

**Patient organisation submission**

**Niraparib as maintenance treatment of recurrent, platinum-sensitive ovarian, fallopian tube and peritoneal cancer that has responded to platinum-based chemotherapy [ID1041]**

<b>Living with the condition</b>	
<p>What is it like to live with the condition? What do carers experience when caring for someone with the condition?</p>	<p><b>Patient:</b> Ovarian cancer is often diagnosed unexpectedly, following a convoluted and protracted pathway to diagnosis or after an emergency admission. 45 per cent of women are waiting over three months from first visiting their GP to receiving a diagnosis.<sup>1</sup></p> <p>Nearly two thirds of women are diagnosed once the cancer has spread beyond the ovary, making curative treatment challenging.<sup>2</sup> 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; over 50 per cent of women with ovarian cancer said they needed support coping with the fear of recurrence.<sup>3</sup> Fears around recurrence are compounded by the knowledge that there are pitifully few treatment options for ovarian cancer and in particular recurrent disease – current clinical guidelines stop after diagnosis and first line treatment.<sup>4</sup></p> <p>An ovarian cancer diagnosis can have a negative impact on many aspects of an individual’s life, from their physical and mental wellbeing to their body image and feelings relating to sexuality. While the majority (80 per cent) of women with ovarian cancer said they had experienced mental ill health since being diagnosed with ovarian cancer, just 36 per cent of women with ovarian cancer said anyone involved in their treatment had discussed their mental wellbeing. Over two thirds of women with ovarian cancer said they had experienced a loss of self-esteem, 73 per cent reported difficulties with intimacy and 84 per cent reported a lower sex drive.<sup>5</sup></p> <p>Mutation in the BRCA1 or BRCA2 gene is a significant risk factor for ovarian cancer, accounting for around 13 per cent of all cases of ovarian cancer. Women are often unaware of their genetic status until after their diagnosis. This</p>

	<p>newfound knowledge and the awareness that members of their immediate family may have inherited the mutated BRCA gene, increasing their personal risk of developing ovarian and other cancers, is an unexpected and unwelcome burden. It is therefore important that as genetic testing is rolled out, as per the new Clinical Commissioning Policy, that women are offered the appropriate support and counselling through genetic services.<sup>6</sup></p> <p><b>Carers:</b> Women are at the epicentre of an ovarian cancer diagnosis, but the shockwaves are keenly felt among the wider family members and carers. Devastation, shock, disbelief, fear and anger are commonly experienced emotions. Sadly, the emotional impact is often overlooked, just 28 per cent of immediate family members report that a health professional had spoken to them on their own about how they were feeling.<sup>7</sup> Family and carers often neglect their emotional wellbeing focusing on the needs of their loved one.</p> <p>The practical implications of an ovarian cancer diagnosis on family and carers are often significant. Keen to support their loved one 40 per cent of immediate family take time off work to attend hospital appointments. Family members are likely to step into new roles and responsibilities within the family unit; 15 per cent report taking on greater care responsibilities for other family members and 26 per cent taking over running the house.<sup>8</sup> This changing family dynamic can put great stress on the whole family and individuals often feel under great pressure to maintain normalcy.</p>
<p><b>Current treatment of the condition in the NHS</b></p>	
<p>What do patients or carers think of current treatments and care available on the NHS?</p>	<p>Patients and carers are concerned about the limited number of treatments available on the NHS, especially for women diagnosed with recurrent ovarian cancer.</p> <p>Target Ovarian Cancer regularly receives emails and phone calls from women and their carers wishing to discuss treatment options available. They may seek impartial advice regarding current treatment options or participating in a clinical trial. Or they may have questions regarding the different channels for accessing the latest treatments.</p> <p><i>“The latest drugs offer hope and the chance that women with progressive disease can enjoy a better quality of life</i></p>

	<p><i>and longer survival. If new drugs are not made available, the current survival rates will continue to be dire in comparison with other cancers and this has to change. Women with ovarian cancer should be given the same right to life as those with other, more widely supported, cancers.”</i> Woman with ovarian cancer</p> <p>Many individuals are confused and frustrated by the different routes they may have to explore to potentially access a drug. They express concerns that drugs are not appraised quickly enough or not approved for use on the NHS.</p> <p><i>“Life is very precious and I do not want to die yet. If science can help beat cancer it makes sense to offer treatment and drugs to patients.”</i> Woman with ovarian cancer</p> <p>Women are keen to consider options that may extend their life or the interval between recurrences. 73 per cent of women with ovarian cancer said they felt it was important to take part in clinical trials so knowledge and treatment can advance. And 66 per cent of women with ovarian cancer wanting to take part in clinical trials were prepared to travel to another hospital to do so.<sup>9</sup></p>
<p>Is there an unmet need for patients with this condition?</p>	<p>For women with recurrent disease there are very few treatment options; Olaparib (Lynparza) is currently available to women with a BRCA mutation, but only for women who have had three or more previous courses of chemotherapy. Bevacizumab (Avastin) is only available for first line treatment. Other than these two cancer drugs, treatment for ovarian cancer has changed little over the past two decades.</p>
<p><b>Advantages of the technology</b></p>	
<p>What do patients or carers think are the advantages of the technology?</p>	<p><b>Choice</b> – niraparib gives clinicians and women another option for extending progression free survival (PFS). Many women welcome the opportunity to be involved in making decisions about their care and treatments they receive, and feel they are able to take some control at what is typically a very uncertain time.</p> <p><i>“Women with ovarian cancer usually have very little time to live. My mum would have liked six months to put her affairs in order and say goodbye to people. If a drug can do this, she should have been able to access it.”</i> Family member of a woman with ovarian cancer</p>

	<p><b>Best possible care</b> – often women are aware of the poor outcomes associated with ovarian cancer. By accepting niraparib as part of their treatment plan, they may feel they are giving themselves the best possible chance of prolonging the disease free interval.</p> <p><b>Physical wellbeing</b> - once a woman has recurrent ovarian cancer she will inevitably go through further treatment cycles for subsequent recurrences. Niraparib offers women the opportunity to extend their PFS and therefore the interval between chemotherapy, this benefit is likely for many to outweigh the possible side effects associated with niraparib. A longer PFS may be beneficial in terms of supporting a better physical recovery from chemotherapy, enabling the individual to successfully undergo subsequent treatment. It is thought that prolonging the interval between treatments is likely to make subsequent treatment more effective.</p> <p><b>Emotional/mental health</b> – once a woman has been diagnosed with recurrent ovarian cancer, further recurrence will be expected as the cancer runs its course. For many, receiving the news that their cancer has returned can be more devastating than the initial ovarian cancer diagnosis. Improvement in PFS offered by niraparib will allow give women valuable time to recover from the mental impact of recurrence and treatment, allowing them to resume normality, and live their lives as fully as possible.</p> <p><b>Mode of delivery</b> – niraparib is administered orally which is well tolerated.</p>
<p><b>Disadvantages of the technology</b></p>	
<p>What do patients or carers think are the disadvantages of the technology?</p>	<p><b>Side effects</b> – Side effects are associated with niraparib, some women will find these more difficult to tolerate, depending upon the side-effect and its severity.</p>

**Patient population**

Are there any groups of patients who might benefit more or less from the technology than others? If so, please describe them and explain why.

While women with a BRCA mutation are likely to see the greatest clinical benefit from niraparib, women who do not have a BRCA mutation currently face limited treatment options following first line treatment and it will offer a new treatment pathway for this group.

**Key messages**

In up to 5 bullet points, please summarise the key messages of your submission:

- Women diagnosed with advanced ovarian cancer are likely to experience multiple recurrences.
- Niraparib offers women with a BRCA mutation the opportunity to access maintenance therapy at an earlier stage than is offered with current PARP maintenance therapies.
- Extending PFS is beneficial in supporting a woman’s physical and emotional recovery between chemotherapy treatment.
- Extending PFS gives women and their families an opportunity to live life relatively normally for an extended period of time between chemotherapy treatments.

<sup>1</sup> Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: [www.targetovariancancer.org.uk/pathfinder](http://www.targetovariancancer.org.uk/pathfinder) [Accessed 5 September 2017]

<sup>2</sup> National Cancer Registration and Analysis Service (2016) Stage breakdown by CCG 2014. Available at: [www.ncin.org.uk/view?rid=3006](http://www.ncin.org.uk/view?rid=3006) [Accessed 9 September 2016]

<sup>3</sup> Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: [www.targetovariancancer.org.uk/pathfinder](http://www.targetovariancancer.org.uk/pathfinder) [Accessed 5 September 2017]

<sup>4</sup> National Institute for Health and Care Excellence (2011) Ovarian cancer: recognition and initial management of ovarian cancer. Clinical guidelines 122. Available at: [www.nice.org.uk/guidance/cg122/resources/ovarian-cancer-recognition-and-initial-management-35109446543557](http://www.nice.org.uk/guidance/cg122/resources/ovarian-cancer-recognition-and-initial-management-35109446543557) [Accessed 1 September 2017]

<sup>5</sup> Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: [www.targetovariancancer.org.uk/pathfinder](http://www.targetovariancancer.org.uk/pathfinder) [Accessed 5 September 2017]

Patient organisation submission

**Niraparib as maintenance treatment of recurrent, platinum-sensitive ovarian, fallopian tube and peritoneal cancer that has responded to platinum-based chemotherapy [ID1041]**

- <sup>6</sup> NHS England (201) Clinical commissioning policy: genetic testing for BRCA1 and BRCA2 mutation. Available at: <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/10/e01pb-brca-ovarian-cancer-oct15.pdf> [Accessed 5 September 2017]
- <sup>7</sup> Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: [www.targetovariancancer.org.uk/pathfinder](http://www.targetovariancancer.org.uk/pathfinder) [Accessed 5 September 2017]
- <sup>8</sup> Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: [www.targetovariancancer.org.uk/pathfinder](http://www.targetovariancancer.org.uk/pathfinder) [Accessed 5 September 2017]
- <sup>9</sup> Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: [www.targetovariancancer.org.uk/pathfinder](http://www.targetovariancancer.org.uk/pathfinder) [Accessed 5 September 2017]