

## Summary of key points

Please summarise the key points of your submission which you would like to emphasise to SMC Committee – bullet points may be helpful.

(See P11 of *A Guide for Patient Group Partners*)

300 words maximum

- Quality of life impact: the threat of recurrent disease looms large over the lives of women with ovarian cancer, the emotional, practical and physical implications for women and their family are significant. This makes it hard for women to plan events and activities that would have a positive impact on their quality of life.
- Limitations of current treatment: platinum-based chemotherapy is the primary treatment for recurrent platinum-sensitive ovarian cancer. However, the risk of developing platinum resistance is high. Treatment for platinum-resistant disease is extremely limited.
- Benefits of new treatment: rucaparib has the potential to extend the time between chemotherapy treatments and therefore potentially prolong the use of platinum-based chemotherapy. This gives women and their families more opportunity to focus on emotional and physical recovery.
- Mode of delivery: rucaparib is given in tablet form allowing women to easily continue treatment in their own home and greatly reducing hospital visits. It also reduces the need for women to live their life around their hospital appointments and treatment.

Please provide details of any individuals who have had a significant role in preparing your submission and who have an interest to declare.

(See P11 of *A Guide for Patient Group Partners*)

300 words maximum

Please tell us how you gathered information about the experiences of patients and carers to help inform your submission.

(See P11 of *A Guide for Patient Group Partners*)

300 words maximum

Target Ovarian Cancer Pathfinder study 2016 and Pathfinder Scotland.

Anecdotal feedback from patients and their families.

Patient survey on access to cancer drugs.

Calls to the Target Ovarian Cancer support line

## 1. How does this condition affect the day-to-day lives of people living with it?

(See P11 of *A Guide for Patient Group Partners*)

500 words maximum

Nearly two thirds of women living in Scotland are diagnosed once their cancer has spread beyond the ovary, making curative treatment challenging. Survival rates for ovarian cancer trail those for other cancers and 350 women die of the disease in Scotland every year. Women with advanced disease are more likely to face a future of recurrent ovarian cancer requiring multiple rounds of treatment to manage their disease.

The prospect of recurrence casts a shadow over the lives of many; 46 per cent of women in Scotland said they needed support coping with the fear of recurrence. Fears around recurrence are compounded by the knowledge that there are pitifully few treatment options for ovarian cancer and in particular recurrent disease.

"I feel now and when I was going through my treatment that ovarian cancer is the poor relation of woman's cancers. No screening programme, reduction in research funding, with a high recurrence. Having ovarian cancer doesn't fill you with high hopes by the time you are diagnosed." Woman with ovarian cancer.

An ovarian cancer diagnosis can have a negative impact on many aspects of an individual's life. Perhaps most notably in the first instance are the practical implications of debilitating treatments rendering individuals unable to work or continue as the primary carer for partners, children and elderly relatives.

As well as the practical impact of an ovarian cancer diagnosis there are physical and mental wellbeing challenges in relation to body image and feelings relating to sexuality. While the majority (85 per cent) of women living in Scotland said they had experienced mental ill health since being diagnosed with ovarian cancer, just 42 per cent of women with ovarian cancer said anyone involved in their treatment had discussed their mental wellbeing. More than half of women with ovarian cancer said they had experienced a loss of self-esteem, 75 per cent reported difficulties with intimacy and 89 per cent reported a lower sex drive

## 2. How well do medicines which are currently available in NHSScotland help patients manage this condition? (See P12 of *A Guide for Patient Group Partners*)

500 words maximum

Treatment for women diagnosed with ovarian cancer currently involves chemotherapy and surgery. In recent years, bevacizumab (Avastin®) has been made available for women with advanced disease and sub-optimal debulking.

Treatment is offered with the intent to cure, however the risk of women diagnosed with advanced disease developing a recurrence is high. Once ovarian cancer has recurred, curative treatment is no longer an option and women face a future of repeat recurrence and treatment.

Platinum-based chemotherapy is effective in reducing tumour load and improving the efficacy of debulking surgery, and helping alleviate the impact of ovarian cancer symptoms. However, platinum-based chemotherapy will cause some side effects which women find difficult to manage, including tiredness and fatigue, hair loss, nausea and vomiting, and tingling and numbness in the fingers and toes.

In order to maximise the benefits of platinum-based chemotherapy it is crucial to increase the time intervals between chemotherapy cycles, this works to reduce the risk of the ovarian cancer developing platinum-resistance, the accumulation of toxicity and the individual developing an allergic reaction. If sensitivity to platinum chemotherapy is maintained women can expect to be effectively treated with this regimen for multiple recurrences, however, most women will eventually become platinum-resistant. Maintaining platinum chemotherapy efficacy is crucial as there are few treatment options available for platinum-resistant disease.

PARP maintenance treatments following treatment for recurrence available in NHSScotland for women with platinum-sensitive disease include olaparib for women with a BRCA mutation (germline or somatic), and niraparib who do not have a BRCA mutation. Maintenance treatments such as rucaparib have been shown to extend the time between recurrence, and the interval between chemotherapy cycles for active disease. Extending this interval is important in potentially maintaining the sensitivity to platinum based chemotherapy and reducing the build up of chemotherapy associated toxicity.

"This is a complex disease, many options are needed." Woman with ovarian cancer

"Right now if the drug helped me to spend more quality time with my family then I would trial it." Woman with ovarian cancer

"Particularly after chemotherapy, there is a very limited range of drug treatments available. Whether a patient receives anything at all can currently depend on the availability of trials. This can be the case even where there is good reason to believe that the relevant treatment might be highly beneficial and extend life significantly were it available." Relative or friend of a woman living with ovarian cancer.



3. Have you been able to consult with patients who have used this medicine?

(See P12 of *A Guide for Patient Group Partners*)

Yes

No

4. Would this medicine be expected to improve the patient's quality of life and experience of care, and if so, how?

(See P12 of *A Guide for Patient Group Partners*)

500 words maximum

Rucaparib has the potential to extend the interval between chemotherapy treatment for recurrent disease. The drug is given as tablets that the patient can take at home without the need for hospital visits. Reducing visits to the hospital reduces the financial burden on the patient in terms of travel time to the hospital and family and carers potentially taking unpaid leave from work to attend appointments.

For women with ovarian cancer extending the time period between recurrences is significant. Living under the shadow of ovarian cancer, and not knowing when the disease will recur can be emotionally draining and debilitating, preventing women from making a full emotional recovery and resuming their day-to-day life. Prolonging the interval between treatment gives women greater opportunity to focus on their physical and emotional recovery. It allows women greater freedom to make plans that have a positive impact on their emotional wellbeing, for example they might plan a holiday or be well enough to enjoy a family event such as a child's wedding or the birth of a grandchild. Having greater freedom to make plans and enjoy a greater sense of normality has a significant positive impact on a woman's quality of life.

5. What kind of impact would treating a patient with this medicine have on the patient's family or carers? (See P13 of *A Guide for Patient Group Partners*)

500 words maximum

An ovarian cancer diagnosis has a huge impact on all the family. The shock and disbelief is keenly felt by family and carers. Bearing witness to their loved one suffer repeated cycles of gruelling treatment is extremely stressful. As well as the emotional impact family members and carers often take the practical strain of an ovarian cancer diagnosis, taking on greater caring responsibilities and running the household.

Treatment for ovarian cancer will usually require women to give up work, putting many families under huge financial strain.

Increasing the interval between chemotherapy treatment is beneficial for family members and carers, helping them regain a sense of normality, make plans with their loved one and create memories together. It gives them a much needed breather, to take control of their emotions and prepare for the further rounds of treatment ahead.

6. Are there any disadvantages of the new medicine compared to current standard treatments? (See P13 of *A Guide for Patient Group Partners*)

500 words maximum

Research has shown that rucaparib can cause side-effects which may have an impact on individuals taking the medicine. The extent to which this impact might be felt cannot be predicted in advance, however, there are a range of approaches that a woman can discuss with her clinical team to reduce the impact of the side-effects while continuing to benefit from the treatment. Quality of life studies have demonstrated that in most cases the advantages of receiving rucaparib as a maintenance treatment outweighs the possible side-effects caused.

The side effects experienced by each individual and the extent to which they are experienced will be unknown until treatment commences. In many cases the impact of rucaparib will be observed by the clinician through blood test results but may not have a discernible physical impact upon the individual. In most cases side-effects can be managed by adjusting the dose of rucaparib or with other drugs.

7. Is there any additional information you think may be useful for the SMC committee to consider? (Optional)

500 words maximum