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Mr Jack Sargeant Chair Petitions Committee Welsh Parliament Cardiff Bay Cardiff CF99 1SN

Our Ref POW/HT/MS

Dear Mr Sargeant

## Re:- Petition P-06-1242 Improve Endometriosis Healthcare in Wales

Thank you for your correspondence dated 3<sup>rd</sup> March 2022 regarding the petition committee considering endometriosis health care in Wales. As requested, we are able to provide you with an update on specific actions being taken forward by Powys Teaching Health Board to address the important issues raised in the petition regarding endometriosis health care.

The health board has an established managed clinical network, known as the Pelvic Health Steering Group, which includes membership for Third sector and voluntary groups to progress the development of the Women's Health Service local work plan in line with the All-Wales Women's Health Implementation Group (WHIG) provision for endometriosis care in Wales. The initial Welsh Government funding supported the Pelvic Health Programme Manager who provides a long-term, strategic leadership function in the development of local patient pathways in accordance with the national guidelines. The Powys Women's Team has been increased with the appointment of the Endometriosis Clinical Nurse Specialist (CNS) and Band 7 Pelvic Health Physiotherapist.

Following their appointment, the CNS workplan included engagement with stakeholders such as GP's, primary care Nurses, visiting Gynaecologists, Outpatients staff, Pelvic Health Physiotherapists, Continence Team, Pain Management Team, Psychosexual Counsellor, Sexual Health Team, All Wales Endometriosis CNSs, School Nurses: therefore, gaining skills and knowledge to develop the Endometriosis / Women's Health Service for Powys.

To help inform the service development for improving endometriosis for Powys residents, a benchmarking exercise was undertaken in November 2021 against the NICE guidelines (NG73) for Endometriosis Diagnosis and

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Management (2017). The benchmarking exercise highlighted the need for a Medical Lead, either Gynaecologist or GP's, to be appointed to support the service. The health board's Endometriosis / Women's Health Service is establishing a holistic MDT approach. This includes collaboratively working with the Pelvic Health Physiotherapists, Continence, Pain Management and Psychology Teams. Strong communication and triage pathways are being developed in readiness for the Women's Health Service for Powys. The collaborative working with the CNSs is providing All-Wales guidance. It is anticipated that having a network of CNSs across Wales will strengthen links with secondary care.

Further strengthening of awareness and knowledge of endometriosis has been made with the recent launch of the Women's Health page on our website. The page gives an overview on endometriosis and links to available support. Through this patient representation we have identified a local endometriosis social online support group, alongside a Virtual Endometriosis Café, which provides support for people with endometriosis or people who think they may have the condition. During March 2022, the health board has been an active participant with Endometriosis Action month. This includes providing Podcasts of general information regarding the condition, symptoms and treatment, alongside raising awareness of the Mid Wales Online Support Group and organised their Worldwide Endo March on the 26<sup>th</sup> March.

Extensive work has been undertaken on a local level to form the outcome measures for the health board. Following initial benchmarking it was clear to see that the data capturing of endometriosis in the health board was limited. The Women's Health Team has worked extensively with the Information Team to devise a robust comprehensive local structure, that will be adopted to track a patients endometriosis journey. This data structure is currently being discussed at WHIG with the aim of having a national data standard.

The consequence of the lack of data currently available impacts on the uncertainty of demand and capacity for the Endometriosis / Women's Health Service in Powys. Due to the lack of data available we are currently uncertain of demand and capacity for the service

Protocols, Standard Operational Procedures and PGDs for the Women's Health Service are currently being developed and the digital management system for the Endometriosis / Women's Health Services is also being advanced. This work needs to be concluded before a full clinical service can be established.

Yours sincerely

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Hayley Thomas

Deputy Chief Executive, Powys Teaching Health Board