

Target Ovarian Cancer: NHS long term plan submission

Target Ovarian Cancer is the national ovarian cancer charity working to save lives and help women diagnosed live their lives to the full, wherever they are in the UK. We do this by improving early diagnosis, finding new treatments and providing support for women.

Introduction

Over 7,000 women are diagnosed with ovarian cancer across the UK each year¹ and UK survival rates are among the lowest in Europe with fewer than half of all women diagnosed with ovarian cancer surviving for five years or longer.^{2, 3}

There are important steps that should be taken in the NHS long term plan to ensure that women with ovarian cancer receive world-class care and treatment. To inform our submission Target Ovarian Cancer has consulted with women with ovarian cancer and their friends and family. Our priorities are based on what they told us.

1. What are your top three priorities for improving cancer outcomes and care over the next five and ten years?

Early Diagnosis

'Investing in the treatment and detection of ovarian cancer to bring the survival rate of ovarian cancer in the UK to match world class standards' Target Ovarian Cancer supporter

'More specific training for doctors in recognising/diagnosing and supporting those with ovarian cancer' Target Ovarian Cancer supporter

The earlier a woman is diagnosed with ovarian cancer the greater her chances of surviving the disease. If diagnosed at the earliest stage (Stage I), 98 per cent of women with ovarian cancer survive one year or more. Of those women diagnosed when their cancer is at the most advanced stage (Stage IV) just 51 per cent survive one year or more.⁴

¹ Cancer Research UK website. Available at: www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer/incidence [Accessed 19 September 2018]

² De Angelis et al. (2014) Cancer survival in Europe 1999—2007 by country and age: results of EURO CARE-5—a population-based study. The Lancet Oncology (15)1:23-34. Available at: [www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(13\)70546-1/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70546-1/fulltext) [Accessed 19 September 2018]

³ Office for National Statistics (2017) Cancer Survival in England- Adults Diagnosed: 2011 to 2015, followed up to 2016. Available at: www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/adultstageatdiagnosisandchildhoodpatientsfollowedupto2016/relateddata [Accessed 30 March 2018]

⁴ Office for National Statistics (2016) Cancer survival by stage at diagnosis for England. Adults diagnosed 2012, 2013, 2014 and 2015 and followed up to 2016. Available at: www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/oneyearnetcancersurvivalforbladderbreastcolorectalkidneylungmelanomaovaryprostateanduterusbystageatdiagnosis/2012to2015/cancersurvivalbystage.xls [Accessed 19 September 2018]

A key way to improve early diagnosis is ensuring that women know the signs and symptoms of ovarian cancer. Target Ovarian Cancer's own research has found that only 20 per cent of women in the general public are aware of bloating, the symptom with the strongest positive predictive value, as a symptom of ovarian cancer. Awareness of the other main symptoms is also low, with just 20 per cent aware of tummy pain as a possible symptom, just three per cent of women recognise the symptom of feeling full and/or loss of appetite and two per cent increased urinary urgency and frequency. In addition one in three women also wrongly believe that cervical screening detects ovarian cancer.⁵

Actions:

Awareness raising activities for rare and less common cancers. There must be a national Be Clear on Cancer campaign which, whether focusing entirely on ovarian cancer or a cluster of cancers, includes the key symptoms of ovarian cancer.

The 28-day target offers huge potential in ensuring more women diagnosed earlier and achieving this for all cancers should be a central part of the long term plan. In order to achieve the target the current cancer pathway should be reviewed and shortened. In Scotland women with suspected ovarian cancer are referred for a CA125 blood test and an ultrasound at the same time, a far shorter pathway than England where an ultrasound can only be conducted after a CA125.

Women should be able to self-refer into Multi-Disciplinary Diagnostic Centres in cases of vague or unexplained symptoms as an additional safety-netting measure.

Timely data

Good quality data is vital in driving forward and improving early diagnosis and treatment. Huge strides have been made in terms of the breadth and quality of ovarian cancer data collected in recent years. This data must now be made available in a timely fashion to the public, clinicians and commissioners to help in ongoing work to drive up standards of care. We welcome the work of the Get Data Out team at the National Cancer Registration and Analysis Service (NCRAS) to improve public access to ovarian cancer data and look forward to seeing more data available in the near future.

Actions:

The cancer dashboard must include data on less common cancers such as ovarian cancer to ensure they remain as much as a focus for Clinical Commissioning groups and Cancer Alliances as more common cancers.

An audit of ovarian cancer would also go a long way to improving care; it would map diagnostic and treatment pathways across the country and enable ovarian cancer data to be used to drive up the quality of treatment.

⁵ Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: www.targetovariancancer.org.uk/pathfinder [Accessed 19 September 2018]

Universal access to world-class surgery

“Best practice sharing so that patients in local hospitals get treatment at the Christie and Marsden levels.” Target Ovarian Cancer supporter

At its best ovarian cancer treatment in the UK is world-leading, however not all women are able to access the best quality treatment. Ensuring all women with ovarian cancer are offered surgery in a specialist centre from a specialist surgeon would in one simple step lead to a significant improvement in ovarian cancer survival rates.

Research has shown that too many women with ovarian cancer are still not having their surgery carried out by specialist gynaecological oncologist in cancer centres.⁶ This is the despite the fact that overall survival is improved by 45 per cent for women treated at specialist centres.⁷

Actions:

All women with ovarian cancer to be offered surgery in specialist centres delivered by a gynaecological oncology surgeon operating on at least 16 women with ovarian cancer a year.

2. What more can be done to ensure that:

a. More cancers are prevented?

There are several genetic faults or mutations that are linked to ovarian cancer, the greatest significance is a mutation in the BRCA 1 or 2 gene with accounts for around 15 per cent of all cases of ovarian cancer.⁸ Awareness of the genetic risk is low among the general public with just 25 per cent of women aware that genetics might be a risk in developing ovarian cancer.⁹ We welcome the new guidance which means that nearly all women with ovarian cancer are now eligible for genetic testing.^{10,11}

However, the decision to be tested can be a difficult one and can have significant implications for women and their family members. It is vital that women are offered genetic counselling in advance of deciding whether to be tested so they can make an informed decision and feel prepared for the possible results. Currently just 61 per cent of women

⁶ Butler et al (2015) Specialist surgery for ovarian cancer in England, Gynecologic Oncology

⁷ Jayson et al (2016) Improved survival from ovarian cancer in patients treated in phase III trial active cancer centres in the UK, Clinical Oncology

⁸ Zhang et al (2011) Frequencies of BRCA1 and BRCA2 mutations among 1,342 unselected patients with invasive ovarian cancer, Gynecologic Oncology

⁹ Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: www.targetovariancancer.org.uk/pathfinder [Accessed 19 September 2018]

¹⁰ NHS England (2015) Clinical Commissioning Policy: Genetic Testing for BRCA1 and BRCA2 Mutations. Available at: <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/10/e01pb-brca-ovarian-cancer-oct15.pdf> [Accessed 19 September 2018]

¹¹ National Institute of Health and Care Excellence (2017) Familial breast cancer: classification, care and managing breast cancer and related risks in people with a family history of breast cancer. Available at: <https://www.nice.org.uk/guidance/cg164> [Accessed 19 September 2018]

report being offered counselling.¹² The need for more genetic counsellors should be considered in workforce planning to meet this demand and as genetic testing becomes more common place a continued focus on the human as well as the medical implications of testing.

b. More cancers are diagnosed early and quickly

'There are too many women who show symptoms but get tested for other illnesses first - delaying treatment' Target Ovarian Cancer supporter

As outlined above there is an urgent need for a public awareness campaign on the symptoms of ovarian cancer. However, symptoms awareness is only one component of improving early diagnosis.

Many women experience delays in diagnosis, with 45 per cent of women reporting it taking three months or longer to receive a diagnosis from first approaching their GP with symptoms.¹³ Ovarian cancer is not always detected by a CA125 blood test and ultrasound. GPs should therefore be made aware of the need for safety netting both to ensure that patients are referred for diagnostic testing in the first place and also in that no cancer is missed if initial tests are negative. This should include ensuring that women return if they are still having symptoms even if their tests are inconclusive.

Symptoms of ovarian cancer can sometimes be with vague or less specific. We welcome the establishment of multi-disciplinary diagnostic centres but they must be rolled out so that they are accessible to all women living in all parts of the country.

c. People can maintain a good quality of life during and after treatment and people with cancer have a good experience of care?

'Better information to support patient choices around treatment option' Target Ovarian Cancer supporter

'More support especially when treatment has finished' Target Ovarian Cancer supporter

Clinical Nurse Specialists (CNSs) can be a vital source of support to women with ovarian cancer, they act as the main contact point and oversee care as well as offering advice. The current level of access to CNSs is good with 93 per cent of women with ovarian cancer report being assigned a specialist nurse.¹⁴

However CNSs report being overstretched, just 46 per cent of CNSs feel their cancer centre has enough nurses to care for all the women being treated and only 48 per cent of CNSs

¹² Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: www.targetovariancancer.org.uk/pathfinder [Accessed 19 September 2018]

¹³ Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: www.targetovariancancer.org.uk/pathfinder [Accessed 19 September 2018]

¹⁴ Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: www.targetovariancancer.org.uk/pathfinder [Accessed 19 September 2018]

report being able to meet woman's broader needs such as mental wellbeing or issues like body image and sex and intimacy as mandated by NICE guidelines.^{15,16}

Women with ovarian cancer also report significant levels of unmet needs with just 12 percent of women reporting that anyone had talked to them about sex and intimacy, and only 24 per cent received support with early onset menopause brought about by their treatment.¹⁷

In order to ensure that women with ovarian cancer get the support they deserve CNSs must be central to future workforce planning. The NHS should develop a metric based on the extent to which people with cancer's needs are met to measure how well CNS's are able to support them. This should be used to inform future workforce planning.

3. How can we recruit, train and retain the workforce to deliver the changes we need and the priorities you have shared?

'More trained cancer nurses for after treatment.' Target Ovarian Cancer supporter

A key priority for the future of the workforce shared by our supporters is ensuring that there are sufficient CNSs to support women during and after their treatment. As well as ensuring CNSs have the time to offer the holistic support women need.

'More training for GPs so symptoms are recognised and taken seriously for earlier diagnosis'
Target Ovarian Cancer supporter

'More specific training for doctors in recognising/diagnosing and supporting those with ovarian cancer' Target Ovarian Cancer supporter

Another strong theme was the need for GPs to be adequately trained in the diagnosis of ovarian cancer. Target Ovarian Cancer has created online training modules with RCGP and BMJ Learning and through our efforts 44 per cent of GPs have been trained. Resources such as these should be sign posted to GPs in training and as part of continuing professional development for qualified GPs.

Research is being undertaken on the efficacy of a screening programme for ovarian cancer. The UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS) looked at the possibility of an ovarian cancer screening programme. An estimated 12.5 million women would be included in the screening programme (if this applied to all women over 50) and it would be expected that two per cent of these would require referrals for ultrasound due to changes in CA125 levels. The final results are due in late 2019 and if screening is deemed to be effective there would be a significant increase in demand on the sonographer workforce.

¹⁵ Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: www.targetovariancancer.org.uk/pathfinder [Accessed 19 September 2018]

¹⁶ National Institute of Health and Care Excellence (2011) Ovarian cancer: recognition and initial management. Available at: <https://www.nice.org.uk/Guidance/cg122> [Accessed 19 September 2018]

¹⁷ Target Ovarian Cancer (2016) Pathfinder 2016: transforming futures for women with ovarian cancer. Available at: www.targetovariancancer.org.uk/pathfinder [Accessed 19 September 2018]

4. How can we address variation and inequality to ensure everyone has access to the best diagnostic services, treatment and care?

Target Ovarian Cancer has found significant variation in the number of CA125 blood tests carried out in different areas with 90 times more tests carried out per 1,000 practice population in the area with the highest number of referrals compared to the lowest. Additionally there is significant variation in the time taken to complete ultrasounds with 80 per cent taking place in within two weeks in some areas compared to almost zero in others.¹⁸ Research has also shown there is a variation in outcomes for women depending on if they are treated in a specialist centre or not.¹⁹

There is also significant variation in survival across regions of England, with a mortality to incidence ratio of 0.64 in the West Midlands and 0.61 in the North East compared to 0.49 in London and 0.51 in the North West. This is compared to an overall ratio of 0.56 in England.²⁰

In order to understand this variation there must be a clinical audit of ovarian cancer. This work is being piloted by ovarian cancer charities and the British Gynaecological Cancer Society but it is vital that it is supported by Public Health England and there are levers put in place to ensure the findings are acted on and, assuming its conclusions prove useful, that this work continues beyond pilot stage.

¹⁸ Target Ovarian Cancer (2017) Regional variation in the diagnosis of ovarian cancer in England. Available at: https://www.targetovariancancer.org.uk/sites/default/files/Regional_variation_in_the_diagnosis_of_ovarian_cancer_in_England.pdf [Accessed 19 September 2019]

¹⁹ Jayson et al (2016) Improved survival from ovarian cancer in patients treated in phase III trial active cancer centres in the UK, Clinical Oncology

²⁰ Office for National Statistics (2017) Cancer registration statistics, England 2016. Available at: www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancerregistrationstatisticscancerregistrationstatisticsengland/2015/cancerregistrations2015final22.05.2017.xls [Accessed 19 September 2018]