

P-06-1242 Improve Endometriosis Healthcare in Wales, Correspondence – Petitioner to Committee, 05.09.22

Many thanks for sending on the latest correspondence regarding my petition, and thank you to everyone for the help they've given with raising awareness of endometriosis through the interview and blog that was put together recently.

I appreciate the ongoing correspondence between Jack Sargeant and Eluned Morgan on this matter, and in regards to the Health Minister's latest letter my thoughts are as follows:

- The Women's Health Quality Statement that was announced is fantastic progress for the various health issues and inequalities that we face. To ensure that the much needed change is delivered for patients in Wales and that tangible progress can be monitored, I would ask that the Committee keep my petition open and on their agenda whilst the Plan is being developed and rolled out;
- The Health Minister has said that *"the Plan must have significant input from service users to ensure women's voices are heard plainly and their concerns reflected"*. I would therefore like to offer my help to the Health Minister regarding engagement opportunities, as I completely agree that it's imperative that patient voices are heard as much as possible during the development of the plan;
- The Health Minister advises that the Women's Health Plan will ensure *"suitable tertiary care is in place to support conditions such as endometriosis"*. One of the questions that I've raised from the start of my petition is regarding the reduction of tertiary care in Cardiff & Vale HB and the lack of tertiary care across the rest of Wales. I therefore still have to ask, what should patients do in the meantime whilst they can't access tertiary care? Why can't the consultant who previously retired (leaving only two endometriosis specialist consultants for the whole of Wales) be replaced whilst the Health Plan is being developed to help address the urgent issue of lack of tertiary care in Wales? Where has the funding gone that was used for his salary? And where are the endometriosis nurses currently signposting the patients who urgently need tertiary care when the waitlists just keep rising?
- I completely concur with the Health Minister's praise of the appointment of the endometriosis nurses. When I was diagnosed, endometriosis nurses weren't in-situ and so I received minimal information and support about the disease and I definitely wasn't signposted to other appropriate services. It was therefore only thanks to the privileged position I'm in of being able to access private healthcare through my work, that meant I was able to seek support to help manage my condition day to day via a private pelvic physio and private mental health support. Even with that, I'm still in pain every day and it's an on-going struggle both physically and mentally (and it's 1 in 10 that have this same chronic illness, but definitely not 1 in 10 who can access private healthcare). I therefore sincerely hope that the WHIG extend the funding of these posts beyond the initial 3 years as it's SO important that progress doesn't end with the endometriosis nurses, and also that we don't see progress eroded at the end of 3 years. Otherwise patients will be back to having nowhere to turn. This is another reason why I ask the Committee to keep the Petition open and help all of us

with endometriosis ensure that the delivery of positive and tangible progress is ongoing;

- Finally, with regard to your point on whether endometriosis will be included in the Quality, Assurance & Improvement Framework for Primary Care, it's not clear whether the Health Minister has answered the question and there's definitely no guarantee that menstrual and gynaecological health conditions will be included. Therefore can the Health Minister offer assurances on this? And how far can patients feed into the process of deciding what might constitute future quality improvement projects?

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

Letter from Health Minister to Petitions Committee

1. **Reference to the Welsh Government's Women's Health Quality Statement** - We would be pleased if the QS made some reference to the #WomensHealthWales Coalition's document, at least as a citation, as it clearly evidences the collaborative and co-productive approach taken by the WG team with third sector partners and patient representatives;
2. **Health boards and trusts are responsible for planning and delivery of women's health services in line with professional standards and the quality attributes set out within the Women's Health Quality Statement** - It would be useful for patients to have some sense of how the WG proposes oversight of this activity, both to ensure standards are met equitably across Wales and that third sector / service-users are involved in design and evaluation of services;
3. **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** - Historically, this has proved problematic due to block funding arrangements in Wales. We would like to see the Welsh Health Specialised Services Committee (WHSSC) playing an active part in these conversations and for national clinical leads and patient advocates to be invited to discuss with them the existing challenges and possible solutions;
4. **Work on the development of the Plan is underway and there will be a process of engagement and ongoing consultation with the Coalition and wider stakeholders to ensure the plan is co-produced and responds to the needs of all women who access our health services** - Beyond the planning stages, we would like to see patient involvement / co-production made a key part of decision-making within implementation groups, and service design / evaluation within each health board. Part of reporting measures should include the degree to which this is taking place. This kind of activity also needs adequate support and resourcing so we would welcome some sense of what plans are in place to provide that sort of sustainability.

Letter from HCRW to Petitions Committee

1. ***We are currently preparing to support the Welsh Government's agenda on Women's Health, therefore your letter is very timely as we consider where the key evidence gaps across a range of issues are, inclusive of endometriosis*** - Can HCRW give some idea of when we might expect to see this reflected in published research priorities / calls? Is HCRW able to provide some sense of the funding that might be attached to women's health-related research projects? Also, can HCRW give some assurances regarding establishing criteria for the co-production of both research topics and project design?
2. ***I am also aware that colleagues in the School of Psychology in Cardiff University have a strong interest in the diagnosis of endometriosis and are supporting Endometriosis Cymru*** - FTWW is pleased to have long collaborated and supported their work on endometriosis. However, longer-term and larger-scale funding is needed to bring some elements of the work to fruition and, indeed, to ensure that they are utilised effectively across Wales, such as digitising the Endometriosis Cymru symptom tracker tool. Might the latter be something with which HCRW could support, or would this be more the remit of Health Education & Improvement Wales?

Please let me know if you require anything further prior to the Petitions Committee meeting on the 19th September.

Best wishes,

Beth Hales