

Unheard: Women's journey through gynaecological cancer

December 2023

Summary

1. The Health and Social Care Committee published *Unheard: Women's journey through gynaecological cancer* in December 2023. This is a summary of our conclusions and recommendations. The full report, and information about our inquiry, is available at www.senedd.wales/seneddhealth.

Gynaecological cancers

2. Each year, around 1,200 people are diagnosed with a gynaecological cancer in Wales. Symptoms vary between different types of gynaecological cancers, and each have different treatment pathways, and affect women and girls in different ways. Some symptoms can include bloating, pelvic pain, bleeding between periods, pain during sex, itching and unusual vaginal discharge. Some gynaecological cancers can present late, with non-specific symptoms (such as ovarian cancer).

3. The five most frequent types of gynaecological cancer are: cervical, ovarian, endometrial (also known as womb or uterine), vaginal and vulva.

Listening to women

4. It is clear from the evidence we received that many women feel they are not being listened to by healthcare professionals.



5. There are many reasons why women are not always listened to by healthcare professionals, including gender bias and preconceptions about women's emotions or pain tolerance. Women's symptoms may be underestimated or attributed to psychological or emotional factors rather than thoroughly investigated leading to delays or missed diagnoses. There has also been a lack of medical research on female subjects, leading to misdiagnoses or inadequate care for women.

6. Not every woman who visits their GP with symptoms of a gynaecological cancer has a bad experience. But when things go wrong, they can go badly wrong, sometimes with tragic consequences. Women know their own bodies and know when something is not right so their concerns should be listened to and acted upon.

7. It is clear that women's health needs to be given a higher priority than has previously been the case. Women need to access the care they need when they need it. The health service needs to be responsive in providing that care. Most importantly, it needs to listen to women and respond to their health concerns appropriately.

The impact of the COVID-19 pandemic

8. While the pandemic inevitably had an impact, it is clear there are long-standing issues in gynaecological cancer services which pre-date COVID-19. Waiting times for gynaecological cancer treatment are very long and compliance with the single cancer pathway target is the lowest for all reported cancers. We also heard of significant capacity issues including a lack of resources, facilities and workforce.

9. We heard of services that were lost due to COVID-19 that have still not been reinstated. We agree with witnesses that the Welsh Government needs to work with health boards to make an assessment of the services that have been affected and reinstate them as a matter of urgency.

Leadership and accountability

10. Gynaecological cancers are more complex than lots of other cancers. There are different types of gynaecological cancers; some are more prevalent than others, and some have symptoms that make them easier to diagnose than others. They all present differently and therefore require different diagnostic approaches

and different clinical pathways. For those reasons, we believe there needs to be strong leadership and support around the work on gynaecological cancers.

11. We are concerned that there appears to be uncertainty between the Welsh Government, the NHS Executive and the Wales Cancer Network about their different roles and responsibilities in supporting the delivery of the gynaecological cancer pathways. This needs to be addressed immediately.

Cancer prevention

12. The main focus of cancer prevention is addressing the known risk factors. There are clear links between certain types of cancer, and smoking and obesity. This is true for some of the gynaecological cancers, and we are concerned that these links are not widely understood by women in Wales. As such, we believe there is a need for further, clearer messaging to better engage the public in the promotion of healthier lifestyle choices and the personal benefits associated with these choices.

Health promotion and symptom awareness

13. The earlier cancer is diagnosed, the easier it is to treat. But recognising the signs and symptoms of gynaecological cancers isn't straightforward because they are easily mistaken for other more common and less serious health problems. Information about the signs and symptoms of gynaecological cancers can be found at <https://eveappeal.org.uk/gynaecological-cancers/gynae-cancers-explained/>.

14. More needs to be done to raise awareness of gynaecological cancers. We are therefore calling on the Welsh Government to work with Public Health Wales and relevant stakeholders to develop and implement a series of campaigns to raise awareness about the signs and symptoms of gynaecological cancer.

Primary care – health professionals

15. We know that GPs are under enormous pressure. We understand that recognising the signs and symptoms of gynaecological cancers isn't straightforward because they are easily mistaken for other more common and less serious health problems. But too many women are being sent away with a misdiagnosis, often of irritable bowel syndrome only to find that, sadly sometimes too late, they actually have a gynaecological cancer.

16. It is therefore vital that GPs are able to access continuing medical education, focusing on gynaecological cancers, along with support from secondary care to assist them in the assessment and referral of patients with potential gynaecological cancer symptoms.

Emergency presentations

17. There will always be a certain number of cancer cases that are diagnosed through emergency admissions. However, in Wales this figure is unacceptably high.

18. The number of women being diagnosed with a gynaecological cancer following an A&E admission suggests that something is going wrong in primary care. The failure to identify those women in primary care settings raises questions about the effectiveness of the system to detect symptoms early, as well as the referral processes.

19. There needs to be a better understanding of whether there are particular types of gynaecological cancer that GPs are having difficulties identifying, meaning women are presenting late with symptoms or via A&E.

Treatment

20. It is disappointing that performance against the single cancer pathway is so poor for gynaecological cancers. We are therefore pleased that the Minister has identified gynaecological cancers as one of her priority areas. We have asked the Minister to set out her ongoing commitment to prioritising gynaecological cancer and to providing the essential attention and resources required to positively impact women's health.

Cancer workforce

21. We were deeply concerned to discover that there is no clear picture of the cancer workforce in Wales. We know there are shortages across all specialties, including radiologists, pathologists, oncologists and nurses. While we understand that people work across different specialties and these are not just cancer-related, we do not accept the Minister's suggestion that this means the cancer workforce cannot be defined. We also know that a high proportion of Wales' cancer workforce is aged over 50.

22. We have therefore asked the Welsh Government to undertake a comprehensive review of the gynaecological cancer workforce in Wales, to

identify where there are, or are likely to be, shortages, and take steps to recruit into those posts.

Information and intelligence

23. Data on the gynaecological cancers is currently pooled together. We were told that the five gynaecological cancers have very different diagnosis and treatment pathways, so when they are collated together, it is difficult to identify where pinch-points are in the system, and therefore the actions needed to make improvements.

24. We welcome the work that is being undertaken to disaggregate performance data so that it can be broken down by type of gynaecological cancer but it is disappointing that there is no timescale for the completion of this work.

Gynaecological cancer research

25. For women with rare gynaecological cancers, clinical trials can potentially be their only way of accessing treatment. Trials can offer innovative therapies that may not be available through standard treatments. However, for some women clinical trials can be hard to come by, as they are dependent on having experts in the field and we heard the infrastructure to support clinicians with cancer research and clinical trials isn't necessarily there.

26. The Welsh Government, therefore, needs to take action to develop Wales' medical research environment so that it can compete with other parts of the UK for research funding.

Palliative and end of life care

27. Palliative care is not the same as end of life care, and patients can be put on a palliative care pathway as soon as they're diagnosed with an incurable cancer to help manage their pain as their illness progresses. Palliative care can include a range of holistic treatments focusing on psychological, social, and spiritual aspects of care.

28. We have called on the Welsh Government to work with health boards and relevant stakeholders to ensure the benefits of palliative care are promoted to patients, general practitioners and clinicians in acute hospital settings to address the misconception that palliative care is only for the very end of life.

Annex: advice and support

If you're worried or have questions about cancer, or would like to access their services, you can contact Tenovus Cancer Care:

Free Support Line - 0808 808 1010
Website: [Tenovus Cancer Care](#)

Jo's Cervical Cancer Trust can answer your questions, provide reliable information or just a friendly voice to talk to:

Call 0808 802 8000
Website: [Jo's Cervical Cancer Trust](#)

If you need information, support or someone to talk to that understands, Target Ovarian Cancer's specialist nurses can help.

Call 020 7923 5475. The support line is open Monday-Friday 9-5pm.
Website: [Target Ovarian Cancer](#)

If you or someone you care about has been diagnosed with cancer, Macmillan Cancer Support is there to help.

Call 0808 808 0000 from 8am to 8pm. It's free to call from landlines and mobiles within the UK.
Website: [Macmillan Cancer Support](#)

If you're worried about any unusual symptoms you've been having, you've just been diagnosed and want to talk to a trained gynae specialist nurse, or are worried about a friend or relative who has been diagnosed, The Eve Appeal is on hand to answer questions and concerns.

Call on 0808 802 0019. It's free to call from landlines and mobile phones.
Website: [eveappeal.org.uk/supporting-you](#)