

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Canserau gynaeolegol](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Gynaecological Cancers](#)

GC 06

Ymateb gan: | Response from: Target Ovarian Cancer





Welsh Health and Social Care Committee- Gynaecological cancers Consultation

Information available and awareness of risk factors and symptoms associated with gynaecological cancers.

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.ⁱ As there is currently no screening tool for ovarian cancer, to improve early diagnosis it is vital that women are not only aware of the symptoms but also the importance of family history so they can contact their GP as soon as they begin experiencing symptoms.

Target Ovarian Cancer found that awareness of the key ovarian cancer symptoms remains worryingly low in Wales, with just 33 per cent of women able to name abdominal pain as a symptom, 27 per cent able to name bloating, 5 per cent able to name feeling full and just 1 per cent able to recognise urinary urgencyⁱⁱ.

Approximately 13 per cent of ovarian cancers are caused by a mutation of the BRCA1 or 2 geneⁱⁱⁱ. However, there is poor awareness among women across the UK of the importance of family history of cancer with only a third of women recognising that family history could be a risk factor for ovarian cancer.

Target Ovarian Cancer welcomed the development of a NICE guideline on inherited ovarian cancers, but a key area not covered in the guideline will be awareness of the risk. We need to see awareness campaigns alongside investment into better prevention options and access to genetic counselling so that those with a family history can make an informed decision about genetic testing.

The most effective way of achieving greater awareness is government funded symptom awareness campaigns. We must ensure that everyone is aware of the key symptoms of ovarian cancer. Concerningly, awareness of feeling full has declined from 5 per cent of women recognising this as a symptom in 2016 to just 3 per cent^{iv}. We urgently need to see government funded awareness campaigns across Wales that highlight the symptoms of ovarian cancer. In 2017 the Welsh Assembly Petitions Committee produced a report calling for a public facing ovarian cancer awareness campaign in Wales. To date there have been no specific awareness campaigns on ovarian cancer symptoms. The case for symptoms awareness is clear as our research also found that just 6 per cent of women in Wales said that they were very confident in naming ovarian cancer symptoms.^v

Awareness of symptoms is key to improving early diagnosis, however, we must also address the misconceptions around ovarian cancer. Target Ovarian Cancer found that 42 per cent of women in Wales wrongly believe that cervical screening detects ovarian cancer^{vi}. We need to ensure that the information provided at cervical screening appointments makes clear that it does not test or screen for other gynaecological cancers and include the symptoms of other gynaecological cancers.

Recommendations

- We need to see Government funded awareness campaigns across Wales that highlight the symptoms of ovarian cancer
- There needs to be campaigns that educate the public on the importance of knowing their family history so they can investigate preventive action
- Consideration should be given to ensuring that materials related to cervical screening are clear that it does not test for the other gynaecological cancers.

The barriers to securing a diagnosis, such as symptoms being dismissed or confused with other conditions

Whether women feel they are being listened to by healthcare professionals and their symptoms taken seriously.

If diagnosed at an earliest stage (Stage I), 93 per cent of women in Wales can survive five years or more, compared to just 13 per cent of women diagnosed at stage IV.^{vii} Currently just over a third of women are diagnosed at an early stage in Wales^{viii}.

Once a woman has been referred by her GP for tests, it is vital that either ovarian cancer is diagnosed or ruled out as soon as possible. However, there can still be unnecessary delays in diagnosis. Ovarian cancer is diagnosed using a CA125 blood test, followed by an ultrasound if the levels are raised. 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^{ix}. Having a CA125 as a standalone test can mean that women with early-stage disease are not referred.

We have also found that there are delays in waiting for test results despite GPs being able to access these tests directly. Target Ovarian Cancer found that one third of women in Wales reported waiting more than three months from their first appointment with their GP to receiving their diagnosis. Given the time taken to get the results of the CA125 blood test and an ultrasound, there is an urgent need to shorten the ovarian cancer diagnostic pathway

We need to see a reduction in the time it takes to get a diagnosis and ensure that more women with an early-stage cancer are identified. By carrying out the CA125 blood test and ultrasound concurrently as is currently done in Scotland, it would allow women to be diagnosed faster and begin treatment as soon as possible.

GP awareness is also key to early diagnosis. However, too many women experience misdiagnosis and delays as a result of GPs not being appropriately educated or supported to diagnose ovarian cancer. Target Ovarian Cancer found that 43 per cent of GPs in Wales believe that symptoms only present in the late stages of disease and one quarter of those diagnosed with ovarian cancer report visiting their GP three or more times before being referred for tests^x.

This is concerning, as symptoms are often present in those with early-stage disease. Appropriate training must be in place at primary care level if we want to ensure more people receive an early diagnosis.

Recommendations

- Shorten the diagnostic pathway for ovarian cancer so that a CA125 blood test and ultrasound are carried out at the same time
- Ensure that GPs are well supported with access to training, Advice and Guidance services vague symptoms pathways and support to use NICE guidance

NHS recovery of screening and diagnostic services, specifically the level of extra capacity that has been provided for services to recover from the impact of the COVID-19 pandemic.

The prioritisation of pathways for gynaecological cancers as part of NHS recovery, including how gynaecological cancer waiting lists compare to other cancers and other specialities.

Target Ovarian Cancer welcomed the introduction of the Suspected Cancer Pathway in Wales and the 62-day target to receive a diagnosis and begin treatment. The pandemic had a drastic impact on urgent referrals for suspected cancer from GPs and treatment wait times. Early diagnosis and beginning treatment as soon as possible are key in increasing the survival rates among women with ovarian cancer.

In 2022 just 34 per cent of gynaecological cancers met the single cancer pathway target, when comparing this to those diagnosed with lung cancer 54 per cent of those diagnosed met the cancer pathway, starting their treatment within 62 days of first being suspected with cancer^{xi}. Understanding why we continue to see delays in diagnosis for gynaecological cancers is crucial. We know that there are many barriers to an early diagnosis for ovarian cancer, such as misdiagnosis and a lack of GP awareness. We must see the pathways for gynaecological cancers prioritised to ensure more people meet the single cancer pathway target and are able to start treatment as soon as possible. Urgent action must be taken to ensure everyone diagnosed with ovarian cancer and other gynaecological cancers have the best possible chance of survival.

Recommendations:

- Prioritise gynaecological cancer diagnostic pathways. Consider reviewing and shortening the diagnostic pathway for ovarian cancer to ensure that it meets the single cancer pathway target.

Whether there are local disparities in gynaecological cancer backlogs (addressing inequalities so that access to gynaecological cancer care and treatment is not dependent on where women live)

This audit will play a crucial role in transforming diagnosis and access to treatment for everyone diagnosed, irrespective of their age or where they live.

Target Ovarian Cancer welcomed the announcement that the full clinical audit to improve ovarian cancer care and treatment across England and Wales. It is vital that the commissioned audit provides in-depth analysis of the diagnosis and treatment of ovarian cancer so that progress can be tracked.

Where you live should not affect your treatment options or outcomes. It is vital that the NHS in Wales proactively identifies ways of tackling any disparity identified in the audit when it reports.

The extent to which data is disaggregated by cancer type (as opposed to pooling all gynaecological cancers together) and by other characteristics such as ethnicity.

Ovarian cancer is often reported as part of a larger set on gynaecological cancers. However, this is unhelpful as the diagnostic and treatment pathways for individual cancers, ovarian, cervical, womb, vulval and vaginal are different so it is difficult to make meaningful assessments of performance in ovarian cancer diagnosis and treatment using aggregated data sets.

Recommendation

- Datasets should be disaggregated by tumour type to ensure we can better understand how services are currently performing and plan interventions.

Whether adequate priority is given to gynaecological cancers in the forthcoming Welsh Government/NHS Wales action plans on women and girls' health and cancer, including details of who is responsible for the leadership and innovation needed to improve cancer survival rates for women.

We welcome the focus the Welsh Government is placing on women and girls' health and gynaecological cancers. However, the Cancer Quality Statement lacks detail on how the Government/NHS will specifically address symptom awareness and the variation in access to diagnostics and treatment for gynaecological cancers in Wales.

It is concerning that just 34 per cent of gynaecological cancers met the single cancer pathway target in Wales. To ensure 75 per cent of people diagnosed with cancer meet the 62-day target we need to see the current diagnostic pathway for ovarian cancer reviewed and shortened, this would allow women to be diagnosed faster and begin treatment as soon as possible.

The focus placed on screening will significantly help other gynaecological cancers such as cervical, however for ovarian cancer there is currently no viable screening programme. To see accelerated progress and achieve earlier diagnosis for everyone diagnosed with ovarian cancer in Wales the action plan needs to consider symptom awareness campaigns that feature the symptoms of ovarian cancer and other less common cancers.

Recommendations

- We need to see continued commitment to improve early diagnosis and treatment of gynaecological cancers
- Ensure that GPs are well supported with access to training and symptom awareness, helping more women presenting with symptoms get diagnosed earlier

The extent to which gynaecological cancers, and their causes and treatments (including side-effects), are under-researched; and the action needed to speed up health research and medical breakthroughs in diagnosing and treating gynaecological cancers.

Research is vital to improving the outcomes for everyone diagnosed with ovarian cancer. However, in recent years we have seen a worrying decline in the UK's spend on ovarian cancer research. Public spend on ovarian cancer research across the UK has decreased by 27 per cent in ten years, from £12.9m in 2010/11 to £10.3m in 2020/2, which is just 3 per cent of site-specific research. This is concerning as the outbreak of coronavirus also saw many medical research charities struggling to retain their funding with £270 million cut from charitable research spend.

One in ten women are diagnosed with a less common tumour type^{xii}, however, rarer sub-types of ovarian cancer have fewer treatment options. When considering how we can improve the treatment offered to everyone with cancer, we must ensure that rarer tumours along with other rare and less common gynaecological cancer types receive the focus and funding they need, so everyone has the best possible chance of survival.

Clinical trials offer those diagnosed with cancer the opportunity to access new cancer drugs and treatment options. This is particularly important for those diagnosed with rarer tumours

or incurable ovarian cancer. Our recent Pathfinder study highlighted that there has been a 10 per cent decline in women being asked about clinical trials between 2016 and 2022. This is despite there being a clear desire to take part in clinical trials with 61 per cent of women who took part in our study and who were not asked to take part in a clinical trial, saying they would have liked the opportunity to take part in a trial^{xiii}. We must ensure that the decline in opportunities to take part in trials is reversed and information about clinical trials is shared.

Target Ovarian Cancer welcomes the commitment outlined in the Cancer Quality Statement that all eligible patients will be offered access to research trials and that Wales will provide supporting infrastructure for cancer research. This is crucial if we are to continue developing lifesaving treatment and new diagnostic tools.

Recommendations

- Patients must be empowered to ask about clinical trials, with signposting to information on clinical trials embedded into interactions between patients and their clinical team.
- We need to see urgent investment in post pandemic studies that will lead to better treatments.

The priority given to planning for new innovations (therapy, drugs, tests) that can improve outcomes and survival rates for women.

No matter where they live or their personal circumstances everyone diagnosed with ovarian cancer must have access to specialist support and the best treatment. We welcome the commitment made in the Cancer Quality Statement to ensure more evidence-based surgical techniques, radiotherapies and genomic testing are routinely available. Everyone with ovarian cancer must be able to access the best possible treatment, targeted to their needs.

Surgery is the treatment that offers the best prognosis. Ovarian cancer surgery is a complex, major operation so it is vital that surgery is undertaken at a specialist multidisciplinary disciplinary diagnostic centre. Research has shown that treatment at specialist centres improves survival by 45 per cent^{xiv}.

Genomic testing

The availability of PARP inhibitors to treat the most common type of ovarian cancer is dependent on the presence of a BRCA variation or HRD status which is determined through genomic testing. The presence of a BRCA germline variant also has implications for family members as they may also have the gene, so women need the right support when undergoing BRCA germline testing.^{xv}

We found that there is good access to genomic testing in Wales of those we surveyed:

- 79 per cent had BRCA germline testing
- 42 per cent had BRCA somatic testing
- 8 per cent report HRD testing (available across the whole UK from December 2021)

However, 65 per cent said they weren't offered specialist counselling to help them decide if they wanted to be tested.

Recommendations

- Everyone that would benefit from specialist surgery must be able to access it regardless of age or geographical location.

- There must be a consistent approach to consenting for genomic testing, with access, where required, to genetic counselling maintained for those having BRCA germline

ⁱ [Cancer Incidence in Wales, 2002-2019 - Public Health Wales \(NHS, Wales\)](#)

ⁱⁱ Target Ovarian Cancer, Awareness Measure. (2022)

ⁱⁱⁱ Pathfinder 2016: Transforming futures for women with ovarian cancer.

^{iv} Target Ovarian Cancer, Awareness Measure. (2022)

^v Target Ovarian Cancer, Awareness Measure. (2022)

^{vi} Target Ovarian Cancer, Awareness Measure. (2022)

^{vii} Welsh Cancer Intelligence and Surveillance Unit Cancer survival by stage of diagnosis. Available at: www.wcisu.wales.nhs.uk/cancer-survival-by-stage-at-diagnosis-in-1

^{viii} Pathfinder Wales 2022: Faster, Further, Fairer (2022). Target Ovarian Cancer.

^{ix} 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

^x Pathfinder Wales 2022: Faster, Further, Fairer (2022). Target Ovarian Cancer.

^{xi} StatsWales: Cancer Waiting Times. <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Cancer-Waiting-Times/Monthly/suspectedcancerpathwayclosedpathways-by-localhealthboard-tumoursite-agegroup-gender-measure-month>

^{xii} Target Ovarian Cancer's data briefing on Ovarian Cancer. 2018. Available at: <https://targetovariancancer.org.uk/sites/default/files/2020-07/Target%20Ovarian%20Cancer%27s%20data%20briefing%20for%20ovarian%20cancer%20in%202018.pdf>

^{xiii} Pathfinder Wales 2022: Faster, Further, Fairer (2022). Target Ovarian Cancer.

^{xiv} Khoja, L., et al. 'Improved Survival from Ovarian Cancer in Patients Treated in Phase III Trial Active Cancer Centres in the UK'. Clinical Oncology (Royal College of Radiologists (Great Britain)), vol. 28, no. 12, Dec. 2016, pp. 760–65. PubMed, <https://doi.org/10.1016/j.clon.2016.06.011>.

^{xv} Pathfinder Wales 2022: Faster, Further, Fairer (2022). Target Ovarian Cancer.