

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

### **Interventional procedures**

#### **Patient Organisation Submission IP1833 Percutaneous endovascular forearm- arteriovenous fistula creation for haemodialysis access**

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. 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.**

<b>About you</b>	
1. Your name	
2. Name of organisation	Kidney Care UK
3. Job title or position	
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	We are the leading UK kidney patient support charity providing advice, support and financial assistance to thousands of people affected by kidney disease every year. We run a Facebook support group of over 9,000 members and provide personal indepth support to over 200 people every week. We are funded by charitable donations. Kidney Care UK is not a membership organisation.
5. How did you gather the information about the experiences of patients and carers to help your submission?	
Information has been gathered from ongoing interactions with patients through support services and online forum, one to one discussions with colleagues, patients and/or carers.	

**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?

Being diagnosed with kidney failure is a major life event and marks the beginning of a life-long 'career' as a kidney patient. It is the start of a long journey of decision making about treatment choices and very careful management of diet, fluid intake and medication to manage associated problems like high blood pressure. Kidney disease affects different people in different ways, both physically and emotionally, with debilitating fatigue being an often unrecognised complication. CKD can impact on many aspects of life, including personal relationships, jobs and social life. This, as well as the changes in health and how you view yourself, can take its toll on mental health and emotional wellbeing. Up to one in three patients with kidney disease will experience depression at some point. Treatment for kidney failure (less than 15% kidney function) are dialysis or transplant and both place a considerable burden on the patient, in order to keep the transplanted kidney healthy and, in the case of dialysis in hospital or a unit, travelling to and from four hour dialysis sessions, usually four times a week.

**Advantages of the procedure or operation**

7. What do patients (or carers) think the advantages of the procedure or operation are?

Offers increased patient choice regarding dialysis access, improves the aesthetics of the fistula which many patients report as extremely important to them (they don't want 'those lumps' on their arms) and which is likely to have really important quality of life benefits, less invasive surgery and the likelihood of minimal scarring following the procedure.

**Disadvantages of the procedure or operation**

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

Not currently aware of likely disadvantages.

<b>Patient population</b>
9. 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.  n/a
<b>Equality</b>
10. Are there any potential <a href="#">equality issues</a> that should be taken into account when considering this topic?  n/a
<b>Other issues</b>
11. Are there any other issues that you would like the Committee to consider?  Vascular access is one of the most important and challenging aspects of kidney care. Good dialysis care depends on it so it should be ready at the start of dialysis and looked after so that it is functioning correctly. Needling has consistently been one of the lowest scoring areas in the Renal Association/Kidney Care UK Kidney Patient Reported Experience Measures <a href="#">report</a> , with patients commenting on the pain of needling, sometimes as a result of poor technique, and staff not using different sites. Any beneficial impact of the procedure in this area would be valued by patients.
<b>Key messages</b>

12. In no more than 5 bullet points, please summarise the key messages of your submission.

1. Aesthetic outcome of vascular access procedures has been reported as a major concern of patients and should be an important consideration within the appraisal
2. The appraisal should consider whether wider implementation of this technique would have implications on waiting lists for vascular access surgery.
3. Increased patient acceptance of this technique may encourage patients not to delay vascular access surgery, which may encourage a well-planned and managed transition to dialysis which has important health benefits.
4. Informed patient choice and consideration of patient lifestyle, goals and preferences must be fundamental to decisions around vascular access procedures.
5. Any impact on pain in needling should be considered, as this is currently a problem area for many patients.

Thank you for your time.

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