

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission

Ultra-radical (extensive) surgery for advanced ovarian cancer IP964/2

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, 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	████████████████████
2. Name of organisation	Ovarian Cancer Action
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>Ovarian Cancer Action is the UK's ovarian cancer research charity.</p> <p>Ovarian Cancer Action funds research into early detection and better treatments, raises awareness of risk and symptoms to improve prevention and early diagnosis, and gives a voice to all those affected by ovarian cancer. Since 2006, Ovarian Cancer Action has funded over £12 million in research projects and launched the first ever dedicated centre of ovarian cancer research in Europe. Their research is focussed on early detection and treatment of ovarian cancer to transform how long and how well women live after an ovarian cancer diagnosis.</p> <p>The charity raises funds through a variety of sources, the majority through individual public giving, philanthropic donations and charitable trusts and foundations. A small % is raised from gifts from corporate organisations including pharmaceuticals.</p> <p>It is not a membership organisation.</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>Discussions with Healthcare Professionals and Patients over seven years working for Ovarian Cancer Action. Published and unpublished research. Conferences.</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?

A diagnosis of ovarian cancer can be devastating, significantly affecting the quality of life of patients.

Women not only suffer from the consequences of the disease but also have to live with the long-term impact of its treatment and the uncertainty of whether the disease will return. Most women diagnosed with ovarian cancer are diagnosed at stage 3 or 4, and so the majority of women diagnosed with ovarian cancer have a poor prognosis. This has a significant impact emotionally with patients experiencing high levels of fear and anxiety. Even after a seemingly successful course of treatment there is still fear and anxiety due to the possibility of a recurrence, as recurrence rates for ovarian cancer are around 70%. This creates a sense of uncertainty about the future and this is difficult for many women to live with. This fear and anxiety is not just experienced by patients but family and friends too.

In addition to the emotional impact of ovarian cancer, patients experience a number of physical symptoms that result from the disease itself (ascites, bloating, abdominal pain) and side effects from its treatment.

During surgery the ovaries, which are the origin of the disease, have to be surgically removed. For younger women this then inevitably results in premature menopause, with its resulting effects. Chemotherapy causes a number of short and long term effects that impact quality of life.

For an ovarian cancer patient, their condition affects every aspect of their life – their relationships, work, family life and social life. And, in many cases there can be additional challenges due to stigma, cultural insensitivity, a feeling of isolation and in some cases unaddressed psychosexual issues. Furthermore, family members and carers are also impacted by all of these issues.

Many of our patient group members have experienced a recurrence and this is a very difficult time for them. Some patients experience severe side effects with chemotherapy with one carer stating:

“I was witness to the heavy side effects. The side effects were even worse the second time around”.

From one of our supporters: *“To live with OC is like learning to ride a bike through a bog of mud. It is a journey that you don’t want to have to make - or push upon those you love. But there is little choice in the matter and one way or another you find the path that works for you. For me personally after the initial diagnosis and first lot of treatment I thought there is just no way I can do that again. Chemotherapy is so tough. You have the trauma of knowing it is most likely coming back.”*

The husband of a lady who sadly died from the disease in 2017 said: *“Life for both the patient and carer becomes totally consumed by the disease – when the next hospital appointment will be, managing side effects, organising childcare, sleepless nights – it is a vicious circle that never seems to end.”*

A patient who first developed ovarian cancer at the age of 37 and is currently being treated for platinum resistant recurrence said *“When you have ovarian cancer you are not yourself - life revolves around the disease and in the very worst moments you have no interest in your family, friends and general life outside of the disease and what it is putting your body and mind through.”*

A patient who has been having treatment over the course of the last seven years said *“Quality of life is poor – reasonable at best when on treatment. There is a desire to cram as much into life as possible due to not knowing what is going to happen next but being bound by the horrific side effects such as complete exhaustion, severe pain, nausea and vomiting and mouth ulcers from the chemotherapy that make it almost impossible to eat.”*

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?

Many patients actively seek out the procedure ie ultraradical surgery for advanced ovarian cancer, in an effort to achieve the best chance of surviving the disease. This can be measured by the large number of patients who request a second opinion for their treatment options at Hammersmith Hospital, Imperial College London – one of the leading Centres in the UK performing ultra radical surgery.

These patients understand that the surgery is extensive, since their disease is equally extensive and any surgery to remove all lesions needs to address all affected sites in their tummy. As any big surgery, it carries potential associated risks and the patients need to know in advance which those are, and discuss them in extent with their doctors. However, as also research has shown, for most patients, the greater chance of surviving their disease is prioritised over the risk of the potential side effects like readmission, reoperation or even risk of a stoma which is comparatively low in these operations despite the very high rate of bowel resections at surgery.

The procedure is well established as standard of care in the USA and Europe. In the UK increasingly more centres perform it; the main limitations for its broad implementation are theatre space, ward and intensive care availability, long waiting lists/ overload and poor surgical training.

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?

Improved outcomes

It has huge potential to improve patient outcomes. Currently the best survival rates in the UK are at the Hammersmith Hospital, Imperial College London – the leading Centre in the UK for ultra-radical surgery.

The single biggest prognostic factor linked with improved survival is the amount of residual disease left after surgery. No macroscopic residual disease is only achievable using ultra radical surgery.

Multiple research studies have found that the ultra radical surgical approach improves both progression free survival and overall survival. That way, patients will need less treatment for recurrent disease, can return back to their work and normal lives and achieve overall longer survival. One study comparing surgical approaches in Finland showed an overall survival benefit of 24 months.¹

Reduce the risk of recurrence

A recently published cohort study showed that ultra radical surgery was significantly associated with lower probability of recurrence.² Recurrent disease affects around to 85% of all patients, and lowering the probability of recurrence would have huge advantages – both for patients (significant reduction in anxiety and QOL issues, fewer hospital visits, less need for additional rounds of treatment) and for major cost saving for the NHS.

Disadvantages of the procedure or operation

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

Ultra radical surgery can lead to long term side effects – e.g 10% of women will need a stoma after surgery. It is vital that patients fully understand the possible risks for undertaking the surgery. While it is never easy to live with these huge life changes, most patients we speak to are more grateful to be alive and learn to adjust. They have no regrets about the choice they made.

“During the operation, my doctor discovered that the cancer had also spread through part of my bowel. I woke up having been fitted with a stoma bag, which I was told was irreversible.

Recovery from the operation was tough, lying in the hospital bed trying to process the fact I would never have children, I had cancer and I now had a stoma bag. These were all hard pills to swallow, especially as I was too weak to get up, even sometimes to talk. I spent the first few days staring at the wall unable to speak. I soon found my strength however and made great progress in hospital and was able to go home.

I received my all-clear a month ago and whilst I still remain on a preventative treatment, I feel pretty much back to my (new) normal self. I will always carry the pain of not being able to have children and the embarrassment of a stoma bag, but that pain will be less intense as time goes on. I am so grateful to every nurse and doctor that has helped me on this journey and allowed me to still be here today.

I now look back on the six months and feel such a sense of achievement as opposed to sadness, and yes I am still completely petrified and weighed down with the worry that it could come back, but at least I now know that I can do it.” – A 23yr old patient diagnosed with ovarian cancer.

“Learning to live with a stoma is a steep learning curve, but I'm getting there! In fact I even bling it on the odd occasion, may as well own it (I even have a dedicated Instagram account for it).” Patient who underwent surgery.

¹ <https://www.sciencedirect.com/science/article/pii/S0090825822002050>

² <https://assets.researchsquare.com/files/rs-1329637/v1/ebe03c7c-6a54-4705-b08d-f090cd0f93d3.pdf?c=1648801806>

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>There is a fragile balance between the survival benefit of ultra radical surgery and its life changing side effects. Adequate patient selection and allocation of the right patient to the optimal treatment pathway is vital for overall success.</p> <p>Survival benefit has been shown to be more significant in patients diagnosed at FIGO Stage 3 than Stage 4. Patients who are fit and healthy are likely to have less side effects than those who have more co-morbidities or are frail. Some of these patients will simply not be well enough to undergo a major surgery which has been likened to the same physical effects of running a marathon.</p>
Safety and efficacy
<p>11. What are the uncertainties about how well this procedure works and how safe it is?</p> <p>None it is well established as standard of care in many other countries.</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

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

All patients who could benefit from this operation should have access to it. At the moment a very small number of patients receive the surgery. There is an enormous post-code lottery. A small number of expert Centres should be designated across the UK and all eligible patients from surrounding areas should be offered the opportunity to benefit from this surgery. Smaller numbers of expert Centres will mean there is sufficient volume of patients to ensure surgeons are truly specialist. ESGO Quality Indicators prioritise the Number of Cytoreductive Surgeries Per Center and Per Surgeon Per Year as an important prognostic factor.

Ultra radical surgery requires specialist centres with specialist expertise. It is not just specialist surgeons with adequate training, but the whole clinical team and infrastructure (i.e ICU bed availability) that supports the optimum environment for this procedure.

Currently UK gynae-oncology surgical training is inadequate to train the next generation of ovarian cancer surgeons to perform this surgery. Training must be overhauled to include sufficient upper abdominal surgery experience.

Key messages

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

1. Ultra-radical surgery has a significant survival benefit for women with ovarian cancer.
2. It is well established as standard of care in the USA and Europe but currently less widespread across the UK. Currently a comparatively small number of Centres in the UK perform this surgery.
3. It requires specialist centres with specialist expertise. It is not just specialist surgeons but the whole clinical team and infrastructure (i.e ICU bed availability) that supports the optimum environment for this procedure.
4. Currently UK training is inadequate to train the next generation of ovarian cancer surgeons to perform this surgery.
5. Despite the extent of the surgery and potential side effects, patients want access to this surgery and levels of second opinions seeking it out are high.

Committee meeting

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

Yes.

Thank you for your time.

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