NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission

Minimally invasive radical hysterectomy for early stage cervical cancer IP51/3

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	[redacted]
2. Name of organisation	Jo’s Cervical Cancer Trust
3. Job title or position	[redacted]
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	We are the UK’s lead cervical cancer charity. We are primarily funded by voluntary donations through individuals, companies and foundations. We are not a membership organisation

5. How did you gather the information about the experiences of patients and carers to help your submission?

(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to one discussions with colleagues, patients or carers, telephone helplines, focus groups, online forums, published or unpublished research or user-perspective literature.)

Information gathered in a number of ways including informal one to one discussions with members our community, via our support services (Ask the Expert, online Forum and helpline), information days for those living with and beyond a cervical cancer diagnosis, through our Jo’s Voices patient feedback group and through research such as our 2017 work looking at the long term consequences of cervical cancer treatment

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?

Cervical cancer has significant consequences for those diagnosed as well as their loved ones. These consequences are both psychological and physical. Our experience through our services along with the research we have carried out over the last 6 years has shown that those living with and beyond a cervical cancer diagnosis experience high levels of anxiety, particularly fears around the cancer returning.

The diagnosis and subsequent treatment affects all aspects of life including the ability to work, relationships, physical wellbeing (including changes to bowel, bladder, sex and intimacy, lymphoedema, pain and fatigue), loss of fertility. Quality of life can be severely impaired.

Treatment can have long term consequences for those affected which is why our services exist. Many of those affected feel an acute sense of enduring isolation and loss of self confidence. Even receiving an all clear does not reduce the fear of recurrence.

Partners and carers are also greatly affected; alongside the fear of losing a loved one, they too are affected by loss of sex and intimacy caused by treatment and with equal significance, being unable to complete or start a family. The practicalities of running a home and/or a family whilst their partner is receiving and recovering from treatment is also a significant worry.
The financial implications of a diagnosis adds an additional layer of anxiety for both partners, particularly if the woman is unable to return to work.

Advantages of the procedure or operation

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

   We have not received direct feedback from patients regarding their thoughts on the advantages of this type of treatment.

   Depending on the conversations they have/had with their consultant examples may be reduced morbidity, shorter stays in hospital, being able to recover faster and thus get on with their daily routine. It might also be that they believe it improves longer term survival. But it is important to note that this is all a subjective response and not something we confirm at this stage.

Disadvantages of the procedure or operation

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

Currently we do not believe that patients are aware of any disadvantages to this type of treatment due to lack of information. But we have not had direct conversations with them about this and so this is a subjective response based on our knowledge.

Patient population
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. This will primarily benefit those with early stage cervical cancer (Figo Stage 1 – meaning the cancer is only in the neck of the womb (cervix). As a result they won’t need to have chemotherapy and / or radiotherapy. If the cancer spreads wider then this treatment along won’t be the most effective option.
Equality
10. Are there any potential equality issues that should be taken into account when considering this topic? Currently patients living in certain areas (potentially linked to socioeconomic factors) would not be given the option between having the two different types of surgery. Many hospitals are now only offering this minimal access surgery meaning that women would need to cover the cost of travel to clinics offering alternate surgery options. This would place additional and unacceptable pressure on patients to agree to the only surgery being offered in their hospital.
Other issues

11. Are there any other issues that you would like the Committee to consider?

There are increasing concerns as to whether minimally invasive surgery offers the best long term survival due to a number of worldwide research papers over the past year that have shown survival is improved through open surgery.

A recent review of data in England by NCRAS appears to confirm the findings of the US and other publications showing that outcomes for both minimal and open surgery were very positive - 93.1% after 4.5 years for those who received minimal access surgery however, for those who had received open surgery this increased to 97.2% and so is significantly better.

There were some gaps identified in the NCRAS research including that the data does not enable specific detailed analysis beyond the parameters defined by the routinely collected data fields, and cannot identify whether the difference in outcomes seen between open and minimal access surgery relates to all tumour sizes or specifically relates to women undergoing radical hysterectomy for treatment of larger cervical cancers (e.g. greater than 2 cm in diameter).

The gaps in research which the NCRAS analysis has identified need addressing urgently as we must ensure women having treatment for early stage cervical cancer are receiving the best possible treatment type and that consistency of approach exists across the country.

Minimal access surgery has previously been favoured over open surgery due to faster recovery and fewer complications or side effects, however the NCRAS analysis indicated no difference in post-surgical complications for the two. This potentially provides further weight to open surgery having better outcomes in terms of mortality and morbidity, however further research is needed to better understand this.

The British Gynaecological Cancer Society recommended that clinicians and patients exercise caution when considering undergoing minimal access radical hysterectomy for the management of early-stage cervical cancer and that gynaecological oncologists and nurse specialists counsel patients regarding the potential risks and benefits of short term morbidity versus long term survival in surgery for early-stage cervical cancer, to enable women and their families to make a fully informed choice regarding the surgical options.

Jo’s Cervical Cancer Trust are aware of surgeon’s who have taken the decision to no longer offer minimal access surgery as a result of the increasing evidence worldwide around improved outcomes through open surgery.

The charity also feels it is unreasonable to expect patients to be able to make such a difficult decision about their treatment. The guidance currently relies entirely on the ability of clinicians to fully communicate risks and benefits without any bias and without access to robust research and data outcomes. This will make an already incredibly difficult time for women far more stressful.

Key messages

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

1. Should all minimal access surgery be stopped until there is greater clarity?
2. More research is urgently needed to understand the NCRAS data better
3. It seems unreasonable to expect patients to make such a difficult choice between the surgery types
4. How will hospitals address the issue of not providing access to alternate surgeries which places additional pressure on patients to have the minimal access surgery offered?

Thank you for your time.

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