

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	Jenni Cozon
2. Name of organisation	Syncope Trust And Reflex anoxic Seizures (STARS)
3. Job title or position	Patient Services Co-ordinator
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	<p>STARS works together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures.</p> <p>Over 115,000 patients have registered and 40,000 HCPs. We cannot depend on annual funding so are supported in many ways.</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>As with many charities, our patients and their carers look to us for support and share their experiences, good and bad. Our helpline is always busy and many individuals ask us to share information if it will help others and the work we do. Medical professionals will highlight research papers.</p>	
Living with the condition	
<p>Syncope (fainting) is just one of the symptoms of bradycardia. Chest pains, dizziness and extreme fatigue add to the debilitating life patients endure.</p> <p>Some forms of bradycardia produce no symptoms and the first warning is an abrupt loss of consciousness. People of all ages can experience syncope, including children (reflex anoxic seizures) due to unexpected stimuli or shock.</p> <p>Individuals who faint regularly cannot drive and are prone to injury when falling, sometimes serious. Employers are reluctant to employ them because of health and safety. It is a very lonely life for some.</p>	

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 to be innovative?

Patients have embraced this as they see it as less invasive and not so frightening as there are no leads. Also it must reduce the risk of infection which we are all conscious of today.

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?

Any procedure that can be done as a day case is a positive for the patient and the hospital, reducing waiting lists. Recovery time is likely to be shorter and monitoring is likely to be remote.

Disadvantages of the procedure or operation

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

Currently, I believe everyone is positive.

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>Those who are struggling with bradycardia and no warning of sudden loss of consciousness (syncope) must be in line for this procedure, which would allow a return to work, return to driving and the confidence to enjoy life again.</p>
Safety and efficacy
<p>11. What are the uncertainties about how well this procedure works and how safe it is?</p> <p>None to my knowledge</p>
Equality
<p>10. Are there any potential equality issues that should be taken into account when considering this topic?</p> <p>Absolutely not.</p>
Other issues
<p>11. Are there any other issues that you would like the Committee to consider?</p> <p>Syncope is a symptom not a condition and, as in bradycardia, it is a condition that must not be ignored. Sadly syncope clinics are being closed in cost cutting exercises with patients waiting up to a year as syncope not deemed as serious. This procedure has to be a positive step in restoring quality of life and reducing costs with less visits to A&E and 999 calls.</p>
Key messages

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

1. Will allow the patient to return to normal life
2. Reduce infection
3. Reduce waiting lists
4. Ultimately will be cost saving
5. Life saving for some
- 6.
- 7.

Committee meeting

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

Not in person

Thank you for your time.

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