

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## **Interventional procedures**

### **Patient Organisation Submission**

#### **Hysteroscopic morcellation of uterine fibroids (IP1056/3)**

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:

1. the experience of having the condition or caring for someone with the condition
2. the experience of having the procedure or operation
3. 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)
4. 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.)
5. 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	Sarcoma 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?)	<p>Sarcoma UK is a national charity that funds vital research, offers support for anyone affected by sarcoma cancer and campaigns for better treatments. It is the only cancer charity in the UK focusing on all types of sarcoma. It funds research into sarcoma, information and support for anyone affected by sarcoma, and campaigns for access to effective sarcoma treatments.</p> <p>It is entirely by voluntary giving.</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>We have worked across a number of years to improve awareness of the risks of morcellation, and the potential of uterine sarcomas being missed and made worse as a result of this procedure. Throughout this time, we have worked with patients to collect information on the outcomes of this procedure.</p> <p>The Sarcoma UK Support line has spoken to over 5000 individuals with, or carers of sarcoma, it gives us a unique understanding of living with the condition. Users of our Support Line are split 50% patients and 50% carers; this gives us a balanced view of sarcoma which affects all ages and demographics.</p>	
Living with the condition	
<p>6. What is it like to live with the condition or what do carers experience when caring for someone with the condition?</p> <p>██████████, whose mother had morcellation for suspected fibroids, said that:</p>	

“Because fibroids are common and sarcoma is rare, doctors are encouraging women to have minimally invasive hysterectomies. The doctors tend to tell you all the pros of having a minimally invasive surgery. They tend to tell you 'quicker recovery, no scar, you'll be out of hospital the next day, less risk of infection...'. So this all sounded wonderful to us. You know if this is only a fibroid, and this is gonna benefit Mum's recovery, well it's easier just to have it removed minimally invasively. But what we didn't know at the time is that, no one explained to us, that because Mum's fibroid was quite large to get it out vaginally, it would have to be cut up. We didn't realize that at the time so, Mum had her vaginal hysterectomy in March and it was a few weeks later that we received the news that it wasn't only a fibroid, that it was actually a sarcoma cancer... It was only then a few months later when Mum went back for a follow-up appointment and had a re-scan just before her 59th birthday that the scan showed that Mum now had multiple tumours all over, all over her abdomen.”

#### Advantages of the procedure or operation

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

There are no advantages for those with undiagnosed uterine sarcomas.

#### Disadvantages of the procedure or operation

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

Sometimes the uterine tissue or fibroid can unexpectedly contain a uterine cancer. If undetected, the morcellation process could cause the cancer to spread and worsen the chances of survival.

#### 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.

The risk of unexpected uterine sarcoma in fibroids is significantly greater for women over 50 especially if they have red flag symptoms such as being post-menopausal, going through menopause or experiencing post-menopausal bleeding. Ethnicity, a family history of certain cancers, the use of certain drugs can all influence the likelihood of uterine sarcoma.

The risk of unexpected uterine sarcoma in fibroids depends on your age and is higher around the time of and after your menopause. Various studies have quoted this risk as ranging from:

- 1 in 65 to 1 in 278 (if you are over 60 years of age)
- 1 in 158 to 1 in 303 (if you are between 50 and 59)
- 1 in 304 to 1 in 1250 (if you are younger than 50).

Equality
<p>10. Are there any potential equality issues that should be taken into account when considering this topic?</p> <p>Fibroids are more common in black women and the chances of uterine sarcoma may also be higher</p>
Other issues
<p>11. Are there any other issues that you would like the Committee to consider?</p> <p>We do not oppose morcellation as a practice. We simply are in favour of informed consent for women, so that they are aware of the potential implications of this treatment.</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"><li>1. Sometimes the uterine tissue or fibroid can unexpectedly contain a uterine cancer. If undetected, the morcellation process could cause the cancer to spread and worsen the chances of survival.</li><li>2. Women have not previously been given adequate information on the risks of this process.</li><li>3. The interventional procedure guide should include more information on the potential risks, and how this could be prevented.</li><li>4.</li><li>5.</li></ol>

Thank you for your time.

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