or user-perspective literature.)</p> <p>I have been the prosthetics support officer since 2013 and have worked closely with Veterans and Limb Centres, including Defence Medical rehabilitation Centres at Headley Court and now Stamford Hall. My information is based on my direct dealings with veterans that have had DSF or that are desperate for this solution to be more widely available.</p>

**Living with the condition**

6. What is it like to live with the condition or what do carers experience when caring for someone with the condition?

From my dealings with many amputees I can say with some certainty that the biggest issue they have is with the socket interface. This can lead to significant problems with the residual limb and for some, traditional, and even innovative, sockets just simply do not work well for them. This can mean they can not walk and resort to using wheelchairs, when otherwise they are fit, healthy and wish to be active.

**Advantages of the procedure or operation**

7. What do patients (or carers) think the advantages of the procedure or operation are? Why do you consider it be to be innovative?

Removing the socket from the prosthetic equation for some will be life changing. This is not innovative, it is widely used in other areas of the world and where clinically indicated it is a game changer.

8. Does this procedure have the potential to change the current pathway or patient outcomes? Could it lead, for example, to improved outcomes, fewer hospital visits or less invasive treatment?

I believe that this intervention, for the right patient, will reduce repeat visits to limb centres, promote a more active and rewarding lifestyle and lead to improved outcomes in many areas.

**Disadvantages of the procedure or operation**

9. What do patients (or carers) think the disadvantages of the procedure or operation are?

Having a permanent external abutment can be problematic for some, but on the whole, everyone I have met that has this DSF tells me it is only a slight issue and nothing compared to having a socket, especially one that doesn't fit well. Infection control and hygiene are key.

<b>Patient population</b>
<p>10. Are there any groups of patients who might benefit either more or less from the procedure or operation than others? If so, please describe them and explain why.</p> <p>Transfemoral and bilateral transfemoral are most likely to benefit in my observations. This group have the most issues with sockets.</p>
<b>Safety and efficacy</b>
<p>11. What are the uncertainties about how well this procedure works and how safe it is?</p> <p>From what I have seen this is not different to any other procedure. The indications are it will work well on the right patient and clinical pathways should be clear and help ID suitable patients.</p>
<b>Equality</b>
<p>10. Are there any potential <a href="#">equality issues</a> that should be taken into account when considering this topic?</p> <p><b>I do not believe there are any equality issues that will impact tis. Patients will be identified based on their level of limb loss and chance of success.</b></p>
<b>Other issues</b>
<p>11. Are there any other issues that you would like the Committee to consider?</p> <p>There are potential patients out there right now that could be getting on with their lives in a much better way if this was currently available to them.</p>
<b>Key messages</b>
<p>12. In no more than 5 bullet points, please summarise the key messages of your submission.</p> <ol style="list-style-type: none"> <li>1. Mobility is fundamental to good health outcomes</li> <li>2. Increased independence is achievable</li> <li>3. Reduction in return visits to limb centres will save time and money</li> <li>4. Not everyone that is eligible for DSF will want to access it</li> <li>5. Overall this is a significant opportunity to improve lives and enable people to thrive</li> </ol>
<b>Committee meeting</b>

13. Would you be willing to attend the interventional procedures committee meeting to provide the view from your organisation in person?

Yes

Thank you for your time.

Please return your completed submission to [helen.crosbie@nice.org.uk](mailto:helen.crosbie@nice.org.uk) and [ip@nice.org.uk](mailto:ip@nice.org.uk).