P-06-1242 – Improve Endometriosis Healthcare in Wales - Correspondence from the Petitioner to the Committee, 14 January 2025

- **What are your thoughts on the attached document?**

  The publication of the Women's Health Plan is a long-awaited and positive step forward for Women's Health in Wales. I'm very hopeful that this is the start of the change we need to achieve equality for future generations. I'm particularly pleased that the development of the Plan has been a collaborative piece of work, as it's vital that patients lived experiences inform the decisions made by Welsh Government.

- **Does it adequately address the issues that you raised?**

  The issues I initially raised regarding endometriosis care in Wales stemmed from the inequalities that women, girls and those assigned female at birth are faced with due to insufficient healthcare, and how this impacts lives more widely on a social justice level. The Women's Health Plan is a step in the right direction, but until tangible results from the Plan are seen, we unfortunately won't know if it adequately addresses the issues regarding endometriosis healthcare in Wales.

  For example, the Plan mentions the importance of research and 'data-driven decision-making', but this is only possible if we have the ability to collect data regarding specific conditions such as endometriosis. Historically there hasn't been a specific data code for endometriosis, and instead Health Boards have only been able to review date for gynaecological conditions more widely. Knowledge is power, so I'd hope that elements such as this are addressed as the Plan progresses.

- **Do you have further questions in response?**

  I'd ask that the Petitions Committee write to the Minister for a response on the question raised by Jenny Rathbone MS during Plenary on 10 December 2024, as I don't believe the question was answered - *"my question around this is that we can't go on having only one tertiary centre, because Cardiff simply cannot fund this on the basis of one in, one out, given that these operations can take up to eight hours, involving several specialist clinicians. So, two medium-term issues: the financial model, and I wonder if you can say a bit more about how we're going to develop this financial model for further tertiary centres, because it really isn't fair that people from north Wales or west Wales have to come all the way to Cardiff, and, frankly, the people in Cardiff already have a very long waiting list. So, we clearly need more endo consultants. If you could say a little bit more about that medium-term thing, because this is something that we've really been asking for a very long time."*

The lack of tertiary care is one of the main points I've been trying to raise via my petition and now that the Women's Health Plan has been launched I'd hope there is some more detail that could be provided on how/when help is coming for patients in the form of increased numbers of specialist surgeons. We're repeatedly informed about the endometriosis nurses, who are a fantastic resource, but it is only the endometriosis specialist consultants who can diagnose and treat the condition.

- **Is there anything additional that you would like the Committee to know at this stage, either in response to this document or as an update to the Committee?**

  I would like to put on record my appreciation for the ongoing support I've had from the Petitions Committee and the clerking team - you have given me and my family much needed hope that our voices can be heard regarding this issue, which continues to have such a huge impact on our lives.

  I would also like to note that the Endometriosis Task and Finish Group Report highlighting the issues with endo care in Wales was published in 2018, my petition closed in 2022 and the Women's Health Plan was launched in 2024, so after 7 years we're now hoping to see the start of change with this issue. I fully understand that change takes time, especially when there is no quick fix, but please understand that patients are not able to ask the progression of this disease to patiently wait and stop the ongoing damage. My endo health issues are relentless and I'm still only able to get support for the condition through private healthcare. My daughters have grown up seeing first-hand the impact of this disease and the inequality they are faced with due to their gender. I hope that my petition can be kept open until answers to the questions raised in my response are answered, but if not I ask for them that if tangible progress isn't made over the next year as the Women's Health Plan progresses, the Committee will agree for a future petition on endometriosis to be accepted and re-considered.

  Finally, I would also ask that the Petitions Committee consider the following response from the charity Fair Treatment for the Women of Wales who I volunteer with as one of their endometriosis champions:

  - ***What are your thoughts on the attached document?***

    FTWW is pleased that endometriosis and adenomyosis feature so prominently in the Women's Health Plan, and that this is based on extensive feedback from the patient community. We note also that the theme of women and patients not feeling like their voices are heard when it comes to their symptoms and health-related experiences and care is prioritised as per findings from the 'NHS Wales Discovery Report'.

  - ***Does it adequately address the issues that you raised?***

We understand that the Women's Health Plan in its current form is not an implementation or delivery plan, and that this will come next, following the creation of associated task & finish groups set up to explore various health issues and themes in more detail, and oversee the implementation of recommendations. However, it's important to note that a very comprehensive set of recommendations was developed following the year-long 2017-18 Welsh Government endometriosis task & finish group, and we have not yet seen all those fulfilled. ***We would strongly advise that the work of that group be reviewed, and outstanding recommendations revisited, completed, and reported against.***

Structural issues in the Welsh NHS need to be considered and actively addressed as a matter or urgency, including the problems presented by block funding *to health boards, and how this can prevent 'regional collaboration' recommended by the former Cabinet Secretary for Health & Social Care (now First Minister) Eluned Morgan, particularly when it comes to accessing specialist tertiary services only available in one or two health boards.* ***Our understanding is that the NHS Wales Joint Commissioning Committee (NWJCC, formerly WHHSC) has been consulted on commissioning and appropriately funding tertiary endometriosis services for Wales but, as yet, we have not heard any conclusions to these conversations; we and the patient community would appreciate further updates on this.***

Provision in Primary Care for endometriosis as a chronic illness: *It's important to be aware that endometriosis is a chronic disease with the same prevalence in women and people registered female at birth as diabetes or asthma. Whilst we appreciate the ongoing Welsh Government commitment to specialist endometriosis nurses in each health board, the number of nurses per head of affected population is not sufficient.* ***Wales should aim to have an equivalent number of nurses in primary care for menstrual & gynaecological health conditions like endometriosis as it offers for diabetes / asthma****. Patients with a chronic illness of this type deserve the same access and monitoring of their conditions / treatments as is offered to conditions which aren't gender-specific.*

We would urge the Committee to enquire as to how the ***GMS contract and Quality and Assurance Framework*** *therein can be amended to include menstrual and gynaecological health conditions which are currently not referenced (https://www.gov.wales/sites/default/files/publications/2022-02/quality-assurance-and-improvement-framework-2021-2022.pdf#:~:text=Disease%20Registers%20are%20lists%20of%20patients%20registered%20with,this%20will%20be%20written%20into%20the%20contract%20regulations) – it is our belief that their inclusion would lead to better, more robust data collection and improved care. However, as yet, we have not been able to progress this issue further. It may be that work on the Women's Health Plan and 'Women's Health Hubs' focuses on this, but we believe that* ***the Committee's support and influence in this area would be beneficial****.*

Endometriosis and Mental Health: *In terms of managing endometriosis, the vast majority of patients surveyed by Endometriosis UK in 2020, stated that they would benefit from psychological and mental health support to help them manage chronic pain, other symptoms, and potential fertility challenges. We would like to see a* ***Welsh Government commitment to investment in community mental health services for patients living with chronic physical illness.***

Endometriosis Research in Wales: *Finally, it's also worth pointing out that recent NICE guidance on endometriosis still fails to include* ***endometriosis post-menopause or outside of the pelvis****. Lack of robust research and data on these topics is one reason for their continuing exclusion from scope, so* ***we would ask that these two issues be recommended for further research in Wales, as part of the Welsh Government's commitment to 'women's health research'.***

- ***Do you have further questions in response?***

  As an organisation and Chairs of the third sector Women's Health Wales Coalition, we are pleased to have had ongoing engagement with the Clinical Network for Women's Health throughout the development and publication of the NHS Wales Women's Health Plan. However, we would welcome more clarity as soon as possible on how this will continue as the Plan is implemented. ***We are particularly keen to understand how the Clinical Reference Groups posited will be administered and their findings fed back into the Women's Health Leadership Group.*** *We remain concerned that the absence of third sector representation on the leadership group means that patient priorities / experiences and the operational requirements of organisations outside of the NHS may not be adequately considered or discussed at this level. This is particularly important in the context of third sector organisations as equitable partners, sometimes commissioned by the NHS and / or the Welsh Government to deliver services. There is a risk that the interface between clinical advisory and leadership groups may not be adequately resourced or sufficiently robust, running the risk of miscommunication and inefficiencies.* ***We would welcome assurances on this and, indeed, a commitment to revisiting arrangements if needed.***