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 20
Ymateb gan: | Response from: Endometriosis UK

RESPONSE SENEDD HEALTH & SOCIAL CARE COMMITTEE CONSULTATION ON WAITING TIMES IN WALES

OVERVIEW

There were problems with long waiting times for endometriosis care in Wales before the pandemic, in particular for gynaecology/endometriosis specialist centre appointments and surgery. The pandemic has predictably made this worse.

In particular, those needing tertiary (specialist) care, such as complex surgery at an endometriosis specialist centre are in some cases being told they will now wait for several years for that surgery. Long waits for surgery can have a negative impact on quality of life including ongoing chronic pain and debilitating symptoms that leave some unable to work. In addition, the stress of uncertainty surrounding when in the future surgery might take place along with to deal with ongoing symptoms can worsen mental health. 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.

Difficulties getting NHS care for endometriosis during the pandemic, especially when accompanied by worsening symptoms, was found in our Covid impact survey[a] to be a key driver of worsening mental health. When speaking to individuals on a waiting list for endometriosis surgery in Wales, they told us that they would rather know how long they might wait, even if it was years, then be kept “in limbo”.

This consultation provides an opportunity for us to reiterate the changes needed to deliver high quality endometriosis care for all in Wales who need it, which include:

- Full implementation of recommendations of 2018 Welsh government review on endometriosis care[1] in line with NICE guideline NG 73 and NICE quality standard QS 172[2] - this is happening, but got hampered by the pandemic
- Undertake or commission an audit to identify the gaps and challenges to implementation of the 2018 review/NICE guidance
- Address gaps in existing NICE guidance including non-pelvic endometriosis, post-surgery including hysterectomy care, menopause care, pain management and psychological support
- Bring tertiary endometriosis care under the remit of the Welsh Health Specialist Services Committee (WHSSC)[3] to overcome existing funding challenges and end the postcode lottery resulting in some patients not being able to access the specialist care they need.
- 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.

- Reducing 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
  - 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 including menstrual wellbeing education in Welsh schools and funds for public awareness campaigns

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[a] Endometriosis UK undertook a survey on the impact of Covid on those with endometriosis in July 2021.

The 2020 All Party Parliamentary Group (APPG) on Endometriosis inquiry[4] found that pre-diagnosis, those with symptoms of endometriosis in Wales:

- 56% visited their GP more than ten times
- 37% had 5 or more hospital appointments, 23% had more than 10
- 59% went to A&E, and 26% went to A& E more than three times

Not only are repeated appointments that fail to identify a cause for symptoms distressing to the individual concerned, they are also a poor use of NHS resources. Streamlining care pathways and addressing gaps could reduce "repeat" or "wasted" appointments and free up NHS resources, important at a time when the NHS in Wales has a huge backlog of elective care.

In relation to the consultation questions, Endometriosis UK has the following recommendations in addition to those mentioned above:

- Increasing access to pain management services for those on waiting lists for gynaecology/endometriosis specialist centre appointments including surgery
- Improving access to mental health support for those with confirmed and suspected endometriosis including incorporating mental health support into relevant care pathways.
- Health Boards/hospitals providing regular updates on matters such as:
    - Service recommencement
    - Waiting times for appointments and procedures
    - How waiting list patients should contact Health Board/hospital and how they can access services such as psychological therapies, pain management and pelvic physiotherapy

- Health Boards and gynaecology departments/endometriosis specialist centres work together to improve patient communications for those on gynaecology waiting lists in particular:
    - Regular communication to patients, even if only to say they remain on waiting list
    - Reduce onus on patients to have to contact the hospital/their consultant if they want information about being on the waiting list
    - Send "do you still need your operation" forms with accompanying assurance that the individual has not been taken of the waiting list

- Arrangements for cross-border referrals to BSGE centres in England need to be strengthened to ensure they are available for all those who need them. Currently despite arrangements existing, some individuals are told such referrals are not possible.
- Explore the use of digital technologies to support ongoing patient care, where clinically appropriate and acceptable to the patient.
- Once planned gynaecology care is fully restored, it is essential that the backlog is tackled based on clinical need for example as per the RCOG Covid-19 prioritisation framework[5], including prioritising those with severe endometriosis who had surgery cancelled or postponed.

Endometriosis UK would be pleased to work with the Senedd and NHS Wales to support implementation of these recommendations.

ENDOMETRIOSIS AND WAITING TIMES IN WALES

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. Symptoms vary from one individual to another; some may have minimal symptoms, whereas for others endometriosis can be debilitating.

The 2018 Welsh government review on endometriosis care[1] concluded that service provision was not meeting needs resulting in insufficient access to appropriate care across Wales. We also know from the 2020 APPG on Endometriosis inquiry[4] 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%)

In addition to long waiting times for gynaecology appointments and surgery, we also heard pre-pandemic from the endometriosis community in Wales concerns about lack of access to:

- Gynaecologists with expertise in endometriosis as required by NICE guidance[2] including those sufficiently skilled and trained to undertake diagnostic laparoscopy.
- Tertiary (specialist) care in a British Society of Gynaecological Endoscopy (BSGE) accredited endometriosis specialist centre[6], for example in cases of suspected or confirmed deep endometriosis as per the NICE guidance[2].

In Wales there are two BSGE endometriosis specialist centres, a fully accredited centre at University Hospital of Wales in Cardiff, and a second, provisional centre at the Singleton Hospital in Swansea. For those requiring tertiary (specialist) care in North Wales, the nearest BSGE centres are in England, and while arrangements exist for cross-border referrals and such referrals do take place, typically to NHS trusts in Merseyside, we have heard of cases where individuals were told such a referral was not possible.

The problem of lack of access to tertiary (specialist) care via BSGE centres is not helped by inappropriate funding mechanisms. This includes block funding mechanisms which do not reflect the complexity of tertiary care for endometriosis, leaving some complex cases referred to BSGE centres as essentially unfunded. There are also issues in relation to funding not following patients when cross Health Board referrals are required to a BSGE centre. The 2018 Welsh government review[1] noted that the BSGE centre in Cardiff was “inadequately funded” and that this has led to “long waiting times for the most complex surgery”.

The problems of access to care being experienced by some with endometriosis in Wales have, unsurprisingly, been exacerbated by the pandemic. Our research into the impact of the pandemic on those with confirmed and suspected endometriosis in Wales[7] revealed that many with endometriosis experienced difficulties accessing NHS care during the pandemic including:

- Having NHS appointments for their endometriosis/symptoms that might be endometriosis arranged pre-pandemic cancelled or postponed
- Difficulties securing new NHS appointments when care was needed during the pandemic
- Those with confirmed endometriosis who had NHS appointments postponed or cancelled (n= 80) experienced long waits or no new date for rescheduled appointments
  - Just 24% of those with postponed appointments (UK 36%) and 19% of those with cancelled appointments (UK 14%) got a new date within 6 months.
  - 54% had no new date for their postponed appointment (UK 30%), while 47% had no new date for their cancelled appointment (UK 33%), with the majority in both cases receiving no contact.

  - 24% of those with postponed appointments (UK 23%) and 15% of those with cancelled appointments waited more than 9 months for a new date (UK 24%).

- Those with suspected endometriosis had a similar experience of cancelled (n= 15) and postponed appointments (n= 27) including:
  - 43% with cancelled appointments (UK 39%) and 19% with postponed appointments (UK 39%) got a new date within 6 months.
  - 28% of those with cancelled appointments (UK 27%) and 50% of those with postponed appointments (UK 28%) had no new date and the majority had not been contacted.
  - 21% of those with cancelled appointments (UK 19%) and a 25% of those with postponed appointments (UK 22%) waited more than 9 months for a new date

The most commonly cancelled or postponed appointments were for gynaecology/endometriosis specialist centre appointments and surgery including laparoscopy.

Some respondents commented on how difficult it was to get the care they needed and the long waiting times involved:

"The services for endometriosis were difficult to obtain before the pandemic and since have seemed impossible through the NHS."

"The already lengthy surgery waitlist and now even longer. I was listed for surgery before the pandemic but now have been told the waitlist is years. Theatre capacity was already limited due to funding pre pandemic and therefore now demand is higher with less theatre capacity."

"Waiting times have increased majorly so now looking at 2 years before I even get to see a consultant about my symptoms again!"

"My symptoms keep on getting worse and worse with no prevail and I was advised of a 1-2 year waiting list for my surgery."

Our Covid impact survey found recourse to private care was higher in Wales than the UK as a whole, with 24% of those with confirmed endometriosis who completed the survey reporting that they used private care (UK figure 13%) during the pandemic.

Of those who used private care during the pandemic:
- 39% had done so pre-pandemic
- 61% had never done so before the pandemic

When private care was sought, it was most commonly for:
- Gynaecology/BSGE centre appointments
- Surgery including laparoscopy
- Test or scan appointments

A number of respondents who sought private care commented that they felt forced to so due to long waits, in particular for surgery, even when that meant financial hardship:

"I had my surgery cancelled a few days before national lockdown March 2020 and 15 months later I am still waiting, which has pushed me to pay private using all my savings."

“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.”

“The NHS cancelled my scheduled surgery 3 times, even after my gynaecologist had emphasised how important it was that I have the surgery urgently in order to preserve my bowel. Because of this I paid over £15,000 to have two private surgeries that were essential for my health. This has made a huge impact on my finances and my life plans”

“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.”

In addition, other respondents facing long waits or delays in accessing care who did not access private care, made comments about it:

“My NHS salary does not allow me to consider private surgery”

“If you have money then you are ok!”

OUR RESPONSE ON CONSULTATION TOPICS

Services in place for people who are waiting for diagnostics and treatment, particularly pain management support

Despite endometriosis being recognised as a chronic pain condition, for example in the recent NICE guidelines on chronic pain[8], those with endometriosis who need pain management services are not always able to access it.

The 2018 Welsh government review on endometriosis care[1] noted that pain management services for those with endometriosis were in “short supply”. When Welsh consultants were asked about pain management services as part of the review[1]

- 50% said there were unsure of the waiting time for a pain management appointment
- 20% said waiting time was more than 7 months

Pain management is also one of the gaps in the current NICE guideline on endometriosis diagnosis and management[2], a gap which Endometriosis UK believes needs addressing.

Pre-pandemic, when those with endometriosis in Wales (n = 488) were asked about services that they thought might improve their quality of life but has not been offered, in relation to pain management support:

- 26% had been offered pain management support
- 48% had not been offered it, but would have liked to have been
- 27% were unsure, gave no answer, or answered not applicable

The above data indicates that those with endometriosis experienced long and uncertain waits for pain management services before the pandemic and that there was unmet need. Anecdotal evidence from individuals in Wales on the waiting list for endometriosis surgery who shared their experiences with us expressed a desire to have a “long term plan” for their endometriosis care, including while on the waiting list for surgery. One of the services mentioned in relation to the latter was pain management.

Our Covid impact survey identified the following in relation to pain management for those with confirmed endometriosis:

- Pain management was the third most commonly mentioned service (48%) after surgery (68%) and gynaecology/BSGE centre appointments (61%) that those with endometriosis sought during the pandemic but were unable to obtain
- Of those who had appointments cancelled during the pandemic (n= 62), 15% of respondents reported having pain management appointments cancelled, the fourth most commonly cancelled NHS appointment after gynaecology/BSGE centre (59%), surgery (51%) and test/scan appointments (21%).
- 16% of respondents reported that pain management appointments postponed during the pandemic (n= 79), the fourth most commonly postponed NHS appointment after surgery (63%), gynaecology/BSGE centre (58%) and test or scan appointments (28%).

While 15-16% may not seem like a high figure for cancelled or postponed appointments, this may reflect the fact that pain management services are difficult to obtain as outlined above. This could mean that a lower number of individuals with endometriosis had pain management appointments in the first place.

There is a link between poor symptom management, particularly chronic pain, and mental health, which was found in the Covid impact survey and has been found elsewhere (see also comment from endometriosis nurse below).

Our recommendations

Endometriosis UK would recommend increasing access to pain management services for those with suspected and confirmed endometriosis who are on waiting lists for gynaecology or BSGE centre appointments. This may help prevent worsening mental health for some individuals while they wait for diagnosis or the care they need.

Access to psychological therapies and emotional support for those who may be experiencing anxiety or distress as a result of long waiting times

For those with endometriosis, inability 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*"[9].

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 support[1]. This indicates that there was unmet need in relation to those with endometriosis accessing psychological therapies before the pandemic.

When our Covid impact survey asked those with confirmed endometriosis in Wales about the impact of the pandemic on their mental health (n = 102):

- 74% said pandemic had made their mental health worse or much worse
- 23% reported no change
- 3% said their mental health was better or much better

Delays in accessing care and uncertainty over new dates for cancelled or postponed care was most commonly noted by survey respondents as making mental health worse:

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

"No appointment/treatment in sight makes me feel despairing."

"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"

"Not having any appointments and having to deal with the daily pain made me start taking antidepressants"

Not being able to manage symptoms also came up and was sometimes linked directly to delays or difficulties in accessing care:

"My mental health is currently more affected by my increasing symptoms that are difficult to manage"

"It has impacted negatively on my mental health due to my health care needs not being met. My surgery was cancelled and I'm still waiting for a new date."

Comments were also made about lack of help for worsening physical and mental health as a result of the pandemic:

"No one is acknowledging how the increasing pain and depression is worsening during lockdown and less help is being offered"

Our Covid impact survey showed that those with confirmed endometriosis in Wales found mental health support more difficult to obtain during the pandemic. The survey identified the following:

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

Our recommendations

Endometriosis UK recommends improving access to mental health support for those with confirmed and suspected endometriosis including incorporating mental health support into relevant care pathways.

The contribution the third sector can make in providing peer support and information to patients waiting on an NHS waiting list

Endometriosis UK offers support to those with endometriosis in Wales though:
- Online information
- A webinar series
- Support groups in Cardiff and Mid-Wales.
- Our helpline, which is staffed by trained volunteers and can offer a friendly listening ear and the chance to talk through issues and options.

- Our online forum, which is moderated by trained volunteers and offers those with endometriosis the chance to anonymously share their experiences with others, ask questions and find out more about endometriosis
- We also share information via our social media channels

We have also been contacted directly by individuals who are on surgery waiting lists who had questions about how long they might expect to wait; some had informally been told it would be more than 2 years as had a number of Covid impact survey respondents:

"In Wales, the waiting list for surgery with the specialist team in Cardiff is now in excess of 5 years."

"When my surgery was cancelled I was told it would a 2-3 year wait, now they've pushed that to 5-6 years. There is no way I could have continued in that much agony for another 5-6 years."

"I'm still waiting for NHS appointments - the waiting list for an Endo laparoscopy in Wales is now 6 years"

Lengthy waiting times in Wales is something we have been asked about on a number of occasions.

Our recommendations

It would be really helpful if Health Boards could provide regular updates on matters such as:

- service recommencement
- waiting times for appointments and procedures
- how patients on waiting lists should contact their Health Board to find out more about their individual case
- how to access services such as psychological therapies, pain management and pelvic physiotherapy which may be helpful to those on waiting lists for appointments or surgery

Endometriosis UK could then use our communications channels including social media, helpline and support groups in Wales to disseminate the information from Health Boards to the endometriosis community in Wales and use it to answer questions we may receive.

The effectiveness of messaging and engagement with the public about the demands on the service and the importance of seeking care promptly

In relation to communications to patients on waiting lists for endometriosis care, our Covid impact survey highlighted how up to half had no new date and had not been contacted at all. This failure to communicate anything to patients leaves them with unanswered questions and can increase anxiety.

In relation to communications from hospitals and healthcare professionals to those on the waiting list, while there was a mixed picture, the overall verdict was "not good enough". Reported experiences from the Covid impact survey and individuals who shared their experiences with us included:

- Not hearing anything from the hospital or consultant despite phoning and/or emailing repeatedly.
- Routine phone calls at the beginning of the pandemic to all those waiting for surgery, then nothing afterwards.
- Receiving several letters about the same appointment.
- Not being notified about appointments that had been cancelled.
- Being told you are on a waiting list or will be put on one, then finding out that has not happened.
- Receiving a "do you still need your operation" form, which worried some, as it made them think they would be taken off the waiting list.

- Endometriosis specialist nurses and consultant staff e.g. secretaries being helpful when contacted.

Comments included:

"Absolutely no contact from my NHS gynaecologist who I have been under for 5 years. Despite my laparoscopy being cancelled, she did not contact me once despite me ringing constantly."

"I have had to fight hard, constantly chasing and requesting appointments."

Our recommendations

Endometriosis UK recommends that Health Boards and gynaecology departments/endometriosis specialist centres work together to improve patient communications for those on gynaecology waiting lists in particular:

- Ensure regular communication to patients, even if only to say they are still on the waiting list
- Reduce the onus on patients to have to contact the hospital/their consultant if they want information about being on the waiting list.
- Make sure that "do you still need your operation" forms are sent with accompanying assurance that the individual has not been taken of the waiting list.

The extent to which inequalities exist in the elective backlog, with deprived areas facing disproportionately large waiting lists per head of population compared to least deprived areas

Analysis of NHS England waiting list data suggests that gynaecology services have experienced the largest increase in their backlog in recent years[10]. Comparable analysis has not been undertaken for gynaecology services in Wales.

However, taking into account what was revealed in the 2020 APPG inquiry[4] and the 2018 Welsh government review of endometriosis care[1] in relation to waiting times for gynaecology appointments and gynaecology surgery in Wales pre-pandemic, it is not inconceivable that gynaecology services in Wales may be in a similar situation.

Due to Wales only having two endometriosis specialist centres, one in Cardiff and one in Swansea, there are geographical inequalities in relation to accessing tertiary (specialist) care, due to current funding arrangements making cross Health Board referrals difficult. For example, when asked about this, the BSGE centre at the Singleton hospital in Swansea said it was accepting out of area referrals for tertiary care on an "ad hoc basis". In addition, the arrangements for those in North Wales requiring tertiary (specialist) care for endometriosis to be referred to BSGE centres in England needs to be strengthened as some are told that such referrals are not possible.

Our recommendations

In order to end the postcode lottery for specialist care in Wales and overcome existing funding challenges:

- Tertiary (specialist) endometriosis care should be brought under the remit of the Welsh Health Specialist Services Committee (WHSSC).
- Arrangements for cross-border referrals to BSGE centres in England need to be strengthened to ensure they are available for all those who need them.
- 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.

Plans to fully restore planned NHS care in Wales

In relation to the ideas for planned care outlined in the Welsh government's Covid-19 Looking Forward plan[11], we would note the following:

- Increased use digital technology to support online appointments could be helpful, in particular where patients need routine check-up/follow-up type appointments where physical examination is not required. However, this must be a choice for patients and those for whom it is not suitable, should be offered face-to-face appointments.

- The introduction of "straight to test" approaches so that necessary tests are conducted prior to the first consultant appointment could be helpful for those with suspected endometriosis as it is a way of streamlining diagnosis. However, this must be accompanied by appropriate scaling up of diagnostic capacity, so that patients do not face long waits for their test/scan appointments.

- The annual plans that NHS organisations in Wales will need to prepare in relation to endometriosis should include:
  - How organisations will work with the Women's Health Implementation Group (WHIG) to fully implement the recommendations of 2018 Welsh government review on endometriosis care in line with NICE guideline NG 73 on endometriosis: diagnosis and care and NICE quality standard QS 172.
  - Address gaps in NICE guidance, in particular access to pain management services and the integration of mental health support into care pathways.

- For the endometriosis care in Wales as a whole, it is also necessary to:
  - Recognise and measure the scale of endometriosis care needs in Wales and ensure appropriate resources to meet clinical need are planned and delivered
  - Commit to reduce average time to diagnosis from the current 9 years to under 4 years by 2025 and under one year by 2030
  - Speed up diagnosis to help reduce repeated NHS appointments that fail to identify the cause of symptoms
  - Reducing diagnosis time will include: clear pathways for diagnosis, investment in diagnostic capacity in gynaecology departments, as well as improving healthcare practitioner and public awareness and understanding of endometriosis.

Our recommendations

- Improve funding arrangements for tertiary (specialist) care to the two BSGE centres in Wales from other Health Boards to help minimise geographic inequality in access to specialist care.
- 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.
- Streamline diagnosis to reduce "wasted" GP, A&E and hospital appointments through planning and building NHS capacity 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
- Explore the use of digital technologies to support ongoing patient care, where clinically appropriate and acceptable for the individual.

- Once planned gynaecology care is fully restored, it is essential that the backlog is tackled based on clinical need for example as per the RCOG Covid-19 prioritisation framework[5], including prioritising those with severe endometriosis who had surgery cancelled or postponed.

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.

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[1] 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

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

[3] Welsh Health Specialised Services Committee

[4] Endometriosis in the UK – Time for Change, Inquiry Report of APPG on Endometriosis, October 2020

[5] Restoration and Recovery: Priorities for obstetrics and gynaecology – a prioritisation framework in response to Covid-19, Royal College of Obstetricians and Gynaecologists, last updated 21 April 2021

[6] British Society of Gynaecological Endoscopy (BSGE) accredited endometriosis specialist centres

[7] Endometriosis UK Covid Impact Survey, July 2021 (unpublished)

[8] 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

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

[10] Women bear the brunt of indirect impacts of Covid-19 as new analysis shows gynaecology waiting lists have shot up by 60% in three years, LCP, 4 July 2021

[11] Health and Social Care in Wales – Covid-19 Looking Forward, Welsh Government, 22 March 2021