

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy'n aros am ddiagnosis neu driniaeth](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment](#)

WT 40

Ymateb gan: | Response from: All Party Parliamentary Group on Endometriosis

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All Party Parliamentary Group on Endometriosis  
House of Commons  
London  
SW1A 0AA

Mr Russell George, MS  
Chair, Health and Social Care Committee  
Senedd Cymru/Welsh Parliament  
Cardiff Bay  
Cardiff  
CF99 1SN

Dear Mr George,

As Joint Chairs of the UK Parliament's All Party Parliamentary Group on Endometriosis, we welcome the Senedd Health and Social Care Committee's consultation on the impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment.

Endometriosis is a condition affecting 1 in 10 women and those assigned female at birth from puberty to menopause, although the impact may be felt for life. It is where cells similar to those lining the womb (uterus) grow elsewhere in the body. Common symptoms include chronic pelvic pain, painful periods, pain during or after sex, painful urination and bowel movements, fatigue and difficulty getting pregnant. The cause of endometriosis is not known, and there is no cure. There are treatments available to manage the condition, which include surgery.

The issue of waiting times is an important one for the endometriosis community in Wales. We know from our 2020 endometriosis inquiry<sup>1</sup>, that pre-pandemic, waiting times for endometriosis care in Wales were longer than the UK average:

- 44% got gynaecology appointment within 6 months of referral (UK average 69%), while 41% were waiting 7-12 months (UK average 19%)
- 52% waited 0-6 months for surgery (UK average 70%), 48% waited more than 6 months (UK average 30%) and 15% waited more than 1 year (UK average 7%)

It currently takes an average of nine years to get a diagnosis of endometriosis in Wales<sup>1</sup> which means that some spend years undiagnosed and not receiving the right care. The only way to definitively diagnose endometriosis is through laparoscopy, a form of keyhole surgery. Longer waiting times for gynaecology appointments including diagnostic laparoscopy due to the pandemic, will not help reduce the time it takes to get a diagnosis in Wales.

We have heard from Welsh MPs that the pandemic has worsened the waiting times situation for those with endometriosis in Wales, in particular for those awaiting surgery, who can experience chronic pain and other symptoms, which negatively impact on their quality of life.



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Our 2020 inquiry<sup>1</sup> found that access to services such as pain management and mental health support was sometimes lacking for those with endometriosis in Wales before the pandemic:

- 48% would have liked to have been offered pain management services, but were not
- 77% would have liked to have been offered mental health support, but were not

For those requiring tertiary (specialist) care such as complex surgery for deep endometriosis, there are only two endometriosis specialist centres<sup>2</sup> in Wales, a fully accredited centre at University Hospital of Wales in Cardiff and a provisional centre at the Singleton Hospital in Swansea. The 2020 inquiry heard that these centres had long waiting times for surgery before the pandemic.

At a recent UK parliament debate on endometriosis and PCOS, Hywel Morgan, MP for Arfon highlighted the lack of specialist care for those with endometriosis in North Wales. Mr Morgan noted that individuals are referred to endometriosis specialist centres in England, but that this involves long travel times and lack of service provision in the Welsh language.

There is a need to invest in tackling the waiting times backlog for those with endometriosis in Wales, and we hope that this consultation goes some way to identifying how that can best be done. This should also include ways to improve the support offered to those on waiting list for endometriosis care.

We wish the Senedd Health and Social Care Committee all the best in this endeavour.

Yours sincerely,

Hannah Bardell MP

Emma Hardy MP

Joint Chairs, APPG on Endometriosis

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<sup>1</sup> [Endometriosis in the UK – Time for Change](#), Inquiry Report of APPG on Endometriosis, October 2020

<sup>2</sup> There are 63 British Society of Gynaecological Endoscopy (BSGE) accredited endometriosis specialist centres across the UK including in the NHS in England. For more information: <https://www.bsgge.org.uk/endometriosis-centres/>, for a list of centres: <https://www.bsgge.org.uk/centre/>