Claire's campaign

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Peter Fox MS, Chair
Health and Social Care Committee
Senedd Cymru
Cardiff
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Our Ref: 001/PF/Unheard
Your Ref:

Dear Mr Fox,

Thank you for this opportunity to respond to the correspondence issued by the Welsh Government in response to the Health and Social Care committee enquiries concerning implementation of the *Unheard* report recommendations.

Before issuing our response Committee questions we also want to express our sincere gratitude to the Health and Social Care Committee for finding the time to revisit their earlier inquiry into gynaecological cancer services that led to the publication of the *Unheard* report and conducting this short inquiry before the end of the current Senedd term.

We trust you understand our sense of urgency and ongoing desire to implement the report findings. We at Claire's Campaign continue to find that too many women have poor gynaecological cancer experiences. We collectively have a responsibility to ensure that the bravery and honesty of women like Judith Rowlands and Claire O'Shea, who shared their stories with the Committee during its inquiry - and have subsequently died - is not in vain.

**1. Prioritisation and the Women's Health Plan**

*1.1 What specific outcomes or actions are missing by not including gynaecological cancer directly in the Women's Health Plan?*

Given the broad scope and range of issues related to the poor outcomes described in the "Unheard" report, inclusion within the Women's Health Plan offered an opportunity to take a holistic approach over a decade. We would have the time and space to work with the women affected to plan for, develop and resource the necessary interventions. Ten years would allow for an iterative approach to activity, drawing out and scaling up what works.

Instead, some activity related to gynaecological cancer planning is within the "integrated" cancer plan, vying with four other "priority" tumour sites. That plan is due to expire in 2026.

Inclusion within the Women's Health Plan would ensure dedicated funding, workforce planning, and public-facing accountability for all issues related to gynaecological cancers, rather than being part of a broader, more diffuse cancer plan.

*1.2 Do you feel the current national cancer strategies are not sufficiently addressing the needs related to gynaecological cancer?*

At the time of the *Unheard* report's publication (December 2023) gynaecological cancer had been made one of three priority tumour sites by the Welsh Government. Responsibility for gynaecological cancer (and addressing many of the report's recommendations) fell on the NHS Executive's Cancer Recovery Programme (part of its Strategic Programme for Planned Care – where there was no third sector representation) and in more broad terms on the Wales Strategic Network for Cancer (where third sector representation was nominally located), this is where the gynaecological cancer site group would be found.

Scrutinising and holding to account these two bodies would prove a struggle. In practice, responsibilities and accountability spanned the NHS Wales Executive (now NHS Wales Performance and Improvement), Public Health Wales (screening, prevention, data), Health and Care Research Wales (research, trials, innovation), health boards (local delivery) and Health Education and Improvement Wales (workforce culture and training). This complex matrix of ownership is not published, nor is it easily understood by those of us in the third sector with years of experience.

*1.3 Is the concern more about visibility and accountability, or are there specific service gaps?*

The recent integration of the Cancer Recovery Programme and Strategic Network for Cancer offers hope that lines of accountability are clearer, and scrutiny by the third sector should be more viable. However – twenty months on from publication of the Unheard report - there is no transparent framework assigning accountability for delivery, leaving patients, the third sector, and the Senedd unable to reliably track progress against commitments.

From insight we acquired relatively recently we understand that the Gynaecological Clinical Implementation Network (CIN) held quarterly meetings with representation from partners from across the then NHS Wales Executive, reviewing progress against the *Unheard* report recommendations. This information was not referred to in the response from the Cabinet Secretary to the Committee. We understand that the CIN last met in March 2025.

*1.4 What would help reassure you that gynaecological cancer is being treated as a priority?*

We welcome the assertion in the recent Integrated Cancer Workplan that gynaecological cancers remain a priority, that is not in doubt. Welsh Government should publish an accountability framework setting out which body or programme lead is responsible for each recommendation, with clear lines of oversight and a mechanism for reporting progress. This would enable meaningful scrutiny, reassure stakeholders and restore confidence that accepted commitments are being actioned.

Transparent accountability and, public reporting on progress against specific, measurable indicators (i.e. reduction in waiting times, progress on pathway redesign/optimisation, publication or sharing with the third sector of more granular - tumour site - data).

**2. Progress on Recommendations**

*2.1 Which parts of the response do you feel represent real progress?*

The commitment to prioritising gynaecological cancers, despite the ongoing challenges across the NHS is positive and welcome, we do not doubt the sincerely held commitment of Welsh Government Ministers to tackling the challenges yet translating that commitment into a transparent plan of action is lacking.

We also welcome the production of Unheard training for GP CPD, but we don't know whether there was patient involvement in the production of the content.

Recent work by Hywel Dda UHB demonstrates how *smarter service design* can ease pressure on urgent cancer pathways. Their Enhanced Community Gynaecology Service offers a consultant-led, one-stop clinic with on-the-spot diagnostics, allowing women to receive a diagnosis and treatment plan in a single visit closer to home. Early evaluation indicates significant benefits: reduced pressure on urgent pathways, release of radiology capacity through clinician-delivered ultrasound, and estimated savings of £268 per patient (over £4.4m if scaled across Wales).

While this development is highly positive for women on HRT, it also demonstrates that gynaecological cancer services more broadly can be reimagined to deliver faster diagnosis, reduce unnecessary pressure on urgent pathways, and improve patient experience. It is proof that more can and should be done — if such innovation is possible in one area, it should drive wider ambition for gynaecological cancers across Wales.

*2.2 Where do you think the biggest gaps still lie?*

Recognition and inclusion in the Women's Health Plan, a decade long plan for targeted, resourced, meaningful action rather than the alternative, a twelve-month long integrated cancer work plan that's incentivised to prioritise "easier" to diagnose and treat cancers to improve overall waiting times.

*2.3 What would help you feel more confident that the recommendations are being taken seriously?*

We believe in the ongoing sincerity of everyone to want to improve gynaecological cancer outcomes, but processes and systems have not felt up to the challenge. We need to move from "work in progress" and lack of transparency to demonstrable outcomes in this space.

An accountability framework would assist. Would be transparent, enable meaningful scrutiny, reassure stakeholders and restore confidence that accepted commitments are being actioned.

*2.4 Do you think the planned women's health hubs will meet the needs of women with gynaecological cancers?*

The Cabinet Secretary's response and later Welsh Government communications have placed emphasis on the forthcoming women's health hubs under the Women's Health Plan. These hubs aim to deliver services around menstrual health, menopause, contraception, and pelvic health—but they were not a recommendation from the Health Committee. Details about their remit remain limited; current commitments centre on workforce scoping and pathfinder models by 2026, with the framing skewed toward menopause and menstrual conditions. There is no explicit indication of how hubs will interface with gynaecological cancer pathways, screening, or early diagnosis.

Therefore, while hubs may represent a positive development in women's health, they cannot be interpreted as progress against Unheard report recommendations on gynaecological cancers. Without clear links to cancer data, access, or pathways, there is a risk that they remain parallel initiatives rather than core components of the Committee's stated priorities.

**3. Transparency and Accountability**

*3.1 Does the Welsh Government's response provide enough clarity and accountability?*

The Cabinet Secretary's assertion that "many recommendations do not lend themselves to ongoing reporting" is a concern and seems to justify a lack of transparent tracking, especially when we know that the Gynaecological Clinical Implementation Network (CIN) has attempted to track progress against the *Unheard* report recommendations on a quarterly basis. The Welsh Government could have made the

assertion in response to the publication of the *Unheard* report or in the plenary debate in 2024, but chose not to do so, what has changed in the intervening months?

*3.2 What kind of reporting or updates would help you feel confident?*

See our response to 1.4, above.

*3.3 Are there specific areas where you feel more urgent action is needed?*

The following have been drawn from the Executive Summary of our Senedd Briefing: Implementation of the *Unheard* Report Recommendations

**Leadership, Governance & Strategic Direction**

1. Nearly two years after the Senedd called for action, gynaecological cancers still don't feature meaningfully in the Women's Health Plan. Women with gynaecological cancers do not have the visibility or priority they demonstrably need in national policy.

2. Targets delayed, progress unclear – Welsh Government accepted the need for measurable NHS targets on gynaecological cancers almost two years ago, and said work was "already underway." But no targets have yet been published, while performance has swung from 52% in March 2025 to just 36% two months later. Patients and staff deserve clarity and stability.

3. Variation across Wales – Cardiff & Vale reached 62.5% of patients treated on time in May, while Hywel Dda managed only 16.7%. National planning and regional working is needed to make sure timely cancer care doesn't depend on where you live.

**Research, Innovation & Clinical Trials**

4. A missed chance for focus – Nearly two years on, the idea of a specialist gynaecological cancer research centre hasn't been explored. For cancers with some of the poorest survival rates, this feels like unfinished business.

5. Trials standing still – There are still only 13 gynaecological cancer trials open in Wales — the same as when Government first responded. Without a plan to expand access or recruitment, patients are left with limited options.

6. Aspirations need follow-through – Investment headlines look good, £3m for a Women's Health Centre, £750k for research, but without ring-fenced gynaecological cancer funding translating into delivery is patchy and reliant on ad-hoc bids. One welcome funding theme is around clearer communication with women and girls about their health needs, something that could strengthen gynaecological cancer work if taken forward.

**Screening, Prevention & Early Detection**

7. HPV vaccine progress but gaps remain – Wales is still short of the WHO's 90% HPV coverage target. Uptake among 15-year-olds is around 73%, leaving thousands of girls and boys at risk of preventable cancers.

8. Emergency diagnoses remain too high – Around 41% of women with ovarian cancer in Wales are diagnosed following an emergency admission, a route linked to worse outcomes. Rare gynaecological cancers like Claire O'Shea's face the same challenge. The Unheard report recommended a targeted review, but this has not been commissioned, we were desperately

disappointed when the Welsh Government rejected this recommendation. Yet, NHS Performance and Improvement are commissioning research into routes to cancer diagnosis that include the emergency route, a welcome development. Without this pathway optimisation remains an unaddressed dream.

**Diagnosis, Pathways & Primary Care**

9. Measuring impact matters – GPs are being offered training via GatewayC, but without evaluation we don't know if referrals are improving or cancers being caught earlier. Right now, we cannot measure or scrutinise progress.

10. Health hubs need clear links – Women's Health Hubs could become an important resource, but their current focus is on menopause and menstrual health rather than cancer. Unless clear linkages and referral pathways are built into the new Hubs there's a risk of missing an important opportunity to listen to women and diagnose more gynaecological cancers earlier.

**Dignity, Respect & Experience of Care**

11. Turning promises into practice – The Women's Health Plan commits to women being 'listened to,' but gynaecological cancers are absent. Despite calls from Tenovus Cancer Care and the Unheard report, they weren't included at all. That means no plan, no standards, and no way to measure whether women with these cancers are being heard.

**Palliative & End-of-Life Care**

12. Securing the future – The national specification is out for engagement, but without a sustainable funding model and clear milestones for boards, families may still face variation in end-of-life support.

**4. Waiting Times**

*4.1 Do you feel the Welsh Government's explanation and current actions are sufficient?*

The Cabinet Secretary highlighted an improvement cancer waiting times from 27% of patients starting their cancer treatment within 62 days of diagnosis (Dec 2023) to 45.5% (Apr 2025). However there remains volatility in gynaecological cancer waiting times 45.5% (Apr 25), a sharp drop to 36.5% (May 25), before rising again to 47% (Jun 25) and sharply falling again to 32.4% (Jul 25). This is in stark contrast with the national average across all tumour sites, which has remained broadly steady and increased from the mid-50s to low-60 percent. Why the difference?

Variation remains a critical concern: earlier this year (May 2025) Cardiff & Vale reached 62.5%, while Hywel Dda was just 16.7%, yet in July 2025 Cardiff & Vale's waiting times has fallen to 28.6% while Hywel Dda had risen to 40% . Without published, accessible thresholds or milestones to hold services accountable, progress remains inconsistent, fragile, and prone to fluctuation rather than steady improvement. It's also important to remember and reflect that behind all these percentages are people with a cancer diagnosis and their families. In far too many cases, depending on where they live, the likelihood that they'll receive timely gynaecological cancer treatment comes down to something between a roll of the dice and a coin-toss

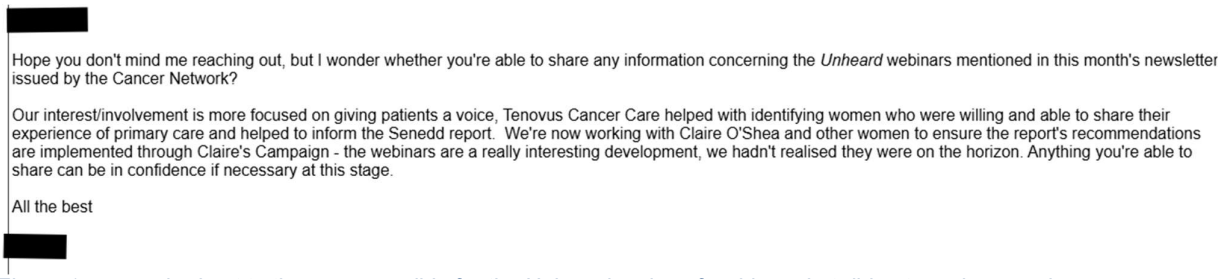
*4.2 What further steps or transparency would you like to see?*

See our response to 1.4, above.

## 5. Patient and Public Involvement

*5.1 Do you feel that people affected by gynaecological cancer are being meaningfully involved?*

In those few instances where we manage to secure the ear of those involved in the development of programmes of work and delivery of services, we feel that Claire's Campaign has been listened to, but that's not the same as being meaningfully involved. For example, earlier this year we became aware that "Unheard" themed CPD for GPs was in development. We reached out to the then NHS Executive to better understand the proposal (and hopefully share insight) but heard nothing back (fig 1).



Hope you don't mind me reaching out, but I wonder whether you're able to share any information concerning the *Unheard* webinars mentioned in this month's newsletter issued by the Cancer Network?

Our interest/involvement is more focused on giving patients a voice, Tenovus Cancer Care helped with identifying women who were willing and able to share their experience of primary care and helped to inform the Senedd report. We're now working with Claire O'Shea and other women to ensure the report's recommendations are implemented through Claire's Campaign - the webinars are a really interesting development, we hadn't realised they were on the horizon. Anything you're able to share can be in confidence if necessary at this stage.

All the best

*Figure 1 we reached out to those responsible for the Unheard series of webinars but did not receive a reply.*

Constraints on our limited capacity, and the change in Claire's condition earlier this year, meant that we were unable to follow up.

Conversely, there have been instances over the past couple of years when the campaign has been kept informed of developments – we were kept informed of plans to commission a clinical fellow to better understand cancer diagnosis in an emergency setting. This has been appreciated since the work goes some way to addressing the rejected Unheard report recommendation 15.

*5.2 What would better engagement look like?*

We feel that our suggestion under 1.4 (above) for an accountability framework would be the correct forum/process for setting engagement-related expectations.

Representatives from Claire's Campaign are present at engagement events that are related to the Women's Health Plan to better understand developments related to listening and acting on women's concerns (recommendation 1 in the *Unheard* report).

## 6. Rejection of Recommendation 15

*6.1 Do you feel the current focus on prevention and early detection is balanced with the need to support those in emergency settings?*

We feel that it is not. The rejection of this recommendation by the Welsh Government was alarming and demonstrated a lack of commitment to understanding the full patient journey, especially for those with the most critical needs. The rejection was based on the Committee's proposed deadline of six-months and associated pressures. Rather than propose a longer, less pressured timescale, the Welsh Government chose to reject the approach outright.

We therefore welcome the subsequent decision by the then Cancer Recovery Programme to develop and commission a clinical research fellow to examine routes to cancer diagnosis, including the emergency route. A cancer recovery fellow will start in September 2025 to review routes to diagnosis across several priority tumour sites (including ovarian cancer) using existing data sources and the SAIL Databank. This

piece of work will help us all to identify and understand areas to improve pathway efficiency, including the emergency route. While this research will not cover all gynaecological cancers it is an important start.

The focus on early detection is vital – so is tackling the poor cancer waiting times from suspicion to treatment, however these cannot be used as an excuse to ignore the problem of emergency presentations, which are associated with late-stage cancers and poorer outcomes, as well as additional pressure on A&E services.

*6.2 What would you expect to see from the Welsh Government to ensure these patients aren't left behind?*

We would expect the Welsh Government to commit to implementing the findings of the routes to diagnosis research are implemented when they are published.

**7. Identified Barriers**

*7.1 Do you feel the Welsh Government has clearly identified and committed to overcoming the barriers?*

While the Welsh Government has identified a critical barrier (capacity) and has had time to plot, plan and resource a course of action it has yet to provide a credible plan. In the meantime, campaigns like Claire's Campaign have expended considerable amounts of time and energy "trying" to inform, scrutinise and hold the system to account for those actions and tasks that have some relationship to the findings and recommendations of the *Unheard* report.

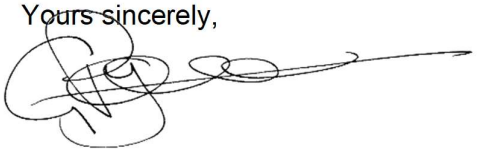
While capacity might well be a barrier for the Welsh Government, we believe that a clear accountability framework is another barrier to the implementation of the Unheard report recommendations.

*7.2 What specific actions or assurances would you expect to see?*

We would expect to see greater recognition of gynaecological cancers within the women's health plan, resolving that omission and facilitating greater engagement with developments in that space – for instance women's health hubs. Also, as per 1.4 (above) an accountability framework, would promote transparency, engagement and overall accountability.

If you require any additional information or insight that might assist the Committee with its short inquiry, please do contact me in the first instance.

Yours sincerely,



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