

## **Written evidence submitted by Target Ovarian Cancer (ECS0022)**

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.

Over 7,000 women are diagnosed with ovarian cancer each year in the UK and more women die as result of ovarian cancer each year in the UK than all other gynaecological cancers combined.<sup>1</sup> It is crucial that we work together to ensure that women in the UK have the best chances of survival from ovarian cancer by ensuring that they are diagnosed early, have access to specialist knowledge and the best treatment.

Target Ovarian Cancer welcome many of the Government's commitments to improving cancer services and the progress that has been made in achieving them. We welcome this opportunity to submit evidence to the Health and Social Care Committee's Expert Panel for their evaluation of commitments made in the area of cancer services.

### **Summary of key points:**

- To achieve earlier diagnosis there needs to be sustained investment in symptom awareness campaigns to increase knowledge of the symptoms of ovarian cancer to encourage women to contact their GP as soon as they experience symptoms
- The current ovarian cancer pathway must be reviewed and shortened. Reviewing and shortening the diagnostic pathway, with a CA125 blood test and ultrasound taking place concurrently is key to achieving an earlier diagnosis and better outcomes of women with ovarian cancer.
- Funding needs to be made available in order to develop screening and new treatments that will help women diagnosed with ovarian cancer have the best possible chance of survival.
- It is vital there is specific focus and investment in support services, specifically psychological support, and that every woman diagnosed with ovarian cancer has access to a CNS.
- The differences in access to ovarian cancer treatment must be addressed if ovarian cancer outcomes are to be improved. This means ensuring that the recently commissioned ovarian cancer audit leads to a transformation in treatment across England, so that neither age nor location determines a woman's chance of survival. This transformation cannot happen without also making sure that every woman undergoing ovarian cancer surgery has this performed by a specialist gynaecological oncology specialist in a multidisciplinary centre.
- Funding needs to be made available in order to develop screening and new treatments that will help women diagnosed with ovarian cancer have the best possible chance of survival.

### **Commitment 1:**

#### **The Cancer Workforce Plan committed to the expansion of capacity and skills by 2021**

After diagnosis, it is imperative that the right support is in place to help women and their families through diagnosis, treatment and beyond. Covid-19 exposed the strain the NHS cancer workforce has been under. The British Medical Association conducted a recent survey that showed 23 per cent

of the workforce are suffering worse than before the start of the pandemic and over one in 10 plan to leave the NHS altogether.<sup>2</sup> It highlights how vital it is that we retain, and value our workforce.

### **Cancer workforce**

Clinical Nurse Specialists are the cornerstone of good ovarian cancer care and are a vital part of a women's care experience. They play a significant role from diagnosis to treatment for everyone diagnosed with ovarian cancer by providing specialist knowledge and emotional support.

Even before the pandemic Target Ovarian Cancer found that CNSs were experiencing increasing demands on their time with resources and support and many CNSs lacking administrative support. In England we currently have 227 gynaecological Clinical Nurse Specialists (CNS).<sup>3</sup> 43 per cent of gynaecological CNSs are aged over 50 and approaching retirement, this presents a concerning picture for the future capacity of the gynaecological cancer workforce and how they will be able to cope with added pressure of clinical nurse vacancies.

As we move out of the pandemic it is vital that CNSs have appropriate resources to support their patients and are not overstretched with their time.

### **Conclusions on Commitment 1:**

The Government's commitment to expanding the capacity and skills of the cancer workforce was welcome. Nonetheless achieving the target during a pandemic has been difficult, with a workforce already under pressure.

Target Ovarian Cancer supported joint calls from cancer charities for the Government to urgently invest in our vital cancer workforce. Research carried out by Macmillan Cancer Support showed that the Government needs to provide £124 million to train an extra 3,371 specialist cancer nurses in England.<sup>4</sup> This would ensure that more people with cancer can access the personalised care they need.

### **Commitment 2:**

**A faster diagnosis standard from 2020 to ensure most patients receive a definitive diagnosis or ruling out of cancer within 28 days of referral from GP or from screening**

**By 2028 the proportion of cancers diagnosed at stages 1 and 2 will rise from around 50% now to 75% of cancer patients**

We welcome the commitments made to improve early diagnosis of cancer. The earlier a woman is diagnosed, the greater her chance of survival, however before the outbreak of coronavirus only 33 per cent of women with ovarian cancer were diagnosed at an early stage (Stage 1 or 2).<sup>5</sup>

### **Early diagnosis**

Early diagnosis saves lives. The earlier a woman is diagnosed the greater her chance of survival; 93 per cent of women diagnosed at the earliest stage survive for at least five years compared to just 13 per cent of women diagnosed at the most advanced stage.<sup>6</sup>

Where someone lives can significantly impact how early someone is diagnosed with ovarian cancer. In England the percentage of women diagnosed at stage I or II varies from 56 per cent in the best performing Clinical Commissioning Groups (CCGs) to 29 per cent in the worst.<sup>7</sup> It is vital that this difference is understood and addressed. Target Ovarian Cancer has undertaken in depth work across England with GPs and CCGs to improve GP knowledge and pathways to diagnosis and to understand

where barriers exist. It is vital that the knowledge and expertise of the voluntary sector is used to understand how we can achieve commitment 2.

### **Awareness**

There is currently no viable screening test for ovarian cancer. To improve early diagnosis, it is vital that everyone is aware of the symptoms so they can contact their GP as soon as they think something is wrong. Awareness of symptoms of ovarian cancer remains worryingly low in England, Target Ovarian Cancer found that just 21 per cent of women in England are able to name bloating as a symptom, 20 per cent tummy pain, 3 per cent always feeling full and 1 per cent able to name urinary symptoms.<sup>8</sup>

Government funded symptom awareness campaigns are key to achieving greater awareness of ovarian cancer symptoms. Awareness campaigns would help educate everyone on the symptoms and encourage them to discuss any concerns they might have with their GP.

Target Ovarian Cancer have been calling for symptom awareness campaigns to be implemented in England. We welcomed the inclusion of abdominal symptoms in NHS England's 'Help us Help you' awareness campaign and we need to continue to see sustained investment in this area.

### **GP understanding of ovarian cancer**

Clinical understanding of ovarian cancer, including symptoms of the disease, has progressed rapidly in the past decade. But there are still outstanding gaps in GP knowledge with 44 per cent of GPs wrongly believing that ovarian cancer symptoms only present in the later stages of the disease.<sup>9</sup>

Ovarian cancer symptoms can often be confused with irritable bowel syndrome (IBS). NICE guidelines are clear that IBS rarely occurs for the first time in women aged 50 or over and women this age presenting with new symptoms should be referred for ovarian cancer tests.<sup>10</sup> However, Target Ovarian Cancer found that 21 per cent of women over 50 who visited their GP to discuss symptoms were told they might have IBS.

In order to improve upon this and achieve the commitment of diagnosing 75 per cent of cancers at stage I or II every GP needs to be trained on the symptoms of ovarian cancer and the referral pathway to reduce variation in practice.

### **Ovarian Cancer diagnostic pathway**

To achieve the target of both the Faster Diagnosis Standard and an early-stage diagnosis for more women with ovarian cancer the current ovarian cancer diagnostic pathway needs to be reviewed and shortened.

There is no screening tool for ovarian cancer and the current combination of a CA125 blood test and ultrasound has limitations. The CA125 protein is elevated in 80 per cent of women with advanced disease, but no more than 50 per cent of women diagnosed with stage I ovarian cancer will have a raised CA125.<sup>11</sup>

In Scotland, women with suspected ovarian cancer are referred for a CA125 blood test and an ultrasound at the same time. In the rest of the UK an ultrasound can only be conducted after a CA125 comes back showing a raised result. Target Ovarian Cancer have long called for the current pathway in England to be brought in line with best practice in Scotland. This would lead to a reduction in the time it takes to get a diagnosis and ensure that more women with an early-stage cancer are identified.

There are also delays in accessing tests for women with suspected ovarian cancer. Pre-pandemic women with ovarian cancer experienced delays in diagnosis, with the average waiting time from referral to ultrasound test being carried out taking 31 days.<sup>12</sup> Women also face delays once they are referred to secondary care with an average wait of 69 days between referral and starting treatment.<sup>13</sup> This data emphasises why it is so important that we have an individual timed pathway for ovarian cancer, so that women can start treatment as quickly as possible.

### **Conclusion on Commitment 2:**

The government needs to focus on the factors that are preventing commitment 2 from being fully achieved. The variation in diagnosis needs to be addressed in order to strengthen efforts to diagnose 75 per cent of cancers at stage I or II by 2028.

Target Ovarian Cancer have outlined the importance of shortening the diagnostic pathway and sustained investment in symptoms awareness campaigns. We need to ensure that regardless of where someone lives, they receive the same access to diagnosis and treatment.

### **Commitment 3- By 2021 where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support**

Target Ovarian Cancer welcomed the commitment from the Government to ensure every person diagnosed with cancer has access to personalised care and support. However, progress on this ambition has been limited as a result of the pandemic with 27 per cent of women with ovarian cancer told us that they were unable to access the same care and support as before the pandemic.

### **Impact of coronavirus on support**

The uncertainty around treatment and the disruption with the introduction of shielding led to over half of women saying the pandemic had a negative impact on their mental health.<sup>14</sup> Many women reported feeling lonely and isolated as a result of government guidelines asking the most vulnerable to shield. Women diagnosed with ovarian cancer were left unable to see friends and family and take part in their usual daily activities.

### **Conclusion on Commitment 3:**

Target Ovarian Cancer has called for there to be specific focus and investment in support services, specifically psychological support, and that every person diagnosed with ovarian cancer has access to a CNS.

We need to see a clear strategy on how support services will recover from the pandemic and need to ensure that we continue to improve upon the level of support and care available prior to the pandemic.

### **Commitment 4- Safer and more precise treatments including advanced radiotherapy techniques and immunotherapies will continue to support improvements in survival rates.**

Ovarian cancer kills 11 women every day and survival rates in the UK are among the worst in Europe.<sup>15</sup> In order to provide women with the best chance of survival, that need to develop new and innovative treatments.

### **Access to specialist knowledge and treatment**

Target Ovarian Cancer welcomed the commitment made in the NHS Long-Term Plan to ensure greater access to specialist expertise and knowledge in the treatment of cancers, beginning with ovarian cancer.

While access to ovarian cancer drugs has improved over the last few years, we would like to see more done on access to world class surgery. At its best ovarian cancer treatment in the UK is world-leading, however not all women are able to access the best quality treatment.

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.<sup>16</sup> This is despite the fact that overall survival is improved by 45 per cent for women treated at specialist centres.<sup>17</sup>

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 funding**

In recent years we have seen a worrying decline in the UK's spend on ovarian cancer research. Public spend on ovarian cancer research has decreased by 29 per cent in eight years, from £12.9m in 2010/11 to £9.2m in 2019/20.<sup>18</sup> Research is vital to improving the outcomes of people diagnosed with cancer and a commitment needs to be made to increase funding for ovarian cancer research.

The outbreak of coronavirus saw many medical research charities struggling to retain their funding with £270 million cut from charitable research spend.<sup>19</sup> This needs to urgently be addressed if we are to continue developing lifesaving treatment.

### **Conclusion on Commitment 4:**

In order to achieve this commitment, we need to see a sustained investment in ovarian cancer research with a particular focus on screening tools and new treatments so far there has been little in the Long-Term Plan to address this. We also need to ensure that all women with ovarian cancer are offered surgery in specialist centres.

We would be very happy to discuss any element of this submission in more detail with the Expert Panel.

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<sup>1</sup> Cancer Research UK website. Available at: [www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer/mortality](http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer/mortality)

<sup>2</sup> Pressures in General Practise (2021) British Medical Association. Available at: <https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/pressures-in-general-practice>

<sup>3</sup> Macmillan Cancer Support (2017) Cancer workforce in England. Available at: [www.macmillan.org.uk/about-us/what-we-do/evidence/research-publications/research-and-evaluation-reports.html#283506](http://www.macmillan.org.uk/about-us/what-we-do/evidence/research-publications/research-and-evaluation-reports.html#283506)

<sup>4</sup> Cancer nursing on the line: why we need urgent investment across the UK. Available at: [https://www.macmillan.org.uk/\\_images/Forgotten-C-Nursing-Report\\_tcm9-360416.pdf](https://www.macmillan.org.uk/_images/Forgotten-C-Nursing-Report_tcm9-360416.pdf)

<sup>5</sup> Voices of women with ovarian cancer: the coronavirus pandemic and its impact. Available at: <https://targetovariancancer.org.uk/sites/default/files/202007/Voices%20of%20women%20with%20ovarian%20cancer%20-%20the%20coronavirus%20pandemic%20and%20its%20impact.pdf>

<sup>6</sup> Office for National Statistics (2019) Cancer Survival in England: adults diagnosed between 2012 and 2016 and followed up to 2017. Available at:

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<sup>7</sup> Target Ovarian Cancer, Time is running out report 2020. Available at:

<https://targetovariancancer.org.uk/sites/default/files/2020-07/Time%20is%20running%20out%20-%20the%20need%20for%20early%20diagnosis%20in%20ovarian%20cancer.pdf>

<sup>8</sup> Target Ovarian Cancer (2016) Pathfinder England: transforming futures for women with ovarian cancer. Available at:

[www.targetovariancancer.org.uk/sites/default/files/Campaigns/Pathfinder-England.pdf](http://www.targetovariancancer.org.uk/sites/default/files/Campaigns/Pathfinder-England.pdf)

<sup>9</sup> Target Ovarian Cancer (2018) Data briefing on ovarian cancer. Available at: <https://www.targetovariancancer.org.uk/our-campaigns/our-publications/reports>

<sup>10</sup> National Institute for Health and Care Excellence (2011) Ovarian cancer: The recognition and initial management of ovarian cancer. Clinical guideline 122. Available at: [www.nice.org.uk/guidance/cg122](http://www.nice.org.uk/guidance/cg122)

<sup>11</sup> Scottish Intercollegiate Guidelines Network (2013) SIGN 135. Management of epithelial ovarian cancer. Revised 2018. Available at: [www.sign.ac.uk/sign-135-management-of-epithelial-ovarian-cancer.html](http://www.sign.ac.uk/sign-135-management-of-epithelial-ovarian-cancer.html)

<sup>12</sup> Target Ovarian Cancer, Time is running out report 2020. Available at:

<https://targetovariancancer.org.uk/sites/default/files/2020-07/Time%20is%20running%20out%20-%20the%20need%20for%20early%20diagnosis%20in%20ovarian%20cancer.pdf>

<sup>13</sup> Data briefing 2022: Achieving excellence in ovarian cancer care (2022). Available at:

<https://targetovariancancer.org.uk/sites/default/files/2022-01/Data%20briefing%202022%20-%20achieving%20excellence%20in%20ovarian%20cancer%20care.pdf>

<sup>14</sup> Target Ovarian Cancer, survey on the impact of the pandemic. January 2021

<sup>15</sup> Cancer Research UK website. Available at: <https://www.cancerresearchuk.org/about-cancer/ovarian-cancer>

<sup>16</sup> Butler et al (2015) Specialist surgery for ovarian cancer in England, Gynecologic Oncology

<sup>17</sup> Jayson et al (2016) Improved survival from ovarian cancer in patients treated in phase III trial active cancer centres in the UK, Clinical Oncology

<sup>18</sup> Trends in Disease Site Spend, NCRI Cancer Research Database. Available at: <https://www.ncri.org.uk/how-we-work/cancer-research-database/trends-in-disease-site-spend/>

<sup>19</sup> AMRC (2021) Medical Research Charities: Investing in Research, Available at

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**Jan 2022**