NICE National Institute for Health and Care Excellence

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	[redacted]
2. Name of organisation	Ovacome ovarian cancer charity
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?)	Ovacome is the national UK ovarian cancer charity focused on providing support and information to anyone affected by ovarian cancer. This includes people who have either been diagnosed with the disease or think that they might be at risk, as well as their friends and family and healthcare professionals. We currently have over 4,000 members and each year we support around 18,000 people. We have 12 full time members of staff and 5 part-time members of staff. We are funded through charitable donations, trusts and foundations donations, community fundraising and donations.

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.)

Knowledge and experience from 26 years providing support to those affected by ovarian cancer. Feedback from members collected through My Ovacome online forum.

Living with the condition

Ovarian cancer has a significant impact on quality of life. The majority are diagnosed at Stage III when it has already spread outside of the pelvis. This means they can experience symptoms impacting their health and quality of life, such as ascites. Treatment is therefore aimed at minimising the burden of the disease and maximising periods of wellness between treatments. As treatment lines are exhausted, those diagnosed fear being told there is no more treatment available to manage their ovarian cancer.

The surgery undertaken is most usually a total abdominal hysterectomy and bilateral salpingo-oophorectomy. This operation can have long term effects on

abdominal organs and particularly the bowel with associated continence issues. This may mean having manage a stoma, either short or long term. It will result in immediate surgical menopause. Associated issues include fatigue and changes to body image and function affecting sexuality. Despite these long-term side effects our members report being very motivated to undergo surgery both at initial diagnosis and at recurrence. They are aware that surgery resulting in no residual macroscopic disease is associated with better prognosis.

Those diagnosed live with the anxiety of possible recurrence. This anxiety is not only felt by the patient, but by their family and carers also. The time after treatment whereby patients are under routine surveillance can be psychologically very hard to cope with. They are concerned that treatment options are limited and lines of treatment to control the disease will be exhausted leaving palliative symptom control only. The DESKTOP III trial demonstrated that for recurrent ovarian cancer, cytoreductive surgery followed by chemotherapy resulted in longer overall survival than chemotherapy alone, offering a further hopeful treatment modality for those suitable for surgery, with recurrent ovarian cancer.

For both those living with ovarian cancer and their carers, ovarian cancer can be very isolating, due to its comparative rarity they may not meet anyone else with the same condition or facing the same issues of managing their cancer as a chronic condition rather than aiming for a cure.

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 be to be innovative? One of our members treated in 2013 attributes her continued survival to the surgery. She explains: “My CA125 had gone up to 110 and a scan showed two tumours. The oncologist recommended further chemotherapy and radiotherapy and stated that surgery was very inadvisable. I felt in a deep dilemma because the cancer was still in distinct tumours. I had no symptoms, and I would probably never again be in such a good position to consider more surgery. If my timid streak had taken charge I would have backed off and I wouldn’t be alive now. I knew I had one chance, one window of opportunity and I had to take it. My GP supported me and referred me to a different cancer centre for a second opinion. There the consultant said that secondary surgery might be possible – and it was in my best interests to try. My family was very supportive, but they thought the surgery was a great risk and that if I opted for more chemotherapy then at least we would all have a few more months together. But it was my risk to take – and the surgery was successful.” She experienced no post-operative complications. Another member confirms: “I had radical surgery in 2017 and am doing well still.” Another member was treated in 2020: “The surgeon clearly explained what he was going to do, I understood the potential outcomes and the risks. He was outstanding […] I got access to a specialist oncological surgeon, this was massive surgery and I would not have wanted anyone other than a specialist. I trusted him […] The anaesthetist went through her role with me. I was given pain relief into my back as well as a morphine driver. I don't recall any pain. I received excellent nursing in HDU.” 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? Surgery resulting in no residual macroscopic disease is associated with better prognosis. The DESKTOP III trial demonstrated that for recurrent ovarian cancer, cytoreductive surgery followed by chemotherapy resulted in longer overall survival than chemotherapy alone.
Disadvantages of the procedure or operation

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

It is important that the procedure, risks and complications and follow up are clearly explained to patients as part of the decision-making process, as uncertainty can impact the patient and carer's mental health.

One of our members explains: “if specialist surgeons are coming from a different hospital there should be enough time for the patients and if that is not possible perhaps it should be that all patients can access a specialist hospital for radical debulking […] I think post operative physio should be a given including after you have left hospital, some follow up - again I don't know if covid may have interrupted normal processes […]I did not get a follow up consultation with my surgeon, but in fairness this was because of Covid. So I have never had my surgery fully explained to me. It was explained to me in the days afterwards but I was not well enough to take it in […] I have never received a follow-up re splenectomy, don't know if this is normal or not […] I think the move from HDU to a single room in a general ward was quite a change. I think I was only just well enough to move and probably could have done with more nursing support than was available for a further few days.”

Patient population
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.
Safety and efficacy
11. What are the uncertainties about how well this procedure works and how safe it is?
Equality
10. Are there any potential equality issues that should be taken into account when considering this topic? It's imperative that all patients have equal access to this surgical option where clinically appropriate, and that includes detailed understanding of risk-benefits. For those with English as a second language, or learning disabilities, it's essential that risk:benefit conversations take place in an appropriate and accessible manner.
Other issues
11. Are there any other issues that you would like the Committee to consider? In order to improve survival rates of ovarian cancer, Ovacome believe in improving and equalising access to treatments. Patients should have the opportunity to understand the options and make decisions with their clinicians based on risks:benefit, and that includes access to ultra-radical surgery where appropriate.
Key messages

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12. In no more than 5 bullet points, please summarise the key messages of your submission. 1. Ovarian cancer is frequently managed as a chronic condition rather than curative and therefore expanding treatment options for this group of patients is vital. 2. Surgery resulting in no residual macroscopic disease is associated with better prognosis for those diagnosed with advanced ovarian cancer. 3. If risks and benefits are explained clearly, patients feel confident to make decisions regarding their surgery. 4. Our members report positive views of surgical treatment, including ultra-radical procedures, and are keen to have this option available.
Committee meeting
13. Would you be willing to attend the interventional procedures committee meeting to provide the view from your organisation in person? Yes, either myself or another staff member could attend.

Thank you for your time.

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