

P-06-1242 Improve Endometriosis Healthcare in Wales – Correspondence from the petitioner to the Committee, 15 May 2022.

Many thanks for sending on the responses you've received and for keeping my petition on the committee's agenda.

As seen from the recent media attention surrounding endometriosis, as well as from the Plenary debate on Women's Health in Wales being held on 18th May, this continues to be an extremely important topic. Patient voices are being heard more and more regarding the seriousness of the issue and how long waitlists currently are. This was also discussed again in the Senedd last month when Heledd Fychan raised how a constituent was told to "give up any hope of getting surgery" for endometriosis because of the current issues surrounding tertiary care in Wales.

From reading the attached correspondence this isn't surprising considering CVUHB (who have the only tertiary care facility in Wales), currently have 3 all day operating lists **a month** and are only able to "accept some referrals from neighbouring health boards". If this is the current capacity for the whole of Wales for a disease that affects **1 in 10** women and those assigned female at birth, it's no wonder patients are frequently being left with nowhere to turn.

Surgical treatment is desperately needed by so many endometriosis patients in order for them to have any sort of quality of life, yet the majority are facing up to 7 years wait for treatment unless they have access to private healthcare. It's therefore hugely concerning that the correspondence received didn't include a response on when/how the lack of endometriosis specialist consultants will be addressed.

CVUHB haven't included a reason for the recent reduction in endometriosis consultants without replacement (i.e. numbers reduced from 3 to 2 when the number recommended across Wales is 6), and HDUHB state that "typically patients requiring specialist support are referred onto the tertiary centre in CVUHB, although they are not currently accepting referrals due to capacity challenges". So with patients at best facing a 156 week wait for routine gynaecological surgery and at worst, nowhere to go, I ask that the Petitions Committee continue with their much needed support until progress is seen regarding this.

As previously discussed, the new endometriosis nurses are a fantastic and much needed resource. However, they can only signpost patients so far along a treatment pathway if there are no consultants to refer them onto for what is currently the only treatment for endometriosis (hormones and painkillers are regularly prescribed for patients, but these are used to mask the symptoms rather than treat the disease). This therefore remains a very worrying situation for the women of Wales to be faced with.

From reading through the attached correspondence I would also ask that the following points are considered by the Petitions Committee:

- **Please could my initial question regarding the lack of endometriosis specialist consultants in Wales be pressed further**, especially as this is the action that would have the biggest impact for patients. The Health Minister states that "health boards are responsible for determining the appropriate provision required to meet the needs of their local populations", however PTHB have advised that the demand for service is unknown and HDUHB have

nowhere to send patients needing surgery. The Health Minister also states that “where tertiary services are provided, I expect suitable conversations to take place on a regional basis to ensure appropriate funding arrangements exist and to enable pathways that provide equitable provision across the whole of Wales.” However the Endometriosis Task & Finish Group Report confirmed in 2018 that the funding set-up with CVUHB was “unsustainable” and needed to be urgently addressed. I hope that the Health Minister will continue to work alongside the Health Boards to help them achieve a solution regarding the tertiary care situation and ensure appropriate funding arrangements are indeed in place, as there seems to be some disconnect between the Health Minister’s expectations and the Health Board’s responses;

- **If not already planned, please could the Health Minister look at collaborating with charities such as Fair Treatment for the Women of Wales and a cross-section of patient voices when compiling her new Women’s Health Plan.** This engagement will provide critical information that could hugely benefit the plan and will help ensure that services are developed in a way that work effectively for patients. Women and girls have been suffering in silence for generations and the current inequality faced won’t be fully addressed unless their voices are heard and their lived experiences learnt from;
- **Please could the previous suggestion from the Petitions Committee for an interview to help raise awareness be used to highlight all the fantastic resources that have recently been put in place** (e.g. endometriosis nurses, bloody brilliant campaign, endometriosis Cymru website, etc). This could help raise much needed awareness of the condition and the associated resources to ensure a wider audience learns of the availability, content and most importantly, how to access them. For example, one patient interview could be undertaken per health board and promoted via the Senedd’s social media channels;
- **Please could the data gaps that have been highlighted by PTHB and ABUHB be raised with Health & Care Research Wales and the Welsh Universities to see if they could assist with implementing the suggestions made.** This could help improve the quality of research into endometriosis and lead to the development of much needed treatments;
- **Finally, please could you confirm if you’re still awaiting a response from the Betsi Cadwalader University Health Board.**

Many thanks for your continued support with this issue.

Best Wishes,

Beth Hales

Comments to the Petitions Committee **on behalf of the charity FTWW (Fair Treatment for the Women of Wales)**:

1) Note that there is no response from either Betsi Cadwaladr UHB or Swansea Bay UHB. This is disappointing and frustrating, and speaks to the wider commentary on both 'lack of data' and a lack of accountability which comes from there being no NHS Executive with statutory powers to ensure that health boards provide timely information / data where they can.

2) The HM's response - points to note:

- ***'It is for HBs to prioritise how best to use the funding to address the backlog of patients waiting'***. This is problematic, given historical lack of prioritisation and investment in women's health more generally and gynaecology specifically. The issue has been highlighted by countless evidence papers, most recently RCOG's report, '[Left for too long: understanding the scale and impact of gynaecology waiting lists | RCOG](#)' and, prior to that, the WG's Endometriosis Task & Finish Group's 2018 report. The current approach, where HBs have autonomy to decide for themselves where / how to invest, results in continuing variation and inequality for patients, nor does this approach encourage or incentivise collaboration between HBs. It is a problem compounded by a lack of investment in relevant data collection - how can HBs decide what to prioritise, if they lack meaningful data on prevalence and impact?
- ***'The endometriosis nurses are...liaising with their Multi-Disciplinary Teams'***. Please can we know who the members of these teams are / their roles? To ensure equity, each HB should be able to offer patients access to the same style MDTs. In those HBs pursuing BSGE tertiary status, it is vital that those MDTs comprise surgical interventions by colorectal and urology surgeons - can we be sure that this is happening? Data?
- ***'The endometriosis nurses...help shape a better future for the endometriosis pathways in Wales'***. The appointment of endo nurses is much-welcomed but one CNS per HB is, sadly, nowhere near sufficient (what is the equivalent provision for diabetes, a condition with similar prevalence)? Going forward, Wales needs to be investing in bespoke training opportunities to attract new recruits. Further, it is not possible for pathways to be robust unless there is additional investment in other parts of the pathway too, as Cwm Taf Morgannwg UHB's gap analysis identifies. This should include upskilling of local gynaecologists to improve their offer of minimal access surgery and laparoscopic visualisation and identification of endometriosis (see the Endometriosis T&F Group's findings and recommendations in this regard), universal access to pelvic physiotherapy and pain management MDTs (including mental health support), and then also

ensuring sustainably funded access to tertiary services from wherever the patient is located in Wales. It also means that patients (and staff) need assurances that the existing CNS posts will be funded (by the Welsh Government?) beyond the initial three years and, indeed, expanded to ensure equitable provision as is offered to conditions with similar prevalence.

- ***'Health boards are responsible for determining the appropriate provision required to meet the needs of their local populations'***. This was fraught with problems when the T&F group reported in 2018 and remains so. Several of the HBs mention a lack of data on prevalence, impact (Powys) and non-surgical management (Aneurin Bevan UHB), as well as inadequate coding when surgery is undertaken to record diagnosis / stage of disease / surgical approach (Hywel Dda UHB, Aneurin Bevan UHB). Even now, despite known national / global prevalence, endometriosis isn't included in the Quality, Assurance & Improvement Framework for Primary Care (which is where data on prevalence can be recorded and improvements to care pathways made), which links back to our first comment on the HM's letter - historical lack of prioritisation for conditions predominantly impacting women's health / gynaecology results in a lack of data, which exacerbates a failure to appreciate impact and need and consequent failure to provide appropriate services.
- ***'Where tertiary services are provided, I expect suitable conversations to take place on a regional basis to ensure appropriate funding arrangements exist'***. This could be addressed by facilitating a conversation between patient reps, the RCOG WEC (Welsh Exec Committee) / NSAG (National Specialist Advisory Group) for Obs and Gynae, and WHSSC (Welsh Health Specialised Services Committee) - as recommended by the Endo T&F Group. The fact is that current funding arrangements make it financially unviable for HBs to offer a tertiary service to complex endometriosis patients out of area and a reliance on the good will of HBs to collaborate is not working for either them or their patients as CVUHB points out, ***'There is no funded tertiary care service for endometriosis within south Wales'*** and Hywel Dda UHB confirms, ***'CVUHB (is) not currently accepting referrals due to their capacity challenges'***. A relatively straightforward solution would be for funds for tertiary services to be top-sliced by the WHSSC, ensuring an equitable service and pathway for patients across Wales. We simply need to be allowed a meeting with the Committee to discuss it!!

3) Powys Teaching Health Board's response:

- ***'The Pelvic Health Steering Group...includes membership for Third Sector and voluntary groups'*** - we'd be keen to know who these are (FTWW has one patient volunteer on the group but we don't know of

any others). With Powys being as large as it is, it is very important that patients from disparate locations are enabled to participate, something we would be pleased to help facilitate.

- **'A Band 7 Pelvic Health Physiotherapist'** - again, the size of Powys makes only having one member of staff providing this service a real challenge in terms of patient access. What is being done to address gaps in provision? Physio is one intervention where patient experiences and outcomes are improved if it is available 'closer to home'.
- **'A robust comprehensive local structure'**. The Powys response makes no mention of pathways to surgical intervention, both at a (cross-border, as Powys has no hospital) secondary and tertiary level. Presumably, there would need to be a few pathways to accommodate patients in different parts of Powys but it is surprising that there is no reference to anything of this nature. This was identified as a significant gap when the Endo T&F group reported and remains so, at least as is reported to us by residents.

4) Hywel Dda UHB's response:

- **'The Health Board does acknowledge a 156 wait for routine Gynaecological surgery'**. This does the severity and complexity of endometriosis a disservice. It isn't routine if there is a possibility of kidney loss or bowel obstruction, the chances of which increase the longer a patient waits for surgical intervention to identify the problem and treat it. Waits of this length also have implications for fertility and increased costs for the NHS as more patients are potentially forced to access fertility services.

5) Cwm Taf Morgannwg UHB's response:

- **'Research opportunity within the specialty'**. As a patient advocacy organisation, we'd like to know more about this possibility if only to ensure that any proposal, methodology, and activities are co-produced.
- **'Patient feedback (is) being requested via Social Media and analysed...Co-producing the referral pathways with women within our communities'**. As above, we would like more information on this so that FTWW can assist and ensure some degree of consistency across Wales exists, reducing variation and inequality, whilst acknowledging that pathways will vary depending on resources and location.
- **'Development of referral protocols with the local Specialist Endometriosis Centre'**. Which centre?

6) Aneurin Bevan UHB's response:

- **'We are wary of single condition emphasis in the face of current pressures'**. This condition warrants particular emphasis because of historical neglect, prevalence, and on-costs associated with it (loss of

education, employment, fertility). Again, we go back to mechanisms like the QAIF, which has some 19 disease registers, all of which are prioritised for similar reasons and, yet, endometriosis remains absent. Endometriosis warrants attention, if only to address this persistent inequality.