

**Senedd Briefing:
Debate on the Health and Social Care
Committee report
*Unheard: Women's journey through
gynaecological cancer***



**Estyn gobaith. Estyn llaw.
Give hope. Help cope.
tenovuscancercare.org.uk**

**Call our free Support Line
0808 808 1010
Ffoniwch ein Llinell Gymorth rhadffôn**

Background

Gynaecological cancers include womb (uterus), ovarian, cervical, vulval and vaginal cancers.

In July 2022, when the Health and Social Care Committee started their inquiry into Gynaecological Cancers in Wales only 34.6% of cases met the Single Cancer Pathway target (the percentage of patients starting their first definitive treatment in the month within 62 days of first being suspected of cancer), today that figure stands at 32.2%.

On the 15th May 2024 the Senedd debates NDM8581 tabled by Russell George MS concerning [Unheard: Women's journey through gynaecological cancer](#).

Giving Voice to the *Unheard*

Tenovus Cancer Care has been instrumental in ensuring that the voices of women, and people affected by gynaecological cancers, are at the heart of the inquiry. They are victims of systemic failures.

At the start of the evidence gathering stage, we spoke to Senedd committee and citizen engagement officials and made the case for recording and submitting - as evidence - the voices and experiences of women with gynaecological cancers. We know through our work with people affected by cancer, that stories can be recorded sensitively, and have lasting impact on their audience. Tenovus Cancer Care, and other cancer charities managed to secure the support of several women. Their powerful video evidence was watched by Members of the Committee during the inquiry.

One of the witnesses, [Judith Rowlands, died from her cancer](#) during the inquiry. Judith was a Tenovus Cancer Care service-user with (terminal) endometrial cancer. She was determined to share her story despite her own deteriorating health. Judith sadly passed away shortly after her video evidence was shown to the committee but was determined that other women should not have to go through what she experienced. She found the experience of being able to tell her story empowering and cathartic.

The inquiry report [Unheard: Women's journey through gynaecological cancer](#) was published towards the end of 2023, we remain grateful to the Health and Social Care Committee for acknowledging our role in helping to collate this form of evidence, which we wholeheartedly welcome.

[The Welsh Government responded](#) to the report in March. The Committee invited Tenovus Cancer Care to comment.

The rest of this briefing paper focuses on our comments to the Welsh Government response, which we submitted to the Committee last month.

Accepted Recommendations

We tentatively welcome the fact that 18 of the 26 inquiry report recommendations have been accepted by the Welsh Government – proof, if any were needed, in the powerful evidence delivered by the contributors during the inquiry.

However, we are concerned that most are at least cost neutral, a regrettable signal to women affected by gynaecological cancers that investment in resolving the issues uncovered by the inquiry is not forthcoming despite claims that gynaecological cancers are a priority for Welsh Government and NHS Wales. We also have concerns regarding implementation of these recommendations, and where operational responsibility and consequential accountability lies.

Alongside the Wales Cancer Network's Cancer Improvement Plan, and an existing Cancer Site Group (CSG) for gynaecological cancers, a new Cancer Recovery Programme is being produced by the NHS Executive's Planned Care directorate, following instructions, and funding, from the Cabinet Secretary for Health.

We would welcome clarity from the Welsh Government to ensure that effort and activity are not duplicated; that lines of accountability are clear; and the third sector and other stakeholders - advocating on behalf of patients - are able to scrutinise and contribute to plans that are intended to deliver service improvement.

Accepted in Part Recommendations

Since there are fewer of these, we will focus on each in turn.

Recommendation 2. Our earlier concern about responsibility and accountability applies here too. Without clear lines we fear delays, duplication, and diluted efforts.

Recommendation 8. We welcome the Cabinet Secretary for Health's agreement to provide a written statement concerning HPV vaccination and screening. It is critically important, for the future health of young women and young men that Wales achieves vaccination and cervical screening targets.

The response from Welsh Government fails to mention that the first definitive treatment target rises to 80% from 75% in 2026, we feel it is important to keep this near-future target in mind since it should be informing Health Board planning as set out within the [Cancer Improvement Plan](#) (pg 30). That is unless the 75% target set within the [Cancer Quality Statement](#) (point 20) takes precedence. Clarity from the Cabinet Secretary for Health would be welcome.

Recommendation 12. We query the rose-tinted picture painted by the Welsh Government in the first half of their response.

While all support from the Welsh Government and the NHS is welcome, "amplification" may take the form of social media posts by Government accounts and some local health board accounts. Unless the Welsh Government provides recent evidence to the contrary there is little or no consistency and co-ordination, and no funding or in-kind contributions.

For relatively small amounts of funding, Welsh Government, through the Wales Cancer Network, Public Health Wales and others could develop a range of campaigns, online and offline, targeted at at-risk audiences. It could also develop a more formal framework/process for engaging with cancer charities that have developed and fund their own cancer awareness campaigns.

We are aware of another, albeit non-gynaecological cancer, campaign developed by a member of the Wales Cancer Alliance (and endorsed by NHS England with approved use of its logo) where a request for Welsh Government endorsement was denied. That charity is now examining other routes to securing NHS Wales endorsement.

Recommendation 14. It's unclear what parts of the recommendation the Welsh Government accepts – and what activity will happen. Instead, a long list of activity has been produced.

Also, the picture isn't complete, not all women with gynaecological cancers are presenting/being diagnosed through their GP. A significant number are presenting in A&E, though any attempt to get to the bottom of this will be delayed because of the Welsh Government's response to Recommendation 15 (below).

Accepted in Principle Recommendations

Again, since there are only two, we've responded to these individually.

Recommendation 3. We're disappointed the response rules out specific funding or focus on gynaecological cancer research considering the evidence considered by the Committee. Whilst we understand that the Welsh Government has prioritised gynaecological cancer as one of their three cancer priorities to improve outcomes, we see little evidence of this translating into definitive focus on research into this area of cancer. We feel this is a missed opportunity and trust the Committee will engage with the Wales Cancer Research Centre (WCRC) to explore how the Committee's findings can align with activity resulting from the Cancer Research Strategy for Wales.

Recommendation 17. We welcome the response and appreciate that access to new cancer drugs and new treatments is also becoming more dependent on workforce resources and additional capacity in areas such as genetic testing. We hope the All-Wales Therapeutics and Toxicology Centre (AWTTC) and other NHS bodies consider ongoing engagement with the third sector to consider how these challenges are overcome and how improvements can be made to the

ways they are communicated to the public. If Wales does not get to grips with the wider system changes needed to make new medicines routinely available when they are newly recommended, patients in Wales will quickly become disadvantaged compared to their counterparts in other parts of the UK.

Rejected Recommendations

Finally, we have responded below to the two recommendations which were rejected by Government.

Recommendation 4. The clinicians we spoke to during the inquiry called for the gynaecological cancer clinical capacity that had existed before the pandemic to return. The rationale presented by the Welsh Government, during a period when the number of women starting their cancer treatment within the 62-day target is at an all-time low is baffling.

There has never been any intention, nor wish, to reintroduce the pre-pandemic clinical service model, the clinical capacity lost during the pandemic would service the gynaecological cancers national optimal pathway (NOP) and we will be urging Welsh Government to reconsider this stance within the context of the new Cancer Recovery Plan and the future delivery of the gynaecological cancers NOP.

Recommendation 15. We're disappointed that despite being prioritised by the Cabinet Secretary for Health (alongside lower GI and urological cancers) funding cannot be found and allocated to this piece of much needed work. While the six-month timescale might be challenging, it could have been achieved, adopting a similar method, model, and analysis used to examine A&E presentation of Upper GI cancers. We intend to speak to stakeholders and other interested parties to see how this piece of work can proceed despite rejection by the Welsh Government.

Beyond the *Unheard* Report

One of Tenovus Cancer Care's main aims is to work alongside people affected by cancer to champion their needs, raise awareness of the issues faced and campaign to bring about change.

We are continuing to work to support women with gynaecological cancer to increase awareness of their experiences of their diagnosis and treatment.

We have been shocked at the number of responses we have received in relation to the stories we helped bring to the attention of the Senedd's Health and Social Care Committee as part of their inquiry.

While absolute numbers of patients and patient satisfaction rates might be high, they mask concerning instances of poor patient experience.

A single case is one case too many, lessons must be learnt. The lottery cannot be allowed to continue.

It is vital that Members continue to support women and ensure that the recommendations contained within *Unheard* are implemented in full and with a sense of urgency.

We want the Health and Social Care Committee to review progress against their inquiry recommendations before the next Senedd election in 2026.

Claire's Campaign

Tenovus Cancer Care is collaborating with Claire O'Shea – one of the inquiry witnesses - to develop *Claire's Campaign* where she will shine a light on her experience of a late diagnosis, leading to her terminal diagnosis of cancer.

We are proud to be working in association with both Claire and Deryn Consulting, who are providing practical support on the development of the campaign website and assets and will work to ensure that Claire is supported to spearhead the campaign whilst working in the background to influence positive policy and system change to improve waiting times, and particularly the diagnostic experiences of women with gynaecological cancer.

A separate paper concerning *Claire's Campaign* will be shared with Members prior to the gynaecological cancers inquiry debate on the 15th May.

If you would like more information about how you can support this area of work, please contact Greg Pycroft, Policy and Public Affairs Manager at Tenovus Cancer Care greg.pycroft@tenovuscancercare.org.uk