

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission

IP1192/2 Leadless cardiac pacemaker implantation for bradyarrhythmias

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	Trudie Lobban
2. Name of organisation	Arrhythmia Alliance
3. Job title or position	Founder
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	<p>A-A is a collaboration of patients, caregivers and healthcare professionals working to improve the lives of all those living with an arrhythmia – heart rhythm disorder.</p> <p>We have over 125000 patients and 40000 HCPs and are funding comes from numerous sources – we do not rely any one source.</p>
<p>5. How did you gather the information about the experiences of patients and carers to help your submission?</p> <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>All of the above.</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?

People with bradycardia experience light-headedness and loss of consciousness and their heart rhythm slows and less blood is pumped around the body. It is frightening and cause stress and anxiety. For many they are unable to work, socialise and drive. They can feel isolated and excluded. Injuries can be dangerous and sometimes fatal if they lose consciousness and fatally injure themselves.

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?

Quicker, easier procedure, less risk of infection and no leads and only a very small scar.

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?

Absolutely yes. Shorter stay in hospital – often can be a day case or even just a few hours. Less invasive, monitored remotely so fewer visits to the hospitals, improved outcomes and returning to a normal active life.

Disadvantages of the procedure or operation

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

Have not had any disadvantages reported

Patient population
<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>If bradycardia is causing syncope (loss of consciousness) and impacting lifestyle then everyone who received a leadless pacemaker will benefit</p>
Safety and efficacy
<p>11. What are the uncertainties about how well this procedure works and how safe it is?</p> <p>None</p>
Equality
<p>10. Are there any potential equality issues that should be taken into account when considering this topic?</p> <p>NO</p>
Other issues
<p>11. Are there any other issues that you would like the Committee to consider?</p> <p>Often people with syncope caused by bradycardia are often misdiagnosed and services for this cohort of patients are few and far between. Anything that helps to identify and treat patients restores their quality of life and also cuts costs to NHS as fewer visits to A&E and hospital visits. This treatment option can save lives and save costs to the NHS.</p>
Key messages
<p>12. In no more than 5 bullet points, please summarise the key messages of your submission.</p> <ol style="list-style-type: none"> 1. Life saving 2. Cost saving 3. Safe 4. Can completely eliminate bradycardia 5. Restores the patient back to a person leading a normal, active life able to work and resume usual activities.
Committee meeting

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

Prefer virtual if possible

Thank you for your time.

Please return your completed submission to helen.crosbie@nice.org.uk and ip@nice.org.uk.