

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission Irreversible electroporation for treating prostate cancer IP1020/2

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.

About you	
1. Your name	██████████
2. Name of organisation	Prostate Cancer UK
3. Job title or position	Policy Officer
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	Prostate Cancer UK is a voluntary organisation based in London. It is a registered charity in England and Wales (1005541) and in Scotland (SC039332). Registered company number 02653887.
5. How did you gather the information about the experiences of patients and carers to help your submission?	
<p>Desk research and our own knowledge of the experiences of patients. We have spoken with our specialist nurses about their experience of speaking with patients with regards to this treatment.</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?

Patients with prostate cancer report many different symptoms which affect their daily lives. For those with localised disease, most of these symptoms are associated with the side effects from radical treatment, specifically radiotherapy in conjunction with ADT, which is the current standard of care, which causes damage to normal tissue alongside cancerous tissue. Short term side effects from radiation include irritation and inflammation of the bladder and bowel. When side effects are at their peak, patients may find it more difficult to hold urine within their bladder and may experience an overwhelming urge to urinate. The fear of incontinence/leakage can be distressing, and incontinence pads are often needed. Fatigue can also be a result of external beam radiotherapy and can be exacerbated by any anxiety or distress caused by the cancer or its treatment, and/or other issues such as the daily journey for treatment (which can be considerable for those patients in more rural areas, especially in Scotland), or lack of sleep due to an increased need to urinate at night.

Long-term effects can occur months to many years after radiotherapy. Some of the potential long-term side effects of radiation to the prostate include urinary problems that are potentially the result of urethra stricture (often more likely after combined external beam radiotherapy and brachytherapy). Symptoms include urinary retention, weak urinary flow, bowel problems and bowel damage, erectile dysfunction, hip and bone pain and/or weakness.

Patients in this position will then have regular PSA checks to determine whether the ADT is working to stave off metastasis. This process can cause a high amount of stress and anxiety in a person as it will not be known whether or when metastasis will happen.

Advantages of the procedure or operation

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

Anecdotally, Prostate Cancer UK have heard very few reports with regards to this procedure as it isn't common within the NHS. However, one patient had reported a success due to "having little to no urinary issues 6 months post treatment". As a charity we have heard that for some patients this procedure can work well with regards to low numbers of patients reporting side effects from the procedure.

Disadvantages of the procedure or operation

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

We do not have a patient or carer perspective in this instance, however as an organisation we do know that there is little evidence as yet to suggest that this modality shows an improved level of progression free survival in comparison to the current standard of care, or indeed other forms of focal therapy. We would welcome more clarity on this as the evidence emerges. As such we believe this lack of evidence to be a disadvantage of IRE currently.

Patient population
<p>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.</p> <p>Patients with lower risk disease (who do not wish to have, or are unsuitable for active surveillance) or intermediate disease may be spared some of the side effects of radical treatment if they are treated for focal therapy using IRE. However, we note that there is a lack of evidence demonstrating long term oncological control in these patients.</p>
Equality
<p>10. Are there any potential equality issues that should be taken into account when considering this topic?</p> <p>Many older patients may not be fit enough for treatment with radical prostatectomy and IRE may provide another alternative treatment for this group of patients.</p>
Other issues
<p>11. Are there any other issues that you would like the Committee to consider?</p> <p>none</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. Living with prostate cancer at this stage of disease is often associated with side effects from the treatments themselves. 2. IRE shows great potential in providing an alternative treatment with less side effects <u>that</u> a patient may well experience with the current standard of care such as radiotherapy. Potentially widening treatment options for a cohort of patients whose options are limited due to frailty. 3. More evidence is needed to confirm point 2 above and to demonstrate long term oncological control in comparison to the standard of care and also in comparison to other focal therapies. 4. 5.

Thank you for your time.

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