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This response was submitted to the [Health and Social Care](#)
[Committee](#) consultation on [mental health inequalities](#)

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Ymateb gan: | Response from: Endometriosis UK



ENDOMETRIOSIS UK RESPONSE TO WELSH SENEDD HEALTH & SOCIAL CARE COMMITTEE CONSULTATION ON MENTAL HEALTH INEQUALITIES

ENDOMETRIOSIS AND MENTAL HEALTH

Endometriosis is a disease affecting 1 in 10 women and those assigned female at birth in Wales from puberty to menopause, although the impact may last for life. It is a disease 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.

Endometriosis impacts on mental health in a number of ways:

- Before diagnosis* – having symptoms dismissed as “just a bad period”, not being believed, having multiple GP, hospital and even A&E appointments that do not identify the cause of symptoms.
- After getting a diagnosis - Chronic pain/inability to manage symptoms causes distress, long waiting times and uncertainty in relation to gynaecology appointments and surgery are a trigger for worsening mental health.

*It takes on average 9 years to get a diagnosis for endometriosis in Wales¹.

Our main recommendations for improving poor mental health in those with endometriosis are:

- Recognise the mental health impact of endometriosis, incorporate mental health support into endometriosis care pathways and improve access for those who need it including prior to diagnosis.
- Reduce the time it takes to get a diagnosis of endometriosis in Wales to reduce the impact of having symptoms dismissed and/or multiple medical appointments that do not identify endometriosis.
- Address waiting times for endometriosis care including surgery.

Q1. Which groups of people are disproportionately affected by poor mental health in Wales? What factors contribute to worse mental health within these groups?

Those with suspected or confirmed endometriosis can experience poor mental health. This happens at different stages of the patient journey including pre and post diagnosis.

(a) Factors affecting mental health when seeking a diagnosis

- **Being dismissed, ignored or not believed** by friends, family and healthcare practitioners
“I was diagnosed with stage 4 endometriosis three years ago. Diagnosis has been incredibly difficult, with GPs not believing my pain, or telling me it’s ‘all in my head’”¹
- **Having multiple medical appointments** including GP, hospital & A&E appointments that fail to identify a cause for the symptoms being experienced.

Pre-diagnosis, those with endometriosis symptoms in Wales¹:

- 56% visited their GP more than ten times
- 37% had five or more hospital appointments, 23% had more than ten
- 59% went to A&E, and 26% went to A& E more than three times

(b) Factors affecting mental health once diagnosed

- **Being unable to manage symptoms well** is a common driver of mental health problems. At our 2021 Endometriosis Awareness Month event in Wales, an endometriosis specialist nurse remarked that: *“Most are chronically depressed because they’re unable to do what they want to do, because they can’t control the symptoms”².*

- **Difficulties accessing care including being on a waiting list for treatment or surgery** - It is important to note here that pre-pandemic those with endometriosis in Wales were experiencing waiting times for endometriosis care longer than the UK average:¹
 - 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%)

Our research into the impact of the pandemic on those with confirmed and suspected endometriosis in Wales³ revealed that many with endometriosis experienced difficulties accessing NHS care during the pandemic. This included having NHS appointments for confirmed or suspected endometriosis arranged pre-pandemic cancelled or postponed, most commonly for gynaecology or endometriosis specialist centre appointments and surgery including laparoscopy (a form of keyhole surgery).

Confirmed endometriosis – cancelled or postponed appointments (n = 80)	<p>24% with postponed appointments (UK 36%) and 19% with cancelled appointments (UK 14%) got new date within 6 months</p> <p>54% had no new date for postponed appointment (UK 30%) and 47% had no new date for cancelled appointment (UK 33%), with majority receiving no contact</p> <p>24% with postponed appointments (UK 23%) and 15% with cancelled appointments waited more than 9 months for a new date (UK 24%)</p>
Suspected endometriosis - cancelled (n= 15) or postponed appointments (n= 27)	<p>43% with cancelled appointments (UK 39%) and 19% with postponed appointments (UK 39%) got new date within 6 months</p> <p>28% with cancelled appointments (UK 27%) and 50% with postponed appointments (UK 28%) had no new date and majority receiving no contact</p> <p>21% with cancelled appointments (UK 19%) and 25% with postponed appointments (UK 22%) waited more than 9 months for a new date</p>

Being unable to access care, being on a waiting list for a long time or being told the wait for treatment will be a long time has a detrimental impact on mental health:

“Impacts mental health when you’re told it’s at least 12 months delay on your major excision surgery & total hysterectomy.”

“Due to having surgery cancelled and no follow up support or further support to help manage my symptoms, I felt alone and not listened to and so it definitely made my mental health worse”

The long waits and their impact on physical and mental health pushed some with endometriosis to seek private care, even when this had a negative impact on finances:

“I had to pay privately for a laparoscopy because my mental health was suffering so much as a result of daily terrible pain. I am lucky I could do this - although it has left me £4000 in debt.”

“Had I not been able to access urgent private healthcare for surgery I honestly do not know if I would still be here due to rapidly declining physical and mental health.”

- **Geographic inequalities in accessing care** - There is no tertiary (specialist) care available in North or Mid Wales, as there is only one BSGE (British Society of Gynaecological Endoscopy) accredited endometriosis specialist centre⁴ in Wales at University Hospital of Wales in Cardiff and a second provisional BSGE centre

at the Singleton Hospital in Swansea.

Those requiring specialist (tertiary) care in North or mid Wales need either a cross Health Board referral to the Cardiff or Swansea BSGE centres or a cross-border referral to an NHS BSGE centre in England. We have heard of incidents where those needing specialist surgery at the Cardiff centre who do not live in the Cardiff Health Board area are turned away and told there is no funding as they are 'out of area'. Those needing specialist care in North Wales can be referred to the NHS BSGE centres in Merseyside such as Arrowe Park Hospital in Birkenhead, and while cross-border referral arrangements exist, they are not always used.

Q2. For the groups identified, what are the barriers to accessing mental health services? How effectively can existing services meet their needs, and how could their experience of using mental health services be improved?

Barriers to accessing mental health support for those with endometriosis include:

- **Mental health support not being integrated into care pathways** – This is also a gap in the relevant NICE guideline. (more information in Q3).
- **Difficulties accessing mental health support** - Pre-pandemic, when those with endometriosis in Wales were asked if there were services they would have liked to have been offered, but were not, 77% of respondents said psychological support¹. This indicates unmet need in relation to those with endometriosis accessing mental health support before the pandemic.

Our Covid impact survey² showed that those with confirmed endometriosis in Wales found mental health support more difficult to obtain during the pandemic, although the proportion reporting this was low, which may be due to difficulties obtaining such care in the first place:

- When asked about care sought but not possible to obtain during pandemic, 37% of respondents (n= 92) mentioned mental health support; same proportion as GP appointments.
- 90% who answered question (n= 59) on whether pandemic affected their ability to get NHS mental health appointments said it was more difficult or much more difficult.
15% with NHS appointments cancelled (n= 62) had mental health appointments cancelled.
- 9% with NHS appointments postponed (n=79), had mental health appointments postponed.

Q3. To what extent does Welsh Government policy recognise and address the mental health needs of these groups? Where are the policy gaps?

The main policy gaps that the Welsh Government can address in relation to the mental health needs of those with suspected or confirmed endometriosis are:

- Recognising the impact endometriosis can have on mental health
- Ensuring that mental health support is integrated into endometriosis care pathways in Wales
- Call on NICE to update its guideline on endometriosis (NG 73 on endometriosis diagnosis and management) to address mental health support.

Q4. What further action is needed, by whom/where, to improve mental health and outcomes for the groups of people identified and reduce mental health inequalities in Wales?

Given that lengthy diagnosis times, poor symptom management and long waiting times for endometriosis care are all triggers for mental health problems in those with endometriosis, action to address them can contribute to reducing mental health inequalities. This would include:

- A commitment to reduce average time to diagnosis from the current 9 years to under 4 years by 2025 and under one year by 2030, which will involve:
 - Clear pathways for diagnosis
 - Building NHS capacity in gynaecology departments and endometriosis specialist centres to allow prompt referrals from primary to secondary care, including for diagnostic laparoscopy
 - Improving healthcare practitioner training and education – all HCPs including GPs and A&E practitioners should be able to recognise the signs and symptoms of endometriosis
 - Improving public awareness and understanding of endometriosis through effective implementation of menstrual wellbeing education in Welsh schools (now mandated by the new RSE Code) and support for public awareness campaigns
- Strategic national planning for endometriosis care in Wales including measuring and meeting the demand for endometriosis care to ensure that those who need care can access it regardless of Health Board areas
- Ensure care pathways for endometriosis should be in line with current NICE guidance and addressing gaps identified including but not limited to:
 - Full implementation of recommendations of 2018 Welsh government review on endometriosis care⁵ in line with NICE guideline NG 73 and NICE quality standard QS 172⁶.
 - Undertake or commission an audit to identify any gaps and challenges to implementation.
 - Address gaps in existing NICE guidance including pain management, non-pelvic endometriosis and mental health support.
- Ending the geographic inequalities in access to specialist (tertiary) care for endometriosis in Wales by:
 - Bringing tertiary (specialist) endometriosis care under the remit of the Welsh Health Specialist Services Committee (WHSSC).
 - Strengthening arrangements for cross Health Board referrals to the BSGE centres in Cardiff and Swansea and cross-border referrals to BSGE centres in the NHS England

ABOUT US

Endometriosis UK is the UK's leading charity supporting those affected by endometriosis. We provide information through [our website](#), information leaflets, and direct support through a helpline, support groups, and an online forum. We raise awareness and campaign to improve the lives of all those affected by endometriosis, and are involved in research. We work closely with other women's health organisations including RCOG and RCGP.

We would be happy to discuss this submission in further detail. Please contact us on

¹ [Endometriosis in the UK – Time for Change](#), All Party Parliamentary Group (APPG) on Endometriosis, October 2020

² [Improving Endometriosis Care in Wales – A Panel Discussion](#), Endometriosis UK/Fair Treatment for Women in Wales, Endometriosis Awareness Month Event, 31 March 2021

³ Endometriosis UK Covid Impact Survey, July 2021 (unpublished)

⁴ Further information and a list of British Society of Gynaecological Endoscopy centres can be [found here](#).

⁵ [Endometriosis care in Wales: Provision, care pathway, workforce planning and quality and outcome measures](#), Report of the Welsh Government Endometriosis Task and Finish Group, 16 April 2018

⁶ [NICE guideline NG73 on Endometriosis: diagnosis and management](#), 6 September 2017 & [NICE Quality Standards QS172 on Endometriosis](#), 6 August 2018