

Gynaecological Cancer Inquiry review- Target Ovarian Cancer response

Wales has some of the worst survival rates for ovarian cancer in Europe. Over 300 women are diagnosed with ovarian cancer each year in Wales, and more women die as a result of ovarian cancer in the UK than all other gynaecological cancers combined.

During the inquiry and through our written recommendations we urged the Welsh Government to focus on addressing the barriers to improving early diagnosis by increasing symptoms awareness, improving GP knowledge, addressing variation in treatment and making changes to data availability and support.

We were pleased that many of our recommendations were published in the report and accepted by the Welsh Government, however, we have been disappointed with the lack of progress and priority placed in implementing the recommendations and ensuring that women impacted by gynaecological cancers feel heard.

Women's Health Plan & National Cancer strategies

Whilst the Welsh Government have demonstrated a commitment to improving cancer services through the Quality Statement for Cancer, the three-year Cancer Improvement Plan and the National Cancer Recovery Programme, having multiple initiatives has made it difficult to understand and monitor progress, as well as making accountability unclear.

The Women's Health Plan was a welcome step, and we were pleased to see the Welsh Government recognise the importance of having a plan in place that addresses the barriers women face in accessing a diagnosis. Based on the Welsh Government's response to the Unheard report we had hoped the Women's Health Plan would be an opportunity to improve gynaecological cancers, access to health care and cancer outcomes. However, we were disappointed that the plan instead only focused on cervical screening uptake and did not address any other gynaecological cancer and that there was no public consultation on this. With the current Cancer Improvement Plan coming to an end in 2026 and the Cancer Recovery plan only scheduled to last two years, the Women's Health Plan could have galvanised vital action over the next decade. More regular reporting on progress within the Cancer Recovery Programme would help address some of our concerns.

We recognise there has been progress made with performance against the cancer waiting time target for gynaecological cancers gradually improving to 45.5 per cent and specific action around the national optimal pathway for ovarian cancer, however, to see real meaningful progress we need disaggregated waiting time data and more targeted measures in place to fully address the difficulties faced by women with gynaecological cancers.

Women's Health Hubs

While the establishment of women's health hubs in each health board is a positive step, the focus seems heavily centred on gynaecological health, with a lack of clarity on whether the women's health hubs will be equipped to diagnose ovarian and other gynaecological cancers. There are delays both in accessing tests and GPs then receiving the results. We know that the earlier a woman is diagnosed the greater her chance of survival yet delays in accessing tests stop women from starting life-saving treatment. Research undertaken by Target Ovarian Cancer found one quarter of women in Wales visited their GP three or more times before being referred for tests and that 43 per cent of GPs wrongly believe symptoms only present in the late stages.

It is vital that women are able to access the tests they need. Women Health Hubs present a real opportunity to improve access to diagnostic tests/ provide a one stop shop for gynaecological cancers and make a meaningful difference to women's health in Wales. We would welcome some clarity on what consideration has been given to using Women's Health Hubs to improve the diagnosis of gynaecological cancers?

Progress of implementation & the biggest gaps

Implementing recommendation 11

We were pleased to see the Welsh Government accept recommendation 11 to update cervical screening information to make clear it will not detect ovarian cancer. Currently, 42% of women in Wales wrongly believe cervical screening can detect ovarian cancer. This means that women may think that if their cervical screening was clear they are not at risk of developing ovarian cancer.

However, we have been disappointed to learn that despite this recommendation having minimal cost implication and cervical screening information being updated in February 2024 after the recommendation was accepted, there has been no progress to date on implementing this change. With no viable screening programme for ovarian cancer, it is vital that every woman in Wales knows this information.

Since the report was published we have consistently raised the question asking when this recommendation will be implemented and the importance of ensuring women have access to this knowledge. As expressed above we were disappointed there was not a formal consultation process for the Women's Health Plan and that gynaecological cancers have not been included. Despite this in response to our questions on the importance of this information being updated it has been indicated that information changes such as this will be addressed through the Women's Health Plan, however, there is little to no mention of gynaecological cancers within the plan. We would welcome some clarity on how the Welsh Government see the Women's Health Plan and Cancer Recovery Programme working together to ensure more women are equipped with the knowledge they need on ovarian and other gynaecological cancers.

We understand that that conversations are underway around developing a campaign through the Women's Health Plan looking at making every contact count and improving health information through this. We would urge the Welsh Government to use this an opportunity to implement recommendation 11.

Awareness campaigns

Similarly, it has been disappointing to hear that there has been no progress made on implementing recommendation 12 encouraging Welsh Government to work with Public Health Wales, community leaders and organisations to develop and implement a series of campaigns to raise awareness about the symptoms of gynaecological cancer.

Target Ovarian Cancer has repeatedly called for greater symptom awareness of ovarian cancer. This is an area that means a lot to women impacted by this disease as many of the women we work with in Wales have noted how they had no awareness of ovarian cancer or the symptoms to watch out for. Our research has shown that just 27 per cent of women in Wales are able to recognise the symptom of bloating and just 3 per cent are able to recognise feeling full as a symptom. They are passionate about ensuring more women in Wales have access to this knowledge and have been disappointed to see little progress in this area. Gynaecological cancers have the highest incidence and death rate of the female-associated cancers, after breast cancer. We must see more targeted action to improve awareness of symptoms in Wales.

We have had encouraging conversations with Welsh government and Members of the Senedd around the need to improve awareness and are pleased they have recognised the need for this, however, despite recognising this need little has been to improve public awareness of ovarian and other gynaecological cancers. We understand budget pressures continue to limit the Welsh Government's ability to fund public education and awareness campaigns, however we would urge the Welsh Government to make the most of material already available. For example, in NHS England the help us help you campaign has produced targeted campaigns encouraging women experiencing bloating/ abdominal pain to visit their GP. Adopting campaigns such as this would be a positive step forward and could help more women present to their GP if they are experiencing these symptoms.

Ensuring patients are not left behind - Involvement of people affected by gynaecological cancer in shaping services and decisions

We recently spoke with some of the women who contributed to the inquiry, and they expressed their disappointment at the lack of progress made since the Unheard report was published. They shared they felt they had not been fully listened too and their concern around the lack of ambitious targets. The voices of those impacted by ovarian and other gynaecological cancers are crucial to shaping and improving services. We would urge the Welsh Government to consider providing an update

specifically addressed to those who have had a diagnosis, reassuring them that their concerns are being listened to.

Do you feel the Welsh Government has clearly identified and committed to overcoming the barriers to improving gynaecological cancer care? What specific actions or assurances would you expect to see in the short term

We welcomed the Welsh Government's commitment to improving gynaecological cancer services and making gynaecological cancers a tumour priority site within the Cancer Recovery Plan.

Whilst we believe the Welsh Government have identified areas for improvement and recognise that current wait times are simply not good enough, we think there could be clearer communication on what actions are being taken to improve gynaecological cancer services. We would welcome the Minister's suggestion to provide periodic updates. To reassure the third sector and women impacted by ovarian and other gynaecological cancers we would ask if the Welsh Government would consider providing a timeline and implementation plan for the Unheard report.