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*Ar gael yn ddwyieithog | Available bilingually

Rhif | Number	Sefydliad	Organisation
FGC 01*	Marie Curie	Marie Curie
FGC 02	British Gynaecological Cancer Society	British Gynaecological Cancer Society
FGC 03	Gofal Canser Tenovus & Ymgyrch Claire	Tenovus Cancer Care & Claire's Campaign
FGC 04	Royal College of General Practitioners (RGCP)	Royal College of General Practitioners (RGCP)
FGC 05	Target Ovarian Cancer	Target Ovarian Cancer
FGC 06	Fair Treatment for the Women of Wales (FTWW)	Fair Treatment for the Women of Wales (FTWW)
*FGC 07	Iechyd Cyhoeddus Cymru	Public Health Wales

Unheard: Women's journey through gynaecological cancer

Health and Social Care Committee Short Inquiry

September 2025

1. Introduction

Marie Curie are pleased to provide evidence as part of the Health and Social Care Committee's short inquiry to scrutinise the implementation of the Committee's report *Unheard: Women's journey through gynaecological cancer*.

Our response below focuses on progress in implementing the two recommendations specifically related to palliative and end of life care, highlighting some ongoing challenges that prevent an accurate picture of how women with terminal gynaecological cancers are accessing and experiencing palliative and end of life care.

2. Palliative and end of life care in Wales

2.1. End of life care in Wales is at breaking point. Gaps in care and a system under severe pressure mean too many people are spending their final days isolated, in pain, and struggling to make ends meet.

2.2. Wales has an emerging policy framework for palliative and end of life care. The quality statement sets out a clear destination that government, health boards and providers should be working towards. The forthcoming service specification and commissioning framework for hospice services should support greater consistency in delivery towards these high-level ambitions.

2.3. However, we currently have a significant implementation gap.

2.3.1. 37% of bereaved people reported that healthcare professionals had not discussed death and dying with the person who died.[1]

2.3.2. Almost one in five people in Wales had no contact with a GP either in person or over the phone in their final three months of life.[2]

2.3.3. Of every emergency department attendance in Wales, one in 14 is related to someone in the last year of life.[3]

2.3.4. In 2023, on average, over a fifth of hospital beds in Wales were occupied every day by people in the last year of life.[4]

2.4. It is in this context that women with terminal gynaecological cancer will be seeking care and support.

3. Recommendation 25: The Welsh Government should 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

3.1. The current data landscape makes it very difficult, if not impossible, for organisations such as ourselves to determine whether women with terminal gynaecological cancer are being referred to palliative care at the appropriate time, whether women are accessing palliative care services and whether those services are meeting women's needs.

3.2. Without regular, publicly available data it is very difficult to determine whether the ambitions of the quality statement are being realised, particularly in relation to specific groups of people.

3.3. As the service specification for palliative and end of life care has been developed, we have made clear the need for KPIs underpinned by robust monitoring. The specification is due to be published in October 2025 and we hope that this will include the necessary KPIs and routine monitoring that is essential to the successful implementation of the quality statement.

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[1] Marie Curie (2024) *Time to care in Wales Implications for Wales of 'Time to Care: Findings from a nationally representative survey of experiences at the end of life in England and Wales'*

[2] Ibid.

[3] Marie Curie (2025) *At breaking point: Time to transform end of life care in Wales* https://www.mariecurie.org.uk/get-involved/campaigns/senedd-manifesto

[4] Ibid.

4. Recommendation 26: In its response to this report, the Welsh Government should provide an update on the progress it has made in implementing the quality statement for palliative and end of life care, and specifically how it is ensuring access to palliative care is underpinned by equity

4.1. In the formal response to the Committee's report the Welsh Government provided a short update on how the quality statement for palliative and end of life care is being implemented. A more substantive written statement was laid in October 2024 on improving access to palliative and end of life care.[5] While this was not in direct response to the committee's report, it did provide an important update on progress and ministerial priorities.

4.2. The written statement addressed a number of key issues:

4.2.1. **Funding**: additional funding from Welsh Government to support hospice services is very welcome, including the annual £3m allocated from the 2025-26 budget onwards. The statement referenced an ongoing commitment to find a sustainable funding settlement, including a commissioning framework for Wales. Progress on the commissioning framework has been slow, with it now due for publication by end of March 2026. While commitments have been made to keep hospice providers up to date with the latest iteration of the framework as it's finalised over the autumn, the delay does create challenges as hospices look to set budgets and make operational decisions ahead of the 2026-27 financial year.

The statement also made reference to Further Faster as the vehicle through which out of hours capacity of district nursing and community clinical nurse specialists would be increased. It is not clear what impact Further Faster has had on the delivery of out of hours palliative care. Improving access to primary care, especially out of hours, overnight and at weekends remains a critical issue, which could reduce avoidable hospital admissions for people living with a terminal illness.

4.2.2. **Role of the national palliative and end of life care programme:** the national programme does provide important leadership on

[5] https://www.gov.wales/written-statement-improving-access-palliative-and-end-life-care [Accessed Sept. 2025]

palliative and end of life care and we have enjoyed a constructive working relationship with the board. Recent changes, including the transition from NHS Wales Executive to NHS Wales Performance and Improvement, have impacted on how regularly the programme board has met in 2025-26. Moving into the autumn, it will be important to get back to regular meetings so that stakeholder advisory groups can be fully engaged in the work of the national programme.

4.2.3. **Service specification for palliative and end of life care:** the written statement notes the development of a service specification for palliative and end of life care. This is a critical element of the strategic framework for palliative care, which should support more effective and consistent delivery towards achieving the ambitions of the quality statement for palliative and end of life care. Progress on this service specification has been slow, although we do welcome the ongoing consultation and engagement by the national programme throughout the development process. The service specification is now due for publication in October 2025. Usability will be critically important to ensure that all parts of the health and social care system understand the expectations for palliative and end of life care delivery.

4.2.4. **Workforce**: the written statement notes an ambition to recruit and retain a motivated and skilled palliative and end of life care workforce and the development of a core competency framework. We welcome the development of the competency framework.

If we are to deliver equitable palliative and end of life care we must recognise that people living with a terminal illness get care and support from across the health and social care system, not just specialist palliative care teams. It's therefore imperative that the skills, knowledge and capacity for supporting people with a terminal illness are strengthened throughout the health and social care system. The core competency framework can play a key role in achieving this but must be accessible to all health and social care professionals and be supported with realistic implementation plans and investment, to not only provide newly qualified professionals with the relevant skills but also to upskill the existing workforce.

We still lack a clear picture of the palliative and end of life care workforce in Wales. This is why we have called for a regular palliative and end of life care workforce census to ensure we have an accurate picture to inform workforce planning and development.[6]

4.2.5. **Data:** as outlined above, data remains a critical challenge. It's currently very difficult to get an accurate picture as to whether people are accessing the care they need. This is even more acute when looking to apply an equity lens. We must urgently improve the availability of data so that organisations involved in the delivery of palliative and end of life care can clearly understand the gaps and opportunities at both health board and national level. This is also a critical challenge to overcome if the service specification is to be underpinned by reliable, measurable KPIs.

4.2.6. **Equity:** in terms of equity there is still much to be done. It is near impossible to assess whether current services are reaching people equitably with the available data. This is why we have called for a review to determine whether services are meeting the needs of minoritised and disadvantaged groups.[7]

It's imperative that the forthcoming service specification addresses equity, however the draft that was consulted upon earlier this year needed further work to do this effectively. While high level aspirations were set out this did not translate into tangible actions for health boards, commissioning bodies and providers. We hope this will be addressed in the final version due for publication in October 2025.

For more information please contact:

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[redacted]

Dr Tomos Evans
Policy and Public Affairs Manager, Wales
[redacted]

[6] Marie Curie (2025) *At breaking point: Time to transform end of life care in Wales*
[7] Ibid.

Please find the British Gynaecological Cancer Society Response to Heb lais: Taith menywod drwy ganser gynaecolegol.

We note that finances have been set aside for cancer separately as part of the cancer improvement plan/ Cancer Recovery Programme and the Women's Health Plan is to put funds into areas other than cancer in women's health. There have been some improvements since the initial report of the Unheard: women's journey through gynaecological cancer in December 2023 however there is still a long way to go. The performance with waiting times remains poor with lesser than 50% gynaecological cancer patients starting their treatment within 62 days. There are still issues with recruitment of adequate workforces within Wales. There is no uniformity in care received across Wales and still issues related to patients presenting as emergency admissions. As a final addition we would implore the Senedd to strive for closer integration with the other nation states with respect to data sharing and national audits. These audits are significant driver to improve outcomes across the whole of UK by identifying good practice and highlighting areas of significant need.

Best wishes

Mr Andrew Phillips (He/Him)
Consultant Gynaecological Oncologist
Lead Cancer Clinician at University Hospitals of Derby and Burton NHS FT
British Gynaecological Cancer Society Secretary.

Claire's campaign

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Peter Fox MS, Chair
Health and Social Care Committee
Senedd Cymru
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18 September 2025
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

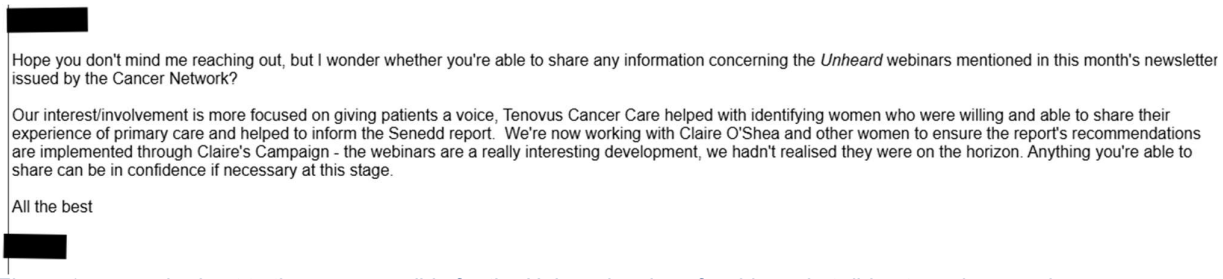
4.2 What further steps or transparency would you like to see?

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.

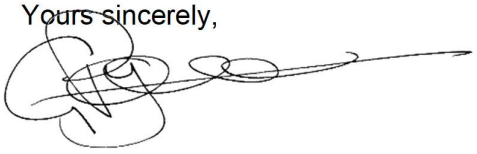
While capacity might well be a barrier for the Welsh Government, we believe that a clear accountability framework is another barrier to the implementation of the Unheard report recommendations.

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,



Greg Pycroft
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Tenovus Cancer Care

tenovus cancer care
gofal canser

Claire's campaign

Senedd Briefing:

Implementation of the Unheard Report Recommendations

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Executive Summary

Our external assessment has been made by a small team from within Claire's Campaign and Tenovus Cancer Care using public sources of information and through conversations with clinical and management staff in the NHS.

From our analysis of these sources of information in the twenty months since the publication of the *Unheard* report, three (3) recommendations have been actioned, seven (7) show partial progress, and fifteen (15) remain undelivered. While there are positive steps in a few areas, significant delays persist across screening, diagnosis, workforce, and data, with real implications for gynaecological cancer patient outcomes and public confidence.

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 and lies at 32.4% in July 2025. Patients and staff deserve clarity and stability.
3. **Variation across Wales** – Cardiff & Vale reached 62.5% of patients treated on time in May 2025, while Hywel Dda managed only 16.7%, in July 2025 that switched, Cardiff & Vale's waiting times has fallen to 28.6% while Hywel Dda has risen to 40%. National planning and regional working is needed to make sure timely cancer care doesn't depend on where you live.

Research, Innovation & Clinical Trials

1. **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.
2. **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.
3. **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

1. **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.
2. **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

1. **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.
2. **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

1. **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

1. **Visible progress** – Palliative and end-of-life care is one area where investment is delivering: £5.5m in cash, £3m recurring uplift, and a new national service specification to guarantee fairer access across Wales.
2. **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.

Progress Assessment as of August 2025

This briefing provides a RAG (Red,Amber,Green) assessment of Welsh Government's progress against the 26 recommendations made in response to the Senedd Health and Social Care Committee's *Unheard* report [1].

This external assessment has been made by a small team of colleagues from within Claire's Campaign and Tenovus Cancer Care using public sources of information and through conversations with clinical and management staff in the NHS.

Twenty months since the publication of the *Unheard* report, 3 recommendations have been actioned, 7 show partial progress, and 15 remain undelivered. While there are positive steps in a few areas, significant delays persist across screening, diagnosis, workforce, and data, with real implications for gynaecological cancer patient outcomes and public confidence.

At a Glance: RAG Summary

RAG Rating	Total # of recommendations	What It Means
🔴 Red	16	No discernible progress or action taken
🟠 Amber	7	Some movement / progress but not sufficient or too vague to be sustained or have impact
🟢 Green	3	Tangible progress made and publicly evidenced

Thematic Grouping

For ease of navigation and to support clearer messaging, the 26 recommendations from the Unheard report have been grouped thematically. These themes reflect broad areas of strategic priority, from leadership and screening to dignity in care. For further detail on each recommendation, please see the table in the next section.

Leadership, Governance & Strategic Direction

2, 5, 6, 16, 19, 20, 21, 22 – Red (5) 🔴 | Green (2) 🟢 | Amber (1) 🟠

This theme captures Welsh Government's strategic role in planning, investment, data transparency, digital delivery, and overall accountability in the gynaecological cancer pathway. It covers eight of the 26 recommendations, few have been delivered, while the rest are either vague in commitment or stalled in delivery.

At the heart of the problem is a failure to give gynaecological cancers a clear position in core strategy. The Women's Health Plan was finally published at the end of 2024 [2], but it does not meaningfully address gynaecological cancers despite the Health Committee's recommendation being partially accepted [3]. The Plan's "iterative" approach creates a sense of hope and yet there's uncertainty about whether and when targeted content will be added and how stakeholders such as Claire's Campaign can shape future iterations.

Targets are another gap. Government accepted the need to set clear, measurable NHS Executive targets for gynaecological outcomes, yet nearly two years later they remain "in development." [3]

The performance picture underlines why these matters. 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) [4].However there remains extreme variability and volatility in overall waiting times 45.5% (Apr), a sharp drop to 36.5% (May), before rising again to 47% in June [4]. This contrasts with the national average across all tumour sites, which has remained broadly steady in the mid-50s to low-60s range in recent years. For example, in December 2024, 61.9% of patients across all cancers started treatment within 62 days of diagnosis, the highest performance since August 2021, while overall national performance has generally fluctuated between 50% and 60% during this period [5].

Variation between health boards remains a critical concern: Cardiff & Vale reached 62.5%, while Hywel Dda was just 16.7% [6]. 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 of 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.

On digital infrastructure, there has been movement but not delivery. Work to tackle ICT barriers and regional coordination is underway (e-forms, shared records), but full implementation has slipped, and the national informatics function was escalated in 2025 over delivery concerns [7] [8]. That raises questions about oversight, governance, and whether cancer, including gynae, is being prioritised as systems evolve.

There are bright spots. Government has reaffirmed prioritisation of gynaecological cancer and improved transparency: monthly performance summaries are now routine, and work is progressing toward more granular tumour-level data (expected by 2026/27) [9] [10] [11]. However, there's still no published timetable setting out exactly what gynae data will be released and when, which leaves the transparency ask only partially met.

On workforce, HEIW has included gynaecological cancers in its pathway workforce planning, a welcome inclusion in theory, but this has yet to translate into funded training places, new roles, or investment in key disciplines (e.g., gynae oncology, CNS, diagnostics)

[12]. Meanwhile, the rapid, six-month specialty-specific review called for by the Health Committee remains unpublished, with the activity subsumed into multi-year workforce programmes that lack gynaecology-specific timelines [13]. Consequently, boards and patients don't know where gaps exist, what hiring plans are in place, or when relief will come.

Finally, although Government reports it oversees the Cancer Informatics System, delivery delays and escalation issues have undermined confidence. The promised informatics system has not been fully delivered, the Cancer Informatics Programme remains incomplete [14]. Although the strategic digital architecture is in place, it remains inconsistently delivered and under-resourced—especially for gynaecological cancer.

Accountability for delivery is another weakness. The Cabinet Secretary's response only references a small subset of *Unheard* recommendations (1, 2, 3, 6, 7, 10, 18, 26), and explicitly states that nothing has been done on items 11 and 12 [15]. For most recommendations, no clear lead body or delivery team is named, making targeted follow-up or inquiries difficult.

At the time of the report's publication (Dec 2023), gynaecological cancer had been designated by Welsh Government as one of three priority tumour sites, alongside urological and lower GI cancers [16]. Responsibility for addressing many of the *Unheard* recommendations was vested in the NHS Executive's Cancer Recovery Programme (within the larger Strategic Programme for Planned Care), which notably lacked formal third-sector presence, while third-sector representation was nominally located through the Wales Strategic Network for Cancer [17].

In practice, responsibilities and accountability span:

- **NHS Wales Performance & Improvement** (formerly the NHS Wales Executive) — the national support and performance improvement function, renamed on **1 June 2025**. [18]
- **Public Health Wales** — responsible for national screening programmes and for cancer registry functions via the **Wales Cancer Intelligence and Surveillance Unit (WCISU).** [19] [20]
- **Health and Care Research Wales** — oversees and funds research, supports clinical trials, and promotes innovation in health and care. [21] [22]
- **Local Health Boards** — statutory bodies with responsibility for planning and delivering NHS services locally. [23] [24]
- **HEIW** — leads on education and workforce planning, including pathway workforce planning tools. [25] [26]

Despite these roles being set out in separate documents, **there is no single, public accountability framework** that assigns named leads for each *Unheard* recommendation across these bodies. The **Welsh Government response** to the report lists

recommendations as “accepted,” “accepted in principle,” or “not accepted,” but does not name lead delivery organisations. Likewise, the **Integrated Workplan 2025–26** sets deliverables at programme level but not recommendation-by-recommendation accountability.

From recent insight we understand that the Gynaecological Clinical Implementation Network (CIN) convened quarterly with partners across the then NHS Wales Executive to review progress against *Unheard* recommendations. Public references to the CIN appear in the **Gynaecology Summit outcomes**, in Welsh Government evidence that a CIN was established, and in the Women’s Health Plan, but minutes or membership lists are not publicly available. [27] [28]

The **integration of the Cancer Recovery Programme and the Strategic Network for Cancer** into a single structure is now explicit: the **Integrated Workplan 2025–26** describes itself as “an amalgamation of the Cancer Network Plan and the Recovery Programme Plan.” [29] This change should in principle simplify lines of accountability and improve opportunities for third-sector scrutiny.

However—nearly two years on from *Unheard*—there is still no transparent, published framework that assigns accountability for delivery at recommendation level, making it difficult for patients, the third sector and the Senedd to track progress against commitments.

Recommendation: 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.

Research, Innovation & Clinical Trials

3, 17, 23, 24 – Red (2) 🔴 | Amber (2) 🟠

This theme highlights the gap between Wales’s stated ambition to lead in women’s health research and the reality for women with a gynaecological cancer diagnosis. While the Welsh Government accepted these recommendations delivery that is focused on gynaecological cancer is largely absent, leaving an underpowered research and innovation landscape at a time when progress could contribute to improved outcomes.

The first recommendation concerned clarity on the research budget underpinning the Women’s Health Plan and whether gynaecological cancers would receive targeted funding. In her response to the Unheard report debate the then Cabinet Secretary confirmed that £700,000 would be directed at women’s health research. The Welsh Government has since confirmed a focused call for women’s health research launched in April 2025, committing £750,000 to research projects, alongside £3m for the establishment of the first Women’s

Health Research Centre in Wales [30] [31]. While this investment is welcome in the context of women's health, there is no indication of ring-fenced funding for gynaecological cancer research within either initiative.

Such an omission risks entrenching existing inequalities. Without dedicated funding, the scale and pace of research projects depend on ad-hoc bids and individual team capacity - rather than a coherent national programme targeted at a cancer site associated with poor outcomes. One of the research call themes focuses on improving clinical communication with women and girls about their health needs, which could indirectly support progress towards some *Unheard* report recommendations, but only *if* projects under this theme are selected. This remains contingent on decisions made by the grant holder later in 2025.

Partners were also urged to strengthen research capacity and explore a dedicated gynaecological cancer research centre (recommendation 23) [32]. Government cited the Wales Cancer Research Centre (WCRC) and the Cancer Research Strategy for Wales (CReSt), but twenty months on there is no options appraisal, no business case, and no timeline. A specialist centre remains unexplored, leaving a strategic gap in a cancer area already marked by late diagnosis and poorer outcomes.

On trials (Recommendation 24), Government confirmed 13 active gynaecological cancer studies in Wales, a figure that has not shifted since the initial response. There is no public plan to expand availability, widen geographic access, or tackle persistently low recruitment. Although barriers for clinicians (protected time, remuneration) are acknowledged, no practical support or incentives have been put in place. That limits growth and risks losing talent to better-resourced research environments.

Access to new treatments is facing the same pattern: process is improving, capacity planning is not. Horizon-scanning has been strengthened through AWTTC/AWMSG and "once-for-Wales" mechanisms, but there is still no published, time-bound capacity plan mapping the expected pipeline of NICE-recommended gynae drugs to the real-world prerequisites, genomics and pathology throughput, pharmacy time, infusion capacity, MDT bandwidth, and data flows. Without that, approvals do not reliably convert into timely access for patients. [33]

Bottom line: Wales's approach to gynaecological cancer research and innovation remains aspirational rather than operational. While the new women's health research funding is a positive step, the absence of ring-fenced investment, specialist infrastructure, trial growth, and treatment readiness planning means opportunities to improve outcomes will continue to be missed.

Screening, Prevention & Early Detection

8, 9, 10, 11, 12 – Red (5) 🔴

Progress on prevention and early diagnosis is lagging where it matters most: vaccination coverage, equity in screening, and practical readiness for new pathways. Wales still falls well short of WHO's 90% HPV uptake ambition by age 15. Public Health Wales' most recent COVER report shows one-dose HPV coverage in the 2024–25 year:

Year 10 (age 14–15): 72.3% overall (75.5% girls, 69.3% boys)

Year 9 (age 13–14): 70.4% overall (73.4% girls, 67.6% boys)

Year 8 (in-year): 0.2%, pending further sessions
[34]

PHW acknowledges persistent inequities in screening uptake, particularly among younger invitees and (in mixed-gender programmes) men; a dedicated group has been established to tackle uptake and equity. It's the right frame, but we have yet to see evidence of targeted, resourced interventions for the under-screened groups the data continually flags.

On self-sampling, there's movement: in June 2025, the UK National Screening Committee recommended offering HPV self-sampling to under-screened people, and Welsh Government issued a written statement confirming that roll-out is expected to begin next year, with PHW "exploring the best way to deliver self-sampling to all those eligible." [35] [36]. This is a positive step, although still short of having a published pathway, resourcing plan, or implementation schedule.

On information clarity, PHW's own materials now state plainly that "the cervical screening (smear) test is not a test for cancer" and explain what HPV testing does and does not cover. The question is whether this clarity is consistently delivered at appointment level across Wales (leaflets, letters, verbal comms) as per the recommendation.

Diagnosis, Pathways & Primary Care

4,7, 13, 14, 15 – Red (2) 🔴 **| Amber (3)** 🟠

Since May 2024, there's been some meaningful movement on the machinery of diagnosis, but accountability is lagging. The all-Wales external evaluation of Rapid Diagnostic Clinics (RDCs) confirms they now operate across every Health Board and benefit patients with vague symptoms—but also flags issues in referral quality, equity of access, 7-day pathways, and inconsistent data capture. While recommendations are clear, there's no public evidence that Health Boards have taken action or that outcomes are improving. [37]

On primary-care support, Wales refreshed the Suspected Cancer Pathway guidance (WHC/2024/07) [38], laying a proper foundation to tighten referral standards and data

reporting. HEIW apparently developed and delivered ‘Unheard’ training in Q1 2025, though it’s unclear whether it included patient input or whether it's a standalone offering or part of ongoing CPD. HEIW also continues to offer GatewayC learning to GPs [39], but no published evaluation shows the impact on referral quality, conversion rates, or staging at diagnosis. Without such data, it’s impossible to tell whether these CPD inputs are translating into better clinical outcomes.

Digital is improving, albeit at a slow pace. DHCW has rolled out new cancer e-forms and updated the planned care referral data standard—both are vital steps toward better query management and feedback loops. However, there remains no publicly available, gynae-specific audit or feedback data reporting actual usage and outcomes. The government previously noted that these advice/query functions are available to secondary care for responding to referrals, but there’s no evidence yet that they are being used systematically. [39][40]

A separate gap is the post-COVID service baseline. The Unheard report noted that gynaecological cancer services lost during the pandemic have not been reinstated and recommended Welsh Government assess and report this. The response did not include a published assessment of what was lost, where, or with what mitigation. Instead, the policy emphasis remains on “transforming” pathways rather than reinstating lost capacity. Without transparency about what was removed and how it’s being changed, it's impossible to appraise whether lost capacity has indeed been "transformed" in practice. [41]

Emergency presentations remain the most concerning diagnostic gap. The Welsh Government declined the Health Committee’s request for a dedicated short-run review, stating:

> *“Undertaking such a review would require detailed case note analysis… this would place an unmanageable burden on already stretched gynaecology and oncology services, and therefore I am not commissioning this work. Our priority must remain improving cancer outcomes through the Cancer Improvement Plan and Single Cancer Pathway.”* [42]

Meanwhile, national audit data—specifically the National Ovarian Cancer Audit State of the Nation Report 2024—reports that 40.6% of women in Wales had an emergency admission within 28 days prior to ovarian cancer diagnosis, a route consistently linked with late-stage disease and poor prognosis. [43]

There is some progress toward understanding these pathways. The new integrated cancer plan will commission a medical fellow to undertake a “Routes to Diagnosis” study, covering multiple tumour sites including ovarian cancer. While this excludes other gynaecological cancers and may take months to complete, its commissioning signals a recognition that this issue must be addressed. The potential benefits of this targeted analysis far outweigh the “burden” objections cited. [44]

Note:

Women's Health Hubs

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. [45] [46]

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). [45b]

Note: 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. In other words, 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.

Dignity, Respect & Experience of Care

1, 18 – Red (2) 🔴

Since May 2024, there's been headline movement (the Women's Health Plan, Dec 2024 [47], and the People's Experience Framework, Apr 2025) [48], but neither translates the *Unheard* report's asks into gynae-pathway, patient-facing delivery. The Plan's language ("women are listened to") is directionally right, and the Framework standardises how boards capture and use experience data, but we still don't see the operational levers that matter on the ground (minimum appointment time standards, mandated training content with uptake targets, and a gynae-specific experience scorecard reported by boards). Most importantly for this

briefing, there's no public evidence that Welsh Government issued the explicit dignity reminder to all boards anchored to the *Unheard* patient stories.

Palliative & End-of-Life Care

25, 26 – Amber (1) 🟠 | Green (1) 🟢

This is the one area where progress is underway. Since May 2024, we've seen several key developments:

1. A Cabinet Written Statement confirmed interim Phase 3 funding review actions, including a £4 million cost-of-living grant to all 12 NHS-commissioned hospices (2023–24) and work progressing toward a national hospice commissioning framework. [49]
2. A National Service Specification for Palliative and End of Life Care has been published for public engagement (May 2025), which hard-wires equitable access, governance standards, KPIs, workforce requirements, and 24/7 urgent response. [50]
3. The 2025–26 budget includes a £5.5 million one-off cash injection for hospices and a £3 million recurrent uplift—a significant financial boost. [51]
4. Multi-year bereavement support grants were awarded to 18 organisations to address inequities in bereavement care. [52]

This direction aligns with the *Unheard* report's recommendations to normalize earlier palliative involvement and embed equity. Caveat: The service specification remains in the engagement phase, and a sustainable, tariff-style hospice funding model is still under development.

The Government has explicitly prioritised palliative and end-of-life care, expanded the national programme team, and funded hospices to stabilise services while a commissioning framework is developed. The Cabinet Secretary's Written Statement confirms PEoLC as a Programme for Government commitment, the role of the National Programme Board, and work to develop a hospice commissioning framework; it also recognises the financial pressure on hospices. [53] Separate government support provided a £4m cost-of-living grant to all 12 NHS-commissioned hospices as part of the Phase 3 review actions. [54]

The 2025 service specification—now out for engagement—pushes earlier, person-centred palliative input, sets expectations for 24/7 urgent response, and codifies equity, governance, measurement and workforce standards. [55] [56] Spring 2025 budget measures added immediate capacity support to maintain hospice services, including a £5.5m cash injection and a £3m recurrent uplift in 2025–26. [57] Translating the specification into board-level delivery plans with public milestones must now follow.

Implementation infrastructure is in place and maturing: the National Programme Board is operational, [53] Phase 2 recommendations to increase weekend/OOH district and specialist

palliative nursing capacity are being taken forward via Further Faster, and Phase 3 interim recommendations were broadly accepted with work started. [58] Bereavement services have secured multi-year grants to 18 organisations, [59] and a national service specification with explicit equity, governance and measurement duties is out for engagement. [55] [56] The 2024 Written Statement sets the direction, acknowledges the pressures/variation in provision and finances, and commits to a sustainable framework. [53]

Our watch-outs: publish the final specification with a time-bound implementation plan and bring forward board-level equity metrics.

Unheard Report Recommendations Table

No.	Recommendation (full text)	RAG	One-line status (as of Aug 2025)
1	Promote gender sensitivity and cultural competence among healthcare professionals through a relationship-based care model that allows adequate time for appointments and empathetic communication tailored to women's needs.	Red	Accepted in principle, but no mandated appointment standards, training curriculum/uptake metrics, or gynae-specific experience measures published.
2	Publish the Women's Health Plan by year-end, with a specific focus on gynaecological cancers to tackle health inequalities, raise awareness, improve access to care, and enhance outcomes.	Red	Plan launched Dec 2024 without a dedicated gynae focus; no route/timeline for adding targeted content.
3	Detail the research budget supporting the Women's Health Plan and clarify priorities, including whether gynaecological cancer research will receive specific funding.	Amber	Women's health research funding identified; no ring-fenced gynae allocation or clear priorities beyond high-level statements.
4	Assess and urgently reinstate gynaecological cancer services lost during the pandemic. Provide timings and reasons if services are not reinstated.	Red	Government rejected reinstatement approach; no published audit of lost services, reinstatement timetable, or explanations.
5	Set clear, measurable targets for the NHS Executive to improve gynaecological cancer outcomes, aligned with the Wales Cancer Network and Cancer Improvement Plan.	Red	Targets remain "in development." Latest data show volatile performance (44.1% Feb, 52.8% Mar, 45.5% Apr, 36.5% May, 47% Jun), with stark variation between health boards (Cardiff & Vale 62.5%, Hywel Dda 16.7%, Powys 0%). No published milestones or accountability framework.
6	Support health boards in overcoming ICT system barriers to enable effective regional working and better coordination of cancer care.	Amber	e-forms and shared records progressing, but full integration delayed; regional benefits and equity impact not evidenced.
7	Evaluate Rapid Diagnostic Centres to improve performance and ensure equitable access across Wales, particularly in underserved areas, reporting back within 18 months.	Amber	National evaluation completed; health-board implementation plans and measured impact not yet published.
8	Work with NHS Wales to meet WHO's 90% HPV vaccine target and report progress on 2030 cervical cancer goals, including incidence trends during this Senedd term.	Red	Uptake remains well below 90%; no transparent acceleration plan to reach WHO targets.

No.	Recommendation (full text)	RAG	One-line status (as of Aug 2025)
9	Review the equity strategy for cervical screening and take targeted action to improve uptake among under-screened groups.	Red	Uptake/equity group exists, but no published, resourced action plan with timelines and owners.
10	Outline how NHS Wales is preparing to implement cervical self-sampling, including any required resource changes.	Red	Momentum noted nationally, but no published implementation pathway, resourcing model, or start dates in Wales.
11	Ensure information at cervical and breast screening clearly states that cervical screening does not test for other gynaecological cancers and highlights symptoms of other types.	Red	As per the Cabinet Secretary's response to the health Committee letter, confirmation has been provided that rec 11 has not been taken forward as of yet.
12	Develop frequent and targeted awareness campaigns on gynaecological cancer symptoms that consider culture, language, and inequality, and promote healthy lifestyle choices.	Red	No coordinated, funded, repeatable campaigns targeted at under-served groups; reliance on general "amplification."
13	Explain plans to evaluate Gateway C and its impact on GP referral rates for gynaecological cancers.	Red	No published evaluation linking GatewayC usage to referral quality, conversion, or stage at diagnosis.
14	Ensure CPD for GPs includes a strong focus on gynaecological cancer, audit GP referrals, provide feedback, and expand specialist support through tools like telemedicine.	Amber	Guidance/CPD has occurred, but is the training a one off, unclear; advice/queries capability exists; no national gynae referral audit-and-feedback loop reported.
15	Urgently review emergency presentations of gynaecological cancers, including trends, risk factors, and access barriers, and report findings within six months.	Amber	Government declined the review; Ovarian cancer routes to diagnosis will be reviewed, study due to be commissioned as part of the integrated cancer plan.
16	Reaffirm commitment to prioritising gynaecological cancer and work with the NHS Executive to publish transparent data on performance and access.	Green	Prioritisation reiterated; monthly performance summaries published; national dashboards in development.
17	Improve understanding and implementation of NICE-approved drugs, and plan for capacity to ensure timely access, including analysis of likely upcoming treatments.	Amber	Horizon-scanning strengthened; no published, time-bound capacity/readiness plan for upcoming gynae therapies.
18	Remind health boards of their duty to treat all patients with dignity and respect, informed by patient stories.	Red	Despite WG outlining a date, no evidence to translate

No.	Recommendation (full text)	RAG	One-line status (as of Aug 2025)
19	Review the gynaecological cancer workforce, identify shortages, and outline recruitment actions, reporting within six months.	Red	No published gynae-specific workforce review or time-bound recruitment plan; activity folded into broader programmes.
20	Ensure HEIW includes gynaecological cancers in its workforce planning.	Green	Included in pathway workforce methodology; translation into funded posts/training places not yet evidenced.
21	Clarify what performance data on gynaecological cancer will be published and when, to support transparency and care quality.	Amber	Commitments made, but no clear timetable for tumour-level gynae data publication. But data and digital roadmap work has started.
22	Outline Welsh Government oversight of the Cancer Informatics System and how it supports digital cancer pathway improvements and value for money.	Red	Oversight described; full rollout delayed and benefits unrealised; delivery escalation undermines assurance.
23	Work with partners to strengthen Wales' cancer research capacity and explore the case for a gynaecological cancer research centre.	Red	No options appraisal, business case, or timeline for a specialist centre; strategic gap remains.
24	Provide data on current gynaecological cancer trials in Wales, plans to increase access, and how clinicians will be supported and remunerated.	Red	13 trials reported; no plan to expand access or address clinician time/remuneration barriers.
25	Promote the benefits of palliative care to patients and clinicians, dispelling the myth that it's only for end-of-life.	Amber	Programme, funding and a draft national spec support earlier, person-centred palliative care; but no coordinated clinician/public campaign yet to dispel the 'end-of-life only' myth.
26	Update on implementing the palliative and end-of-life care quality statement, with a focus on equitable access.	Green	Programme board, draft national spec and bereavement grants advance the Quality Statement; equity-disaggregated outcome data remains thin and board-level reporting isn't yet consistent.

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[7] NHS Exec 25/26 Integrated Work Plan

[8] Audit Wales / WG, Escalation of DHCW, 2025

[9] WG Written Statement, Dec 2024

[10] WG NHS Activity & Performance Summary, 2025

[11] NHS Exec 25/26 Integrated Work Plan

[12] Written Response to the Health and Social Care Committee's December 2023 Inquiry Report on Gynaecological Cancer: "Unheard: Women's journey through gynaecological cancer"

[13] Written Response to the Health and Social Care Committee's December 2023 Inquiry Report on Gynaecological Cancer: "Unheard: Women's journey through gynaecological cancer"

[14] Written Statement: Update on progress of the Cancer Informatics Programme

[15] Response from Cabinet Secretary

[16] Cancer Summit September 2024

[17] A Cancer Improvement Plan for NHS Wales 2023-2026

[18] Welsh Government. *NHS Wales Executive renamed NHS Wales Performance and Improvement*, June 2025

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[28] Welsh Government. *Women's Health Plan* (2024).

[29] NHS Wales Executive. *Integrated Workplan 2025–26* (described as "an amalgamation of the Cancer Network Plan and the Recovery Programme Plan").

[30] Welsh Government. *Written Statement: Women's Health Research* (April 2025) — announcement of £750k call for projects and £3m Women's Health Research Centre.

[31] Health and Care Research Wales. *Integrated Funding Scheme – Focused Call: Communication in women's health*, April 2025 — lifecycle of the £750k call with no published awards yet

[32] Written Response to the Health and Social Care Committee's December 2023 Inquiry Report on Gynaecological Cancer: "Unheard: Women's journey through gynaecological cancer"

[33] AWTTC x Wales Cancer Network SACT — 'Once for Wales' horizon scanning for cancer medicines. Collaboration established to provide unified ('Once for Wales') horizon-scanning to support timely service planning and avoid local duplication.

[34] Public Health Wales. *COVER Report – Vaccine Uptake in Children in Wales, Oct–Dec 2024 (School Years 8–10)* (2024). Coverage: Year 8 – 0.2%; Year 9 – 70.4% (73.4% girls; 67.6% boys); Year 10 – 72.3% (75.5% girls; 69.3% boys).

[35] UK National Screening Committee. *Recommendation: HPV self-sampling option for under-screened people*, June 2025.

[36] Welsh Government. *Written Statement: Self-sampling in the cervical screening programme in Wales*, 11 July 2025 – confirming planned roll-out next year and that PHW is exploring delivery.

[37] NHS Wales Performance & Improvement: *Rapid Diagnosis Clinics Programme* overview notes an external evaluation was published in 2024, identifying gaps in referral quality, equity, 7-day pathways, and data collection.

[38] WHC/2024/07 – Suspected Cancer Pathway Guidance

[39] Gateway C learning

[39] Digital Health and Care Wales. *Digital system for managing cancer data in Wales takes important step forward* (Dec 2024) — confirms e-form rollout and digital improvements.

[40] Welsh Government. *Planned Care Referral Data Set* specification, outlines referral data standards, but no public reporting tools specific to gynaecological referrals.

[41] Unheard: Women's journey through gynaecological cancer (Health & Social Care Committee, Dec 2023):

- Observation that services lost during COVID-19 have not been reinstated.
- **Recommendation 4**: Welsh Government should assess pandemic-related service loss and reinstate as necessary, providing timing or explanation if not reinstated.

[42] Response from Cabinet Secretary

[43] National Ovarian Cancer Audit (NOCA). *State of the Nation Report 2024*. Indicates that 40.6% of women in Wales had an emergency admission within 28 days before diagnosis.

[44] NHS Wales Performance & Improvement. *Integrated Workplan 2025–26*. Specifies upcoming commissioning of a "Routes to Diagnosis" study via a medical fellow.

[45] Welsh Government. *Women's Health Plan for Wales launched to close the gender health gap*, 9 December 2024 — announces creation of women's health hubs in each health board by 2026 as part of a 10-year plan.

[45b] Enhanced Community Gynaecology Service – Using point of care diagnostics to deliver prudent local healthcare" — Bevan Commission.

[46] SBRI Wales. *Improving Health Outcomes for Women and Girls across Wales* — part of the Women's Health Plan pathway: calls for pathfinder women's health hubs by 2026, focusing on innovation, primary and secondary care pathways. Note funding is for demonstration, not cancer-specific integration.

[47] Women's Health Plan December 2024

[48] Welsh Government. *People's Experience Framework: guidance for NHS Wales* (published 22 April 2025), introducing a maturity model and national survey methodology for capturing patient experience.

[49] Welsh Government Written Statement — Vital funding to support Welsh hospices (12 April 2024) confirms a £4m cost-of-living grant to 12 commissioned hospices, part of the Phase 3 funding review.

[50] NHS Wales Performance & Improvement — National Service Specification Engagement page (as of May 2025) announces the PEoLC specification is out for consultation, and includes standards for governance, equity, 24/7 urgent access, workforce KPIs.

[51] Senedd Written Question WQ96397 (Answered 15 May 2025) confirms £5.5 million for hospices plus a £3 million recurrent uplift in the 2025–26 Welsh Government budget.

[52] Welsh Government press release — Bereavement grants (Mar 2025) outlines multi-year grants to 18 organisations to strengthen bereavement support equity.

[53] Welsh Government — Written Statement: Improving Access to Palliative and End-of-Life Care (Cabinet Secretary for Health and Social Care), 18 Oct 2024. Confirms Programme for Government commitment; National Programme Board role; intention to develop a hospice commissioning framework; acknowledges financial challenges facing hospices.

[54] Welsh Government — "Vital funding to support Welsh hospices", 12 Apr 2024. Notes £4m provided to all 12 commissioned hospices (Phase 3 review support).

[55] NHS Wales Performance & Improvement — Service specification engagement page (PEoLC), open May–June 2025. Hosting the national specification for engagement.

[56] NHS Wales Performance & Improvement — National Service Specification for Wales: Palliative and End of Life Care (document), May 2025. Sets equity, governance, measurement, workforce, and 24/7 urgent response expectations.

[57] Senedd (Written Questions) — Hospice funding confirmation, answered 15 May 2025. Confirms £5.5m additional support for hospices and £3m recurrent uplift in the 2025–26 budget.

[58] Welsh Government Annual Report (Annex) 2023–24, published July 2024. States Phase 2 PEoLC review recommendations (weekend/bank-holiday district & specialist palliative nursing capacity) are being progressed via Further Faster; Phase 3 interim recommendations submitted Feb 2024 and broadly accepted with work started.

[59] Welsh Government press release — Bereavement grants (Mar 2025) outlines multi-year grants to 18 organisations to strengthen bereavement support equity.

Health and Social Care Committee
Senedd Cymru | Welsh Parliament

Dear Chair,

Implementation of *Unheard: Women's journey through gynaecological cancer*

Thank you for inviting the Royal College of General Practitioners (RCGP) to contribute to the Committee's short inquiry into the implementation of *Unheard*. We have reviewed both the Committee's correspondence and the Welsh Government's response.

We welcome the fact that the Welsh Government has accepted the majority of the report's recommendations in principle, and note the important groundwork already laid through the Cancer Recovery Programme, Quality Statements, pathway design, and targeted investment. Nevertheless, many changes remain at the planning or early implementation stage, and measurable improvements in patient outcomes, particularly timely diagnosis and treatment, have yet to be demonstrated across Wales. We believe there remain significant gaps which must be addressed if the report's ambitions are to be realised.

Performance against targets

As of March 2025, only 38% of gynaecological cancer patients in Wales are starting treatment within 62 days, well below the 75% target. Although Betsi Cadwaladr and Cardiff & Vale Health Boards are approaching 69%, wide variation remains, with most boards performing far below the standard. Audit Wales' 2024 report on cancer services also highlighted that, despite increased investment, many national targets are not being met. Demand for suspected cancer referrals continues to rise faster than diagnostic and treatment capacity.

The Integrated Cancer Workplan 2025–26 contains welcome commitments to strengthen suspected cancer pathways, multi-disciplinary team working, and diagnostic capacity. Targeted interventions such as post-menopausal bleeding services and "one-stop" outpatient models are also encouraging. However, these plans need clear timescales, publicly accessible progress reporting, and accountability mechanisms to ensure delivery.

Women's Health Plan and exclusion of gynaecological cancer

The Women's Health Plan 2025–35 establishes the National Clinical Strategic Network for Women's Health and sets a monitoring framework. We note, however, that gynaecological cancers were not given specific prominence within the Plan, despite the Committee's recommendations. Greater clarity is needed on why this is the case, and whether this risks reducing the policy priority of these cancers compared with other areas of women's health.

Workforce and diagnostic capacity

Shortages in imaging, ultrasound, and pathology services remain a critical barrier. Demand continues to outpace supply, with backlogs for hysteroscopy investigations extending up to 12 months in some areas, even for urgent appointments. This is unacceptable and requires urgent additional capacity. Expanding access to one-stop gynaecological investigation centres, where diagnostics, treatment, and oncology follow-up are co-located, should be prioritised to provide seamless care through true multidisciplinary working.

Rapid diagnostic clinics are an important tool for patients presenting with vague or non-specific symptoms, but they must be properly resourced with immediate access to imaging and pathology. Alternatively, improving GP access to radiology remains a pressing need, though current waiting lists make this unlikely without significant investment.

Public and professional awareness

Public awareness of symptoms, and primary care confidence in recognising and referring, remains variable. Current interventions, such as GP webinars, are valuable but insufficient at scale. Public health campaigns, delivered via social media, broadcast, print, and in practices, remain essential to raise awareness of gynaecological cancer symptoms and the importance of HPV vaccination.

The option of self-obtained cervical cytology could improve screening uptake, addressing barriers such as time constraints, appointment availability, embarrassment, or previous poor experiences. Wales has previously demonstrated success with self-sampling models, such as the Frisky Wales STI screening programme, and this could represent a significant advance in early cervical cancer diagnosis.

Education and professional development

Ongoing education for healthcare professionals, including GPs and practice nurses, remains critical. This should cover presentations of gynaecological cancers, investigation in primary care, and referral pathway updates. RCGP can play a role in delivering education through webinars, in-person courses, and forthcoming CPD events, including a Women's Health event for members planned in Wales for 2026.

Palliative care

Ensuring access to high-quality palliative care for women with advanced gynaecological cancers is essential. General practice teams are well placed to identify patients who may benefit, to challenge misconceptions, and to support equitable access, particularly where barriers exist due to age, ethnicity, rurality, or socioeconomic status. Education for primary and community care professionals, including district nurses and palliative care teams, should be integral to this agenda.

Areas for further clarification

We would welcome the Committee seeking further detail from the Government on the following:

- **Funding and resources**: whether additional, ring-fenced funding will be allocated to support the recommendations, beyond existing budgets.
- **Targets and measurement**: clear metrics and timelines for reducing emergency presentations, improving waiting times, and achieving treatment standards.
- **Transparency and accountability**: regular public reporting mechanisms on implementation, including progress against each recommendation.
- **Stakeholder involvement**: how patients, charities, and professional groups will be engaged in ongoing implementation planning and monitoring.
- **Barriers and risk management**: what specific obstacles have been identified (e.g., workforce, diagnostic bottlenecks) and how the Government intends to overcome them.

Conclusion

We acknowledge the progress made so far, but remain concerned that without dedicated resources, and robust monitoring, the ambitions of *Unheard* may not be fully realised. We urge the Committee to maintain scrutiny to ensure that women in Wales benefit from earlier diagnosis, timely treatment, and equitable, high-quality care throughout their journey with gynaecological cancer.

Gynaecological Cancer Inquiry review- Target Ovarian Cancer response

Wales has some of the worst survival rates for ovarian cancer in Europe. 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.

During the inquiry and through our written recommendations we urged the Welsh Government to focus on addressing the barriers to improving early diagnosis by increasing symptoms awareness, improving GP knowledge, addressing variation in treatment and making changes to data availability and support.

We were pleased that many of our recommendations were published in the report and accepted by the Welsh Government, however, we have been disappointed with the lack of progress and priority placed in implementing the recommendations and ensuring that women impacted by gynaecological cancers feel heard.

Women's Health Plan & National Cancer strategies

Whilst the Welsh Government have demonstrated a commitment to improving cancer services through the Quality Statement for Cancer, the three-year Cancer Improvement Plan and the National Cancer Recovery Programme, having multiple initiatives has made it difficult to understand and monitor progress, as well as making accountability unclear.

The Women's Health Plan was a welcome step, and we were pleased to see the Welsh Government recognise the importance of having a plan in place that addresses the barriers women face in accessing a diagnosis. Based on the Welsh Government's response to the Unheard report we had hoped the Women's Health Plan would be an opportunity to improve gynaecological cancers, access to health care and cancer outcomes. However, we were disappointed that the plan instead only focused on cervical screening uptake and did not address any other gynaecological cancer and that there was no public consultation on this. With the current Cancer Improvement Plan coming to an end in 2026 and the Cancer Recovery plan only scheduled to last two years, the Women's Health Plan could have galvanised vital action over the next decade. More regular reporting on progress within the Cancer Recovery Programme would help address some of our concerns.

We recognise there has been progress made with performance against the cancer waiting time target for gynaecological cancers gradually improving to 45.5 per cent and specific action around the national optimal pathway for ovarian cancer, however, to see real meaningful progress we need disaggregated waiting time data and more targeted measures in place to fully address the difficulties faced by women with gynaecological cancers.

Women's Health Hubs

While the establishment of women's health hubs in each health board is a positive step, the focus seems heavily centred on gynaecological health, with a lack of clarity on whether the women's health hubs will be equipped to diagnose ovarian and other gynaecological cancers. There are delays both in accessing tests and GPs then receiving the results. We know that the earlier a woman is diagnosed the greater her chance of survival yet delays in accessing tests stop women from starting life-saving treatment. Research undertaken by Target Ovarian Cancer found one quarter of women in Wales visited their GP three or more times before being referred for tests and that 43 per cent of GPs wrongly believe symptoms only present in the late stages.

It is vital that women are able to access the tests they need. Women Health Hubs present a real opportunity to improve access to diagnostic tests/ provide a one stop shop for gynaecological cancers and make a meaningful difference to women's health in Wales. We would welcome some clarity on what consideration has been given to using Women's Health Hubs to improve the diagnosis of gynaecological cancers?

Progress of implementation & the biggest gaps

Implementing recommendation 11

We were pleased to see the Welsh Government accept recommendation 11 to update cervical screening information to make clear it will not detect ovarian cancer. Currently, 42% of women in Wales wrongly believe cervical screening can detect ovarian cancer. This means that women may think that if their cervical screening was clear they are not at risk of developing ovarian cancer.

However, we have been disappointed to learn that despite this recommendation having minimal cost implication and cervical screening information being updated in February 2024 after the recommendation was accepted, there has been no progress to date on implementing this change. With no viable screening programme for ovarian cancer, it is vital that every woman in Wales knows this information.

Since the report was published we have consistently raised the question asking when this recommendation will be implemented and the importance of ensuring women have access to this knowledge. As expressed above we were disappointed there was not a formal consultation process for the Women's Health Plan and that gynaecological cancers have not been included. Despite this in response to our questions on the importance of this information being updated it has been indicated that information changes such as this will be addressed through the Women's Health Plan, however, there is little to no mention of gynaecological cancers within the plan. We would welcome some clarity on how the Welsh Government see the Women's Health Plan and Cancer Recovery Programme working together to ensure more women are equipped with the knowledge they need on ovarian and other gynaecological cancers.

We understand that that conversations are underway around developing a campaign through the Women's Health Plan looking at making every contact count and improving health information through this. We would urge the Welsh Government to use this an opportunity to implement recommendation 11.

Awareness campaigns

Similarly, it has been disappointing to hear that there has been no progress made on implementing recommendation 12 encouraging Welsh Government to work with Public Health Wales, community leaders and organisations to develop and implement a series of campaigns to raise awareness about the symptoms of gynaecological cancer.

Target Ovarian Cancer has repeatedly called for greater symptom awareness of ovarian cancer. This is an area that means a lot to women impacted by this disease as many of the women we work with in Wales have noted how they had no awareness of ovarian cancer or the symptoms to watch out for. Our research has shown that just 27 per cent of women in Wales are able to recognise the symptom of bloating and just 3 per cent are able to recognise feeling full as a symptom. They are passionate about ensuring more women in Wales have access to this knowledge and have been disappointed to see little progress in this area. Gynaecological cancers have the highest incidence and death rate of the female-associated cancers, after breast cancer. We must see more targeted action to improve awareness of symptoms in Wales.

We have had encouraging conversations with Welsh government and Members of the Senedd around the need to improve awareness and are pleased they have recognised the need for this, however, despite recognising this need little has been to improve public awareness of ovarian and other gynaecological cancers. We understand budget pressures continue to limit the Welsh Government's ability to fund public education and awareness campaigns, however we would urge the Welsh Government to make the most of material already available. For example, in NHS England the help us help you campaign has produced targeted campaigns encouraging women experiencing bloating/ abdominal pain to visit their GP. Adopting campaigns such as this would be a positive step forward and could help more women present to their GP if they are experiencing these symptoms.

Ensuring patients are not left behind - Involvement of people affected by gynaecological cancer in shaping services and decisions

We recently spoke with some of the women who contributed to the inquiry, and they expressed their disappointment at the lack of progress made since the Unheard report was published. They shared they felt they had not been fully listened too and their concern around the lack of ambitious targets. The voices of those impacted by ovarian and other gynaecological cancers are crucial to shaping and improving services. We would urge the Welsh Government to consider providing an update

specifically addressed to those who have had a diagnosis, reassuring them that their concerns are being listened too.

Do you feel the Welsh Government has clearly identified and committed to overcoming the barriers to improving gynaecological cancer care? What specific actions or assurances would you expect to see in the short term

We welcomed the Welsh Governments commitment to improving gynaecological cancer services and making gynaecological cancers a tumour priority site within the Cancer Recovery Plan.

Whilst we believe the Welsh Government have identified areas for improvement and recognise that current wait times are simply not good enough, we think there could be clearer communication on what actions are being taken to improve gynaecological cancer services. We would welcome the Ministers suggestion to provide periodic updates. To reassure the third sector and women impacted by ovarian and other gynaecological cancers we would ask if the Welsh Government would consider providing a timeline and implementation plan for the Unheard report.

Fair Treatment for the Women of Wales

www.ftww.org.uk

FTWW Response to Senedd Health and Social Care Committee's Evaluation of the Implementation of Unheard: Women's journey through gynaecological cancer

FTWW is the only patient- and service-user led charity and disabled people's organisation in Wales focused on female health equality, supporting women and people assigned female at birth who are disabled and / or living with long-term health issues. We currently Chair the third sector Women's Health Wales Coalition, whose evidence was instrumental in the Welsh Government's commitment to a Women's Health Plan, and provide patient / third sector representation on the NHS Wales Women's Health Network's Clinical Advisory Group.

Thank you for your invitation to contribute to the Committee's Inquiry into the implementation of the 'Unheard' report. We have reviewed both the Committee's correspondence and the Welsh Government's reply and are pleased to provide the following information in response to the Committee's seven question areas:

1) **Why was gynaecological cancer excluded from the Women's Health Plan, despite it being recommended for inclusion? Can you clarify why the Welsh Government and NHS Wales have chosen not to prioritise it.**

As an organisation with specific interest in chronic menstrual and gynaecological health conditions, and a contributor to the Women's Health Plan, we recognise concerns about gynaecological cancer not being explicitly included in the Plan, whilst also understanding the rationale for recommendations regarding cancer services not featuring directly.

It is our belief that the Women's Health Plan was conceived to address health issues and clinical areas not being prioritised elsewhere within NHS strategy. This is because, historically, there has been limited means to ensure service providers focus on the prevalence and impact of non-cancerous conditions uniquely or disproportionately affecting women and people assigned female at birth. It is a gap which the Women's Health Wales Coalition highlighted as a significant issue contributing to persistent gender health inequities[1], to be addressed in a Women's Health Plan for Wales.

Undoubtedly, however, there are shared systemic and societal issues impacting women affected by either cancer or non-cancerous health concerns which contribute to diagnostic delays, unsatisfactory experiences, and poor outcomes. The 'Unheard' report sets these out very clearly, including the pervasive and negative impact of gender stereotypes and biases; lack of sex and gender disaggregation of existing medical research; lack of investment in training or service provision for health issues affecting women, and poor experiences in healthcare settings, where women report attitudinal barriers such as 'not being heard' when reporting symptoms.

The stated chief aim of the Women's Health Plan is to address these underlying issues, with the intent being to improve women's health-related experiences holistically and throughout the life course, regardless of clinical specialty or disease area: ostensibly, this should include gynaecological cancers. We think that this commonality could be made clearer.

Potentially, the lack of references to gynaecological cancer (and the female experience of other cancers) could be addressed in future progress reports and evaluation of the Women's Health Plan by highlighting how the Women's Health and Cancer Clinical Networks are working together to achieve shared goals. A particular focus on how far healthcare professionals across the two Network areas are fulfilling objectives pertaining to 'women's voices', i.e. identifying and challenging bias, recognising and addressing the real-world impact of gender stereotyping on times to diagnosis, and the need for interventions / treatments which are truly person-centred, would be welcomed.

A vital next step for both the Women's Health Network and Cancer Recovery / Improvement Plans should also be to set out how they will capture, act, and report on data derived from Patient Reported Experience and Outcome Measures, including measurables which focus on the design and roll-out of training which should be coproduced with women themselves. Clearer communication and reporting on

[1] https://ftww.org.uk/wp-content/uploads/2024/07/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf p.7

progress within the Cancer Recovery Programme and Women's Health Plan, and elucidating how the two are linking up would, we believe, help to address some of these concerns.

2) **What specific actions have been taken to implement the recommendations related to gynaecological cancer since the report was published? Can you set out where measurable and identifiable progress has been made, as well as where progress has been slower than anticipated or absent.**

Women's Health Research

We welcome the focus on research. As far as possible, we would like to see a commitment to all Welsh Government-funded health and care research being disaggregated by sex and gender as per the MESSAGE Framework[2], and women's health research being intersectional in nature, with data collection, analysis, and reporting enabling better understanding and improved care for women of diverse backgrounds and circumstances. This is vital if we are to address disparities experienced by underserved groups whose needs are often not considered, not least when it comes to public messaging about symptoms, identifying and / or screening for gynaecological cancers, and access to both support and treatment

We would call on the Welsh Government to strengthen requirements in this regard, alongside an expectation that Public and Patient Involvement be fully embedded and resourced in the design and delivery of health research. We would also like to see an increased focus on coproduction, where patient advocates and community groups are enabled to initiate research projects, with support from academic teams, rather than the opposite always being the case. This approach would amplify women's voices and ensure that research priorities – including where related to gynaecological cancers – are driven by the lived experience of women themselves.

Women's Health Hubs

We believe that the implementation of Women's Health Hubs in each health board presents an excellent opportunity to improve the health-related experiences of patients across Wales, including those affected by gynaecological cancer. However, we feel it's important also to acknowledge and address women's concerns as the Hubs develop, such as anxieties about whether and how far the Hubs will continue to be resourced beyond the initial first year of Welsh Government investment, and how their successes

[2] https://www.messageproject.co.uk/message-policy-framework/

– and gaps – will be measured, reported, and acted-upon in order to drive continuous investment and improvement.

We are pleased that a NHS Wales Implementation Guide has been created to support health boards and associated clinical leads in ensuring that the Hubs meet agreed standards and expectations. However, patients remain concerned that there is – as yet – no certainty on what each Hub will look like: Health Boards have been given autonomy on whether their Hub is 'bricks and mortar' or a digital offer, so there will need to be considerable focus on ensuring that patients both know about the Hubs' existence and how to access the services therein. Geographical variation also presents potential risk of inequity which we hope close monitoring and integration of nationally-agreed Patient Reported Experience and Outcome Measures (PREMs and PROMs), co-designed with patients themselves and standardised across all Hubs, will go some way to preventing / addressing.

Our understanding is that, in their first year, the Hubs should bring together clinical personnel with special interest and advanced skills in supporting patients reporting menstrual health issues, menopause symptoms, or needing to access contraception. We are advised that patients can expect to receive a more 'joined-up' offer, where they are enabled to be active participants in shared decision-making and care planning. Key to enabling this this will be ensuring that clinicians in the Hubs have received comprehensive training on symptom recognition, pathways, and broader 'consulting skills', not least if the Hubs are to be more of a 'one stop shop' where patients with complex needs (including gynaecological cancers) can anticipate compassionate, holistic care, facilitated and overseen by their healthcare provider.

Rapid Diagnostic Centres

Whilst we are pleased to see such centres being evaluated, it is important that rapidity does not override the need for informed consent and access to pain relief / sedation / anaesthetic where this is patients' preference. We continue to hear troubling reports about painful and traumatic diagnostic procedures, including outpatient hysteroscopy and cervical screening / treatment. Negative experiences of this nature can deter women from seeking medical help in the future, with disastrous consequences for them, and longer-term costs for health services.

It is vital that patient experiences are heard and taken seriously, and that clinics are set up to accommodate their needs. For example, we would like to see hysteroscopy clinics set up in a similar way to colonoscopy services, where sedation and intravenous pain relief are provided by appropriately trained clinicians. We also look forward to

seeing if / how the less-invasive WID-Easy[3] test for uterine cancer might be utilised in Wales.

Cervical Screening

Self-administered / home-based cervical screening presents a valuable alternative to existing protocols. However, it is important to also consider those women whose impairments or circumstances leave them excluded from current screening and diagnostic services. For example, disabled and bed-bound patients may require additional support to undertake any sort of screening, home-based or otherwise, whilst women with learning disabilities are less likely to be offered or access services of this type. Carers and district nursing services should be trained to provide services where gaps exist.

Palliative / End of Life Care

Palliative / end of life care needs to be truly person-centred and consider the specific needs and circumstances of women and people assigned female at birth, including location of services and efficacy of treatment. We need clear and accessible reporting on how far these issues are being considered and integrated into plans and service delivery, based on Marie Curie Cymru's recommendations in this regard[4].

3) **How is the Welsh Government ensuring that recommendations related to gynaecological cancer are being implemented effectively and transparently? Can you provide details on how the Welsh Government is tracking its progress and where this is being made public.**

Whilst we understand the complexity in reporting across various policy areas and programmes, we think an approach similar to the annual reporting required within the Duty of Quality might be considered both in terms of the Women's Health Plan and Gynaecological Cancers, with a 'plain language' style and 'right to reply'. The latter should be collated and directed to the appropriate spaces / personnel for actioning, dialogue with respondents, and public communications as appropriate.

We believe that this sort of approach would not only increase transparency, it would also demonstrate that 'women's voices' are genuinely being heard and driving improvement, which the 'Unheard' report underlines as a priority.

[3] https://www.ucl.ac.uk/news/2025/mar/new-womb-cancer-test-available-women-uk
[4] https://ftww.org.uk/wp-content/uploads/2024/07/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf p.110

4) **What are the reasons for the continued poor gynaecological cancer waiting times, and what steps are being taken to address this issue? Why has the situation not improved, despite it being identified as a priority.**

FTWW's work with the Welsh Government in 2017-18 on endometriosis[5] shed light on some of the reasons for long diagnostic and treatment delays for gynaecological issues across our health boards. Partly, delays for all gynaecology patients might well be attributable to the huge numbers of non-cancerous gynaecology patients on long waiting lists for (surgical) treatment locally where they would be better served by accessing more specialist care out of area. This would free-up local clinical personnel and theatre time for gynaecological cancer patients.

The current status quo, where health boards are block-funded, creates systemic barriers to specialist care and causes bottle-necks in local service provision. Funding which 'follows the patient', and / or tertiary centres of excellence commissioned by the NHS Wales Joint Commissioning Committee would go some way to resolving the problem. For example, patients with endometriosis, a condition which affects one in ten women and people assigned female at birth, will make up a significant proportion of those on local waiting lists. However, our findings suggest that surgical intervention in centralised, specialist settings would see them more likely to achieve longer-lasting resolution of symptoms, whilst simultaneously enabling gynaecological cancer patients to access timely care closer to home.

5) **How has the Welsh Government incorporated feedback from cancer patients, healthcare professionals, and relevant community organisations into the implementation of the recommendations?**

Whilst we cannot speak to the level of patient and third sector involvement in The National Strategic Clinical Network for Cancer, we are pleased to be playing a part in the equivalent Women's Health Network, and to have been involved in the development of a coproduction framework for the Women's Health Hubs which might transfer across to work in the cancer space.

As a patient-led organisation very much focused on the value of coproduction in improving health services, particularly gynaecology, where it is so important to hear women's voices and act on their expertise, we would like to see a strengthened commitment to patient involvement at all levels of service-design and evaluation. Examples of how this might be achieved include the setting up of Gynae Voices

[5] https://www.gov.wales/sites/default/files/publications/2019-03/endometriosis-care-in-wales-provision-care-pathway-workforce-planning-and-quality-and-outcome-measures.pdf

Forums[6], such as that developed in Betsi Cadwaladr University Health Board which FTWW helps to facilitate, and initial training and continuing professional development of clinicians in Wales. Certainly, this latter could be instrumental in addressing some of the more pernicious issues many gynaecology patients report in their healthcare encounters.

We are excited at the prospect of supporting HEIW in developing training as the Women's Health Plan is implemented, and to continue supporting BCUHB with its Gynae Voices Forum, as the benefits both bring to service design and delivery are clear. However, we would urge that there be ongoing commitment and resourcing for coproduction of this type, in recognition of the knowledge and expertise that patients and advocacy organisations can bring to the table, not least in ensuring more equitable and preventative care.

6) **Can you provide further detail about why Recommendation 15 (about improving emergency care for gynaecological cancers) was rejected, and what is being done to ensure the issues raised are addressed?**

In 2023, FTWW responded to the Welsh Government and NHS Wales consultation on a Quality Statement for Emergency Care[7]. Issues flagged up by our members then remain of concern now and would certainly warrant attention, not least as they pertain to gynaecological presentations more broadly, with implications for gynaecological cancers specifically.

Many of our respondents described emergency settings as not being equipped with a healthcare professional with adequate knowledge of gynaecological and / or menstrual health conditions to provide appropriate care, either by way of personal communication skills or treatment. Often, gynaecological issues require investigation via ultrasound scan rather than x-ray but scanning is rarely available in emergency settings, especially 'out of hours' or at the weekends. There appear to be few staff enabled to offer these interventions in emergency / urgent care settings, meaning that patients can wait several days to establish a cause for their symptoms and access optimum treatment. Clearly, where a gynaecological cancer is potentially the underlying cause, this is a missed opportunity for expediting appropriate care. It is also a stark example of a gender inequality which can have significant impact on health outcomes, as it tends to be women and girls who are more likely to need to access ultrasound scans.

[6] https://www.rcog.org.uk/media/kz0mhttl/workforce-report-2022.pdf
[7] https://www.gov.wales/quality-statement-care-emergency-departments

In addition to a lack of scanning, the absence of staff skilled in gynaecology within the emergency care setting has meant that a significant number of FTWW's members have had their symptoms misattributed to other 'causes', such as a ruptured appendix or a psychological disorder. Alternatively, members recounted being told simply to 'watch and wait'. They suggested that this demonstrated insufficient awareness of how symptoms like pelvic pain and heavy vaginal bleeding are regularly 'normalised', and a lack of compassion for patients presenting with issues which can sometimes be associated with a gynaecological cancer.

Poorly conducted internal examinations have also been mentioned on several occasions, with members describing staff with limited gynaecological training or expertise, and inadequate spaces in which to carry out such exams. Indeed, the physical environments in which emergency and urgent care are provided are often seen as particularly challenging for patients presenting with gynaecological symptoms. Members describe the experience as both embarrassing and traumatising, for them and other patients in the waiting room, compounded by limited access to adequate toilet facilities, a significant issue if the primary symptom is heavy vaginal bleeding.

It is important to note a growing body of evidence indicating how women's experiences of pain are not taken as seriously as they should be in healthcare settings. In emergency and urgent care, women are less likely to receive pain relief or be treated as promptly as men, and are more likely than men to be given sedatives rather than analgesia[8]. This is particularly problematic for those patients who are reporting pelvic pain, a potential symptom of a gynaecological disorder (including cancer) and one which is regularly under-played and under-investigated.

Unfortunately, the implications of not pursuing care, whether as a result of personal and professional normalisation of symptoms, patient embarrassment, or previous trauma can lead to unexpected and / or severe symptoms, resulting in patients needing to access urgent care. It is therefore imperative that emergency settings are suitably equipped to identify issues and treat patients affected both sensitively and knowledgeably, expediting onward referrals as required. Undoubtedly, this would improve the experience of many patients subsequently diagnosed with a gynaecological cancer. We would suggest that greater awareness for those working in emergency care could be incorporated into the training offer being delivered by HEIW as part of its work in support of the Women's Health Plan.

In terms of service delivery within emergency settings, and how this could be improved to cater to the needs of patients presenting with gynaecological issues / symptoms,

[8] https://ftww.org.uk/wp-content/uploads/2024/07/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf p.8

many FTWW members have described how a dedicated emergency gynaecology unit (EGU) offering 24/7 gynaecology provision within every A&E department would be the ideal solution. This kind of offer would enable patients to access expert knowledge and interventions like scanning in a timely fashion, expediting optimum treatment and reducing the risk of complications or worse outcomes.

Given these findings, we are therefore of the opinion that the Welsh Government should revisit its response to Recommendation 15 (Improving Emergency Care for Gynaecological Cancers) because there is evidence to suggest that there are specific barriers to equitable care for gynaecology patients that are not the same as other cancers and which therefore warrant particular attention.

7) **What barriers have been identified that prevent the full implementation of the report's recommendations, and how does the Welsh Government plan to overcome these obstacles?**

We have taken this opportunity to collate our recommendations from the above sections here, as suggested ways forward for the Welsh Government to ensure it meets the needs of gynaecological cancer patients set out in the 'Unheard' report, and women more generally:

- Annual progress reports evaluating the implementation of the Women's Health Plan and Cancer Improvement Plan should highlight joint working and shared goals, and include a 'right to reply'
- Women's Health and Cancer Networks should set out how they will capture, act, and report on data derived from Patient Reported Experience and Outcome Measures
- Women's Health and Cancer Networks should report on take-up and effectiveness of training relating to women's / the patient experience
- A Welsh Government commitment to the MESSAGE Framework and 'intersectionality' in research undertaken in Wales to enable better understanding of individual needs
- The Welsh Government to strengthen expectations around embedding and resourcing PPIE and coproduction in research
- Health Boards to commit to ongoing resourcing for Women's Health Hubs beyond year one, and inclusion of women's health in their IMTPs going forward
- The Welsh Government to prioritise investment in training for healthcare professionals in Wales on 'women's health', including symptom recognition, pathways, and 'consulting skills'

- Hysteroscopy clinics to offer sedation and intravenous pain relief as per Colonoscopy clinics
- The Welsh Government / NHS Wales Performance and Improvement to fund feasibility testing for WID-Easy usage in Wales
- NHS Wales Joint Commissioning Committee (JCC) to commission specialist / tertiary gynaecology clinics (for endometriosis, for example) to enable more optimal care pathways, including earlier diagnosis and effective treatment, for non-cancer and cancer patients across Wales
- The Welsh Government and NHS Wales Performance & Improvement to strengthen calls for patient involvement at all levels of service-design and evaluation, including Gynae Voices Forums in each health board, and initial training and continuing professional development of clinicians in Wales
- The Welsh Government and NHS Wales Performance & Improvement to commit to providing a dedicated 24/7 emergency gynaecology unit (EGU) within every A&E department in Wales, to include ultrasound scanning
- The Welsh Government should revisit its response to Recommendation 15 (Improving Emergency Care for Gynaecological Cancers) in recognition of unique and specific barriers to equitable care for gynaecology patients.

Thank you for your kind attention to this FTWW response to Senedd Health and Social Care Committee's Evaluation of the Implementation of Unheard: Women's journey through gynaecological cancer.

Please do not hesitate to contact us with any questions or for further information on info@ftww.org.uk

Introduction:

Public Health Wales is pleased to provide this written submission to the Health and Social Care Committee's short inquiry to scrutinise the implementation of the Committee's report *Unheard: Women's journey through gynaecological cancer*.

Public Health Wales is the national public health agency in Wales and exists to protect and improve health and well-being and reduce health inequalities for people in Wales. We are one of the 11 organisations that make up NHS Wales.

Public Health Wales is working with Welsh Government to address relevant recommendations in the report. The Cervical Screening Programme at Public Health Wales welcomes this opportunity to provide updates on our work relating to recommendations 8,9,10,11 and a committee note on vaccination guidance.

Recommendation 8: The Welsh Government should:

- **work with NHS Wales to achieve the WHO's target of 90 per cent uptake of the HPV vaccine; and**
- **by the end of this Senedd, report on the progress made in relation to meeting the WHO's 2030 vaccination, screening and treatment targets for cervical cancer. And as part of this include data on the incidence of cervical cancer amongst women in Wales and how this has changed during the course of this Senedd.**

Update:

As detailed by Welsh Government in its response to the recommendation, Public Health Wales continues to publish regular data on uptake of HPV vaccine at local health board, local authority and school level to support health boards to target improvements and reduce inequalities in uptake.

Recommendation 9: The Welsh Government should work with Public Health Wales to review its equity strategy to:

- **ensure everyone eligible for cervical screening has the opportunity to take up their offer; and**
- **take more targeted action to specifically address those groups of women where take-up of screening is known to be low.**

Update:

The motivations for attending screening are well established:

- Cervical screening can save your life

- Cervical screening means changes to the cells can be found early when you have the best chance of successful treatment
- Regular cervical screening can prevent cervical cancer from developing

Cervical Screening Wales commissioned independent research across Wales in 2024 specifically looking at the barriers to attending for cervical screening. This work concluded that lack of awareness of screening and the benefits are not a barrier, but the following were factors that were reported:

- Cervical screening tests are embarrassing
- Cervical screening tests are painful
- Scared of what the test might find
- Challenges in appointment booking with the GP surgery

Building on the findings of this research, Cervical Screening Wales has reviewed and redesigned the invitation letter and leaflet, using behavioural science to inform the messaging. This has been focussed on the first invitation for screening to address lower coverage in the 25-29 year age group. Initial feedback from focus groups has been positive and this work is now progressing with an in-service evaluation, comparing against the existing resources to determine the impact on coverage.

A pilot project has also been established to offer further support to individuals who have not responded to their screening offer. This has been implemented with a primary care cluster, working in collaboration with the voluntary sector, to reach out directly to these individuals. The outcome of this work will be assessed in October 2025, with a view to extending this in other regions if successful.

Self-sampling will play an important part in targeting groups with lower uptake and work on this is progressing (see Recommendation 10).

Recommendation 10: The Welsh Government should, in its response to this report, outline what work is being undertaken to ensure that NHS Wales is set up to implement self-sampling at pace, if approved. This should include details of any redirection of resources that might be necessary.

Update:

Cervical Screening Wales has established a project team and is actively working through the range of options and requirements to implement self-sampling within the cervical screening programme in Wales.

The UK National Screening Committee (UK NSC) published their recommendation in June 2025 to offer self-sampling as an option to under-screened individuals. Working to this recommendation will allow a more targeted

focus on improving uptake in those who haven't taken up the offer of screening previously.

This is an exciting opportunity to improve our offer of cervical screening in Wales. The Wales Screening Committee will be updated regularly on progress towards implementation which is anticipated to begin rollout in 2026.

Recommendation 11: The Welsh Government should, in its response to this report, advise how it is working with Public Health Wales to ensure the information provided at cervical screening appointments makes clear that such screening does not test or screen for other gynaecological cancers, and includes information about the symptoms of other gynaecological cancers. This information should also be provided when women attend their breast screening appointment.

Update:

Cervical Screening Wales provides training for new and existing sample takers on a regular basis, with refresher training recommended every 3 years. Sample takers are predominantly primary care (practice nurses/GPs) and sexual health clinic-based staff, so are well-versed in taking a person-centred approach to patient care and adopting the 'every contact counts' principles. The sample taker training covers key issues to discuss as part of the consultation with the individual attending for screening. This includes advising that screening is not a test for cancer and to check there are no symptoms of concern that would preclude that individual from undergoing screening. If an individual discloses symptoms, they should not undergo screening and instead be investigated/referred as appropriate. The consultation facilitates natural points at which appropriate signposting can be undertaken, for example during cervical screening the participant is asked for the date of their last menstrual period, which may naturally lead to discussion around menopause and signposting to other services.

Cervical Screening Wales have updated the leaflet that is sent with every invitation for screening to include information that cervical screening does not screen or test for other gynaecological cancers.

The public facing information provided on the PHW website is being re-platformed and due to go live in early 2026 with updated information to ensure it covers the relevant detail. All public facing screening literature needs to be managed carefully to ensure it is comprehensive, clear, and accessible. This information will be considered in review and will factor where additional information may detract or confuse the key messages around screening.

Committee note:

'We note that, in conjunction with Public Health Wales, the Welsh Government has developed a guide to vaccinations for young people in school years 7 to 11, which includes information on the HPV vaccination offer. We would also like to see this expanded to include information about the changes that happen during puberty/adolescence and what is normal or not.'

Clarification and response:

The guide to vaccinations was produced by PHW as part of a suite of information for young people to support consent and promote HPV vaccination in girls and boys.

Whilst information on puberty and teenage development for school children, which could include information of vaccines they are eligible for during their teenage years, may be of value, it is not considered appropriate to use information designed specifically to support and promote vaccination to include information on other things which may complicate or dilute the key message. This is especially important as there is a known barrier with HPV vaccination about parental anxiety about their children reaching sexual maturity, and there is a risk of reinforcing this.

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