

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Gynllun Llywodraeth Cymru i drawsnewid a moderneiddio gofal a gynlluniwyd a lleihau rhestrau aros](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [Welsh Government's plan for transforming and modernising planned care and reducing waiting lists](#)

PCWL 25

Ymateb gan: | Response from: Endometriosis UK



RESPONSE TO SENEDD HEALTH & SOCIAL CARE COMMITTEE REQUEST FOR WRITTEN EVIDENCE ON WELSH GOVERNMENT'S PLAN FOR TRANSFORMING AND MODERNISING PLANNED CARE AND REDUCING WAITING LISTS

OVERVIEW

The Welsh Government's programme for transforming and modernising planned care and reducing waiting lists provides an opportunity to tackle the problem of long waits for endometriosis care in Wales that go back to before the pandemic.

Prior to the pandemic, many with endometriosis in Wales experienced long waits for planned care such as surgery and the pandemic has predictably made this worse. This is particularly acute for those needing tertiary (specialist) care, such as complex surgery at a British Society of Gynaecological Endoscopy (BSGE) accredited endometriosis specialist centre¹, who are in some cases being told informally they may wait for several years for that surgery. This is pushing those who can afford it or are prepared to get in debt, to seek private care, but this is not an option for the vast majority.

To reduce waiting lists and modernise planned care for those with endometriosis, the following key changes are needed:

- Strategic national planning for endometriosis care in Wales including measuring and meeting the demand for endometriosis care including endometriosis specialist centres to ensure that those who need care can access it regardless of Health Board area. This would involve building NHS capacity in gynaecology departments and endometriosis specialist centres to allow prompt referrals from primary to secondary care, including for diagnostic laparoscopy.
- Place endometriosis specialist care under the remit of the Welsh Specialist Healthcare Services Committee (WHSCC)² to ensure that cross Health Board referrals are properly funded and that all patients who need specialist care can access it regardless of where they live in Wales.
- NHS Wales and Health Boards to review patient prioritisation criteria as per the recent call³ from the Royal College of Obstetricians and Gynaecologists (RCOG) in order to incorporate quality of life considerations, which for endometriosis would include ability to perform daily living tasks and impact on long-term health outcomes including avoiding future disability.
- Make sure that the Workforce Delivery Plan for Wales includes specific measures to ensure appropriate staffing in gynaecology including endometriosis care.
- Ensure that gynaecology is adequately represented in the National Diagnostics Board.
- Fully implement the recommendations of 2018 Welsh government review on endometriosis care⁴ in line with NICE guideline NG 73 and NICE quality standard QS 172⁵
- Undertake or commission an audit to identify the gaps and challenges to implementation of the 2018 review/NICE guidance
- Reduce diagnosis time from the current average of 9 years to an average of 1 year or less, which will require:
 - Clear pathways for diagnosis and investment in diagnostic capacity in gynaecology departments and endometriosis specialist centres
 - Healthcare practitioner training and education to ensure all HCPs including GPs and A&E practitioners recognise the signs and symptoms of endometriosis

- Improving public awareness and understanding of endometriosis through effective implementation of menstrual wellbeing education in all Welsh schools and public awareness campaigns

RESPONSE TO QUESTIONS

1. Whether the plan will be sufficient to address the backlogs in routine care that have built up during the pandemic, and reduce long waits

We welcome the intention to address the pandemic backlog and reduce long waits. In relation to gynaecology services for those with suspected or confirmed endometriosis, we note the following:

- Those with endometriosis in Wales experienced longer waits than the UK average for gynaecology appointments and surgery before the pandemic. The 2018 Welsh government review on endometriosis care⁴ concluded that “*service provision across primary, secondary, and tertiary care is not meeting need, resulting in lack of access to appropriate care for women across Wales*”. A 2020 inquiry by the All Party Parliamentary Group (APPG) on Endometriosis⁶ found that those in Wales experienced delays in getting referred for hospital appointments. The same survey found that when those with endometriosis were told they needed surgery:
 - 48% waited more than 6 months (UK average 30%)
 - 6% waited more than a year (UK average 7%)
- The Royal College of Obstetricians and Gynaecologists (RCOG) released a report in April 2022³ which found that across the UK including in Wales, gynaecology has seen the biggest percentage increase in waiting lists during the pandemic, and the Welsh Government plan recognised gynaecology as one of the specialities with the greatest number of people waiting.
- The NICE guideline on endometriosis diagnosis and management (NG 73)⁵ which is adopted in Wales, requires that anyone with suspected or confirmed deep endometriosis is referred to a BSGE¹ endometriosis specialist centre. There are three such centres in Wales; two fully accredited centres at University Hospital of Wales in Cardiff and the Singleton Hospital in Swansea, and a provisional centre at the Royal Gwent Hospital in Newport. This means that many with endometriosis who need specialist care, cannot access that care in the Health Board are they live in thus requiring referral to a BSGE centre in another Health Board area. Those requiring specialist care in North Wales can be referred to BSGE centres in Merseyside and cross-border referral arrangements exist, although are not always used.
- There has never been any national planning for endometriosis care in Wales in order to measure and meet demand in both secondary care (gynaecology) and tertiary care (endometriosis specialist centres).
- Current funding arrangements do not support cross Health Board referrals to BSGE centres, leaving those centres accepting patients from outside their Health Board area with insufficient or no funding. This was identified in the 2018 Welsh government review⁴ which noted that the BSGE centre in Cardiff was “inadequately funded” and that this has led to “long waiting times for the most complex surgery”. Without addressing this funding gap, we fear that it will not be possible to address the backlog in endometriosis specialist (tertiary) care and reduce long waits.
- We welcome the plans to eliminate long waiters and note that additional sessional work at weekends and evenings could be useful in relation to endometriosis specialist care as long as measures for example in relation to staffing and theatre time are put in place to ensure deliverability.

Our recommendations:

- Undertake 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 area. This would involve building NHS capacity in gynaecology departments and endometriosis specialist centres to allow prompt referrals from primary to secondary care, including for diagnostic laparoscopy where required to ensure diagnostics are not a bottleneck in care pathways.
- Place endometriosis specialist care under the remit of the Welsh Specialist Healthcare Services Committee (WHSCC)² to ensure that cross Health Board referrals are properly funded and that all patients who need specialist care can access it regardless of where they live in Wales.
- Strengthen existing arrangements for cross-border referrals to BSGE centres in England for those in North Wales who need such care.
- Address staffing and theatre time at endometriosis specialist centres to enable additional sessional work at weekends and evenings to help eliminate long waiters.

2. Whether the plan strikes the right balance between tackling the current backlog, and building a more resilient and sustainable health and social care system for the long term?

In endometriosis care, tackling the backlog and building more resilient and sustainable care including sustainable planned care capacity are closely connected. The experience of those with endometriosis in Wales of long waiting times before the pandemic indicates that planned care capacity, particularly in tertiary care which takes place in endometriosis specialist centres, was not sufficient to meet demand.

The 2020 APPG report⁶ also found that across the UK there appeared to be insufficient capacity in secondary care (gynaecology) to meet demand for endometriosis services. The aforementioned problems with cross Health Board referrals and funding arrangements for BSGE centres are key factors that need addressing in this respect as well as national strategic capacity planning.

Our recommendations:

- Undertake strategic national planning for endometriosis care in Wales including measuring and meeting the demand for care to ensure access for all who need it. This would involve building NHS capacity in gynaecology departments and endometriosis specialist centres to allow prompt referrals from primary to secondary care, including for diagnostic laparoscopy where required.
- Place endometriosis specialist care under the remit of the Welsh Specialist Healthcare Services Committee (WHSCC)⁶ to ensure that BSGE centres are properly funded to accept cross Health Board referrals enabling all patients who need specialist care to access it regardless of where they live in Wales.

3. Whether the plan includes sufficient focus on: <ul style="list-style-type: none">a. Ensuring that people who have health needs come forward;b. Supporting people who are waiting a long time for treatment, managing their expectations, and preparing them for receiving the care for which they are waiting, including supported self-management;c. Meeting the needs of those with the greatest clinical needs, and those who have been waiting a long time;d. Improving patient outcomes and their experience of NHS services?

Ensuring that those with endometriosis come forward is very much a question of awareness and education of the public and healthcare practitioners. Public education and awareness needs to start in school with menstrual wellbeing education and this was included in the new RSE code in Wales in late 2021. Menstrual wellbeing education teaches children what is normal and what is not about periods, so should someone have symptoms that may be endometriosis, they can recognise the need to seek help.

Healthcare practitioners including GPs must understand the signs and symptoms of endometriosis so that anyone with suspected endometriosis is taken seriously and swiftly referred on for tests, to gynaecology or an endometriosis specialist centre as needed. This requires that GPs understand the NICE guideline NG 73 on endometriosis diagnosis and management. The recent appointment of endometriosis nurses in each Welsh Health Board can play a role in helping to improve awareness and understanding of endometriosis in primary care, but the responsibility cannot fall solely on them. GPs can also access resources including a menstrual wellbeing toolkit⁷ and e-learning module⁸ from the Royal College of GPs (RCGP).

The focus on supporting people waiting a long time for treatment is particularly relevant to those waiting for endometriosis surgery in Wales. The need for support, including advice on how to manage symptoms, pain management and mental health support, for those on surgery waiting lists was identified by Welsh respondents to our 2021 Covid impact survey⁹.

When it comes to supporting those in greatest clinical need who have been waiting a long time, we note:

- As a disease that can be chronic and debilitating, long waits for surgery for endometriosis can involve deterioration in the individual's quality of life including inability to go to work or attend education and difficulties undertaking daily living tasks.

"Waiting lists lead us to accumulate debt to go private or even worse leave us debilitated by pain for years at a time. Creating a domino effect where our day to day lives change, we jeopardise our employment or are unable to be a fit parent and so on"

"I have been waiting for urgent surgery to have a colostomy bag since 2018. It was due to happen 2019 then covid happened. Endo has damaged my bowel beyond repair and things are so bad I can't leave the house"

- If untreated, endometriosis may progress, leading to reduced ability to undertake daily living tasks while waiting and the need for more complex surgical interventions, which are more costly to the NHS as well as having a greater negative impact on quality of life of the patient including longer recovery time.
- While not an official term, endometriosis is often referred to as "benign gynaecology", meaning non-cancer, which gives a false impression of the impact of the disease. We support the recent call from RCOG to stop using "benign" and agree that use of the term may have contributed to de-prioritisation of women's health needs including those with endometriosis, which may partly explain the growth in gynaecology waiting lists¹⁰.
- While the programme acknowledges the need for a "fair and equitable approach to patient prioritisation to minimise health inequalities", which recognises the impact of long waits including continued pain and symptoms, worsening health, and an impact on lifestyle, we feel this is not sufficiently developed. In its report on gynaecology waiting lists³ RCOG have called for an overhaul in the way patients are prioritised including taking wider considerations including quality of life into account alongside clinical need.

Our recommendations:

- Ensure effective implementation of age-appropriate menstrual wellbeing education in all Welsh schools as agreed in the RSE code.
- Work with Health Boards to improve understanding and awareness of endometriosis in primary care, in particular with GPs to ensure that referrals for suspected endometriosis happen in a timely manner.
- NHS Wales and Health Boards to design appropriate support packages for those with endometriosis on waiting lists in consultation with relevant stakeholders including BSGE, RCOG and charities such as Endometriosis UK who represent the endometriosis community. Such support packages should include:
 - improved patient communications
 - information on what to expect from surgery
 - advice on how to prepare for surgery
 - where to find self-management advice and support, for example via the Health Board endometriosis nurses, although we would caution that this cannot be left solely to Health Board nurses
 - signposting and ensuring access to services such as pain management, pelvic physiotherapy and mental health support
 - signposting to further information for example the Endometriosis Cymru and Endometriosis UK websites
- NHS Wales and Health Boards to stop using the term “benign gynaecology”.
- NHS Wales and Health Boards to review patient prioritisation criteria as per RCOG recommendations³ in order to incorporate quality of life considerations, which for endometriosis would include ability to perform daily living tasks and impact on long-term health outcomes including avoiding future disability.

- 4. Whether the plan provides sufficient leadership and national direction to drive collective effort, collaboration and innovation-sharing at local, regional and national levels across the entire health and social care system (including mental health, primary care and community care)?**
- 5. Whether the plan provides sufficient clarity about who is responsible for driving transformation, especially in the development of new and/or regional treatment and diagnostic services and modernising planned care services?**

It is important that primary care, gynaecology and endometriosis specialist centres work together to drive transformation in endometriosis care, which will involve fully implementing existing NICE guidance⁵ and recommendations from the Welsh government review on endometriosis care⁴. It is also important that gynaecology is adequately represented in the National diagnostics board given the aforementioned need to expand diagnostic capacity in gynaecology departments and endometriosis specialist centres.

It currently takes on average 9 years to get a diagnosis of endometriosis in Wales, which means those with endometriosis can suffer both physically and mentally while not getting the right care, nor a name for their symptoms. The delay may result in the disease progressing, along with the distress of repeated GP and hospital visits that fail to identify a cause for symptoms. It is also a poor use of NHS resources. Improving diagnostic services can provide an opportunity to reduce diagnosis time for endometriosis as well as freeing up NHS resources currently spent on “wasted” appointments.

Our recommendations:

- Welsh government, Women’s Health Implementation Group (WHIG), NHS Wales and Health Boards to work together to ensure that full implementation of the recommendations of 2018 Welsh government review on endometriosis care⁴ in line with NICE guideline NG 73 on endometriosis and NICE quality standard QS 172 on endometriosis⁵ This would include, but not be limited to:
 - Managed clinical networks across Wales linking primary, secondary and tertiary care

- All with confirmed or suspected endometriosis have access to a gynaecologist with expertise in diagnosing and managing endometriosis, including laparoscopic surgery; achieving this requires developing and appointing to the role of gynaecologist with expertise in endometriosis, working closely with BSGE and RCOG to define role and competencies.
- Access to pain management including non pharmacological service such as pelvic physiotherapy and psychological support, aligning with NICE chronic pain guideline¹¹
- Undertake or commission an audit to identify the gaps and challenges to implementation of the 2018 Welsh government review/NICE guidance
- Endometriosis specialist (tertiary) care to come under the remit of the Welsh Specialist Healthcare Services Committee (WHSCC) to enable national planning, sufficient funding and equitable access to care regardless of where someone lives in Wales.
- Improve public and healthcare practitioner awareness of the signs and symptoms of endometriosis as well as streamlining referral pathways for diagnosis to help reduce diagnosis time to on average of under four years by 2025 and under one year by 2030.
- Ensure that gynaecology is adequately represented and addressed in the National Diagnostics Board.

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| <p>6. Are the targets and timescales in the plan sufficiently detailed, measurable, realistic and achievable?</p> <p>7. Is it sufficiently clear which specialties will be prioritised/included in the targets?</p> <p>8. Do you anticipate any variation across health boards in the achievement of the targets by specialty?</p> |
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We welcome the targets on first outpatient appointments and eliminating those waiting more than 1 or 2 years. We note that gynaecology is recognised in the programme as being one of the specialties with the greatest number of people waiting. However, we would welcome clarity as to whether gynaecology is included under the “most specialties” in afore mentioned targets.

Our recommendations:

- Gynaecology including endometriosis care should be one of the specialties prioritised in the targets. The reasons for this are that gynaecology is one of the specialties with the greatest number of patients waiting and the problem of long waits in non-cancer gynaecology existed before the pandemic and are thus a long-term problem overdue for addressing.

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| <p>9. Is there sufficient revenue and capital funding in place to deliver the plan, including investing in and expanding infrastructure and estates where needed to ensure that service capacity meets demand?</p> <p>10. Is the plan sufficiently clear on how additional funding for the transformation of planned care should be used to greatest effect, and how its use and impact will be tracked and reported on?</p> |
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In relation to funding endometriosis care it is necessary to measure the demand for services in order to know if funding available is sufficient to ensure capacity can meet demand. This is particularly important in relation to endometriosis specialist centre (tertiary) care.

Our recommendations

- Measure demand for endometriosis care in Wales in both secondary and tertiary care to ensure that capacity can meet demand.

- Place endometriosis specialist care under the remit of the Welsh Specialist Healthcare Services Committee (WHSCC)⁶ to ensure that BSGE centres are properly funded to accept cross Health Board referrals enabling access to specialist care regardless of where someone lives in Wales.
- Make sure that funding and resources for Health Board endometriosis nurses is commensurate with responsibilities and workload and review if significant changes are introduced.

11. Does the plan adequately address health and social care workforce pressures, including retention, recruitment, and supporting staff to work flexibly, develop their skills and recover from the trauma of the pandemic?

We welcome recognition of the need to address health and social care workforce pressures and the development of a Workforce Delivery Plan for Wales.

Workforce issues including the recruitment and retention of clinicians with expertise in endometriosis need addressing in order to be able to tackle the pandemic backlog and deliver sustainable planned care in future. For example, at the BSGE centre at University Hospital of Wales in Cardiff, the number of consultants has reduced from three to two, following the retirement of a consultant last year.

There is a view among some in the endometriosis community in Wales that long waits to access care (including before the pandemic) are linked to insufficient numbers of clinicians with expertise in endometriosis to provide the care needed.

“There is simply just not enough consultants for the demand of women like myself who suffer in chronic pain because of this condition that are able to administer quality treatment and care to the demand and standard we need.”

In gynaecology more broadly, RCOG has identified workforce as an issue that needs tackling to ensure it does not hinder tackling the pandemic backlog and calls on all UK nations to develop and implement gynaecology workforce plans³.

Our recommendations:

- Undertake strategic national planning for endometriosis care in Wales including measuring and meeting the demand for endometriosis care to ensure access for all who need it. This would involve building NHS capacity in gynaecology departments and endometriosis specialist centres to allow prompt referrals from primary to secondary care, including for diagnostic laparoscopy where required.
- Make sure that the Workforce Delivery Plan for Wales includes specific measures to ensure appropriate staffing in gynaecology including endometriosis care to ensure that staffing does not hinder tackling waiting lists or developing sustainable planned care.

12. Is there sufficient clarity about how digital tools and data will be developed and used to drive service delivery and more efficient management of waiting times?

We welcome the use of digital tools and data to support and enable service delivery where appropriate. We would appreciate greater clarity on how national guidance on suitable conditions and patients for virtual reviews will be developed. We welcome the proposed planned care portal with details on waiting times and available support services; lack of information on both is something that was flagged to us by the endometriosis community in Wales. However, not everyone can or wishes to use a health app or have a virtual review for a variety of reasons including digital literacy, access to devices, disability, socioeconomic and cultural factors.

We welcome the use of data to measure performance and develop real time waiting list data by sub-speciality that can help capacity planning.

Our recommendations:

- National guidance on conditions and patients suitable for digital reviews should ensure that any patient wishing to opt out is able to do so, and alternative non digital arrangements will be made available.
- Provision must be made for the information available in the planned care app to be made available offline for those who cannot use such an app or feel uncomfortable to do so.
- Develop standardised data collection on endometriosis services across all Health Boards and consider the establishment of an endometriosis registry.

ABOUT US

Endometriosis UK is the UK's leading charity supporting those affected by endometriosis. We provide information through [our website](#) and 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 with the Committee. Please contact us on

¹ [British Society of Gynaecological Endoscopy – Endometriosis Specialist Centres](#)

² [Welsh Health Specialised Services Committee](#)

³ [Left too long – understanding the scale and impact of gynaecology waiting lists](#), Royal College of COG, 4 April 2022

⁴ [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

⁵ [NICE guideline NG73 on Endometriosis: diagnosis and management](#), 6 September 2017 & [NICE Quality Standards QS172 on Endometriosis](#), 6 August 2018

⁶ [Endometriosis in the UK – Time for Change](#), Inquiry Report of All Party Parliamentary Group (APPG) on Endometriosis, October 2020

⁷ [RCGP Menstrual Wellbeing Toolkit](#)

⁸ [RCGP e-learning module on endometriosis](#)

⁹ The impact of Covid-19 on endometriosis, Endometriosis UK survey, 2021 (Welsh data report submitted in confidence to Senedd Health and Social Care Committee in response to the consultation on waiting times)

¹⁰ [Dismissal of women's health problems as 'benign' leading to soaring NHS lists](#), The Guardian, 2 June 2022

¹¹ [NICE Guideline NG 193: Chronic pain \(primary and secondary\) in over 16s: assessment of all chronic pain and management of chronic primary pain](#), published 7 April 2021,