

## **P-06-1242 Improve Endometriosis Healthcare in Wales, Correspondence – Petitioner to Committee, 30.01.23**

Thank you again to the Petitions Committee for continuing to support my petition and for their ongoing correspondence regarding this matter.

I appreciate the work that the Health Minister is undertaking since the Women's Health Quality Statement was announced. The first phase of the Women's Health Plan is a great step in the right direction for women and girls, however there is still no tangible progress for endometriosis patients or assurances that the issues we continue to face will be addressed as part of the Women's Health Plan. I therefore ask that the Committee keep my petition open whilst the Plan continues to be developed to help ensure our voices are heard.

I fully understand that the development of the Women's Health Plan is on-going, but this isn't justification for the lack of progress made. In the meantime, steps could be taken to improve the most urgent issues faced by endometriosis patients, especially considering these issues have now been **repeatedly** raised since 2018.

We urgently need answers as to why we're still facing such healthcare inequality and we need a tangible response as to how and when things will finally start improving for the the 1 in 10 affected by this disease.

Alternatively, if no help is coming, please could the Health Minister be straight with us and acknowledge that the only way that endometriosis patients can be reassured they'll be able to access the treatment they need is by taking out private healthcare insurance (as that is our current reality).

Regarding the Chair's letter which was included on the agenda of the Health & Social Care Committee meeting on 17th November 2022, please would it be possible to find out if there was any feedback or action points from the noting of this?

The Health and Social Care Committee also wrote to the Minister for Health and Social Services asking whether her commitment to the improvement of women's health services included improving the availability of specialist services to meet women's health needs across Wales. Please could I ask what the Ministers' response was to this question, as the lack of availability to specialist services is one of the main issues endometriosis patients have.

Also, I wanted to bring the Committee's attention to the attached email from the NHS Wales Health Collaborative regarding one of the patient surveys referenced by the Health Minister in her letter. As you will see from the content of the email, there was a breach of the survey participants identifiable data (including my own) that has led to an investigation. When patients have waited as long as we have to be listened to, it's hugely frustrating for there to be such a lack of care when undertaking this important work and dealing with such personal information.

Finally, please see below commentary regarding this latest correspondence from the charity Fair Treatment for the Women of Wales, who I volunteer with as one of their endometriosis champions:

*Members of the Women's Health Wales Coalition are concerned that this first stage document has omissions which we hope to see addressed subsequently and in next stages of the plan's development - this can be achieved so long as there is sufficient time, resource, and capacity to enable full co-production and collaboration. The Women's Health Wales Coalition would like to offer officials its support and involvement, and hope that future*

meetings can be convened to enable sharing of expertise / lived experience, and address underlying intersectional inequalities.

*It is vitally important that any subsequent plan is as inclusive and detailed as possible, enabling a holistic, life-course approach to female health. We understand that this is to be an NHS Wales plan so there needs to be scope to consider a panoply of health services and interventions that can improve patient experiences and outcomes. The Women's Health Wales Coalition's evidence document provides a useful, but by no means exhaustive, starting point: [Womens-Health-Wales-Quality-Statement-English-FINAL.pdf \(ftww.org.uk\)](https://www.ftww.org.uk/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf)*

*Regarding endometriosis specifically, there is still work that can be done to improve patient experiences without waiting for the publication of the women's health plan. This might include Minister / officials / NHS Executive facilitating a meeting of health boards, the Welsh Health Specialised Services Committee, and third sector / patient representatives to explore and better understand why patients with severe and complex endometriosis who should, according to NICE guidance, be referred to a tertiary / specialist endometriosis centre (ie Cardiff) are not always able to access that service and what can be done to address this anomaly.*

*It is our understanding that it is largely due to existing funding arrangements which make out of area referrals for what is a very costly and time consuming multi-disciplinary surgery financially prohibitive for C&V UHB, one which can have a significant onward impact on their own gynaecology waiting times and patients. Of course, lack of access then has knock-on effects on patients' own health boards, because it means patients with severe / invasive disease have to repeatedly utilise less effective services locally, impacting on local waiting lists. These are issues which need to be explored collaboratively and in-depth so that they can be resolved to everyone's satisfaction.*

Kind regards,

Beth Hales