



FTWW

Fair Treatment for the Women of Wales

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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 inequities¹, 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 Framework², 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-Easy³ 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 regard⁴.

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 endometriosis⁵ 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>

Forums⁶, 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 Care⁷. 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/kz0mhtml/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 analgesia⁸. 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