Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Canserau gynaecolegol

This response was submitted to the Health and Social Care Committee consultation on Gynaecological Cancers

GC 07

Ymateb gan: | Response from: Grŵp Trawsbleidiol ar Iechyd Menywod | Cross-Party Group on Women's Health

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WOMEN'S
HEALTH
GROUP

Re the Senedd Health and Social Care Committee's Inquiry on Gynaecological Cancers

The Cross-Party Group on Women's Health met on 15th December to discuss the diagnosis, management, and palliative care needs of those affected by gynaecological cancers in Wales.

Our guest speakers were:

Athena Lamnisos – CEO of The Eve Appeal
Jim Sweet – Patient Campaigner
Bethan Edwards – Senior Policy Officer at Marie Curie Cymru

The Group considered all five gynaecological cancers: Womb, Ovarian, Cervical, Vulva and Vaginal. Individuals affected by any of the five share similar challenges in terms of gaining a timely diagnosis. This is partly because individuals are unaware of their own risk factors but also because symptoms associated with gynaecological disease and the reproductive organs are often taboo, delaying help-seeking and meaningful conversations with healthcare professionals. Another problem is that symptoms can be misattributed to other causes, or normalised.

Each day in the UK, 60 people are diagnosed with a gynaecological cancer; of those, 21 will die. This brutal statistic is largely attributed to late diagnosis, especially ovarian cancer which is the most likely to be diagnosed at a late stage. Unlike breast cancer, there has been no improvement in outcomes for gynaecological cancer in the last 30 years.

Womb Cancer is the fourth most common cancer in females, with over 9300 people affected in the UK every year. Three quarters of those will be post-menopause. Obesity is a significant risk factor, as is a genetic condition called Lynch Syndrome. Vaginal bleeding after menopause, between periods, and unusually heavy bleeding are all key symptoms.

Ovarian Cancer affects around 7500 people each year in the UK. It is the sixth most common cancer in females and has the lowest survival rate out of all the gynaecological cancers. Eight out of ten of those affected will be over 50 years of age. There are also inherited risk factors, including the BRCA 1 or 2 gene, and being of Ashkenazi Jewish heritage. Persistent bloating, pelvic and abdominal pain, unexplained change in bowel habits, feeling full quickly or feeling nauseous during and after eating, and needing to urinate more regularly are the main symptoms.

Cervical Cancer affects over 3000 people every year in the UK, mostly aged between 30 and 45 years of age. It is very rare in under-25s. 99.8% of cervical cancers are preventable, and the UK's cervical screening programme is estimated to save over 4000 lives per year. The pandemic has caused interruptions to both the HPV vaccination and cervical screening programmes, creating gaps in the population which will lead to increased risk.

Vulval Cancer is one of the rarer cancers with about 1,350 cases diagnosed in the UK each year. Around 80% of vulval cancers are diagnosed in females over 60 but more cases are being identified in younger patients. Inflammatory skin conditions like lichen sclerosus present an increased risk.

Vaginal Cancer is the least common gynaecological cancer, with just over 250 people diagnosed in the UK each year. 40% of those diagnosed will be over 75 years of age but it can occur at any age. The incidence of vaginal cancer has remained relatively stable over the last 25 years.

The Group is particularly concerned about the challenges of making a diagnosis of ovarian cancer; NICE guidance on this topic is too vague. Trans-abdominal ultrasound scans routinely used in gynaecological settings may not pick up ovarian cancer until it is more advanced and, if patients' symptoms include a change in bowel habits and abdominal pain, they may be referred to gastroenterology or colorectal departments instead of a gynaecological cause being investigated. This results in a poorer prognosis for these patients.

The Group was informed of research underway in Wales to develop and implement an algorithm which would make symptom attribution more accurate, and the possibility of a single blood test early on in the patient journey to expedite diagnosis. The Group would like to see more investment in this sort of research and for the results to be widely shared and used to improve services in Wales.

The Group would like to also draw the Committee's attention to palliative care. ONS data suggests that in 2021, 456 females died in the UK due to 'genital organ cancers' (i.e., gynaecological cancers). In Wales over the last 5 years, patients with gynaecological cancers have had a higher number of interactions with unscheduled care, more admissions, and more bed days than the last year of life of the population as a whole. The Group would like to see this statistic explored in more depth, to better understand the experiences and needs of this patient population.

Existing research into women's experiences of end-of-life care is inadequate; what there is suggests that there are differences in how some women report symptoms, the pain they experience, and the treatment they receive as they approach end of life. Multiple international studies have shown increased risk of chronic pain among women and there is also evidence to suggest that women must report higher levels of pain (compared to men) for healthcare professionals to identify and document their symptoms. In some instances, women report feeling that their pain is wrongly attributed to a psychological rather than a physical cause.

This can lead to unmet palliative care needs, and ultimately, a poorer quality of life for women living with terminal illness, including a gynaecological cancer.

The Cross-Party Group on Women's Health would like the Health & Social Care Committee to focus on the following issues relating to gynaecological cancers:

- The need for investment in research into the incidence and detection of gynaecological cancers, alongside awareness-raising of the signs and symptoms. Improving health literacy in Wales's population would help take the anxiety out of a gynaecological diagnosis and make conversations with GPs easier.
- Pay attention to those who, due to the pandemic, have not participated in the HPV vaccination or cervical screening programmes.
- Gynaecology waiting lists in Wales are at their longest ever according to evidence from multiple sources, including the Royal College of Obstetricians & Gynaecologists, due to pandemic-related deprioritisation of the specialty. This further increases risks for those with a possible cancer. More needs to be done to address insufficient staff and theatre capacity for gynaecology services, along with misconceptions that gynaecological issues are not as important or as serious as other health areas.
- Integration of services: the lack of communication between gastroenterology, colorectal, and gynaecology departments, particularly in relation to ovarian cancer, is a significant barrier to effective care.

- The need to develop Women's Health Hubs to promote more holistic services and provide greater opportunity to talk to women about health risk factors.
- Better diagnostic guidelines and systemic implementation in Wales: NICE guidelines on ovarian cancer are currently under review and set to be published in 2024. The Group agreed that improved guidelines are insufficient if there is no enforcement process in place.
- Investment in research looking specifically at sex- and gender- inequalities in end-of-life care, specifically in a Welsh context, to make sure that women can have the end-of-life care experience they desire.

13th January 2023