Written evidence submitted by Endometriosis UK (CBP0049)

Endometriosis UK welcomes the Health and Social Care Select Committee's inquiry into the backlog in NHS care created by the Covid-19 pandemic.

SUMMARY

Our research into the impact of the pandemic on those with confirmed and suspected endometriosis in England revealed that the majority have 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
- Long waits or no new date for rescheduled appointments following cancellation or postponement
    - Nearly a fifth of those with confirmed endometriosis waited 9 or more months for a new date
    - 50% of those with suspected endometriosis had no new date and had not been contacted

The most commonly cancelled or postponed appointments were for gynaecology/endometriosis specialist centre appointments and surgery including laparoscopy. Analysis of NHS England waiting list data suggests that gynaecology services have experienced the largest increase in their backlog in recent years. This indicates an urgent need to address the gynaecology backlog including surgery for benign gynaecology.

Tackling the endometriosis care backlog requires:

- Fully implementing existing NICE guidance on endometriosis care in England, which can help streamline care and reduce unnecessary appointments that fail to diagnose the condition, thus freeing up NHS resources for other conditions
- Addressing the gaps in NICE guidance including access to pain management, mental health support and care pathways for endometriosis outside the pelvic cavity
- Strategic planning to measure and meet the demand for endometriosis care in England

RESPONSE TO QUESTIONS

Size of the backlog

What is the anticipated size of the backlog and pent-up demand from patients for different healthcare services including, for example, elective surgery; mental health services; cancer services; GP services; and more widely across the healthcare system?

It is reported that analysis of NHS England waiting list data shows that gynaecology services have experienced the largest increase of all specialities since the pandemic began at 34%, equating to a 60% increase over three years.[1]

In May 2021, Endometriosis UK undertook a survey on the impact of Covid-19 on those with endometriosis in England[2], which received over 1500 responses, 85% from those with confirmed endometriosis. Respondents

[1] LCP "*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*", 4 July 2021, https://www.lcp.uk.com/media-centre/2021/07/women-bearing-brunt-of-indirect-impacts-of-covid-19-pandemic-as-new-analysis-shows-gynaecology-waiting-lists-have-shot-up-by-60-in-three-years/

answered questions about their experience of accessing NHS care for endometriosis during the pandemic and the impact of the pandemic on daily life including managing their endometriosis.

Respondents with confirmed endometriosis:
88% tried to get NHS care for endometriosis during pandemic three quarters (77%) of whom said it was difficult or more difficult to obtain. The NHS care most commonly reported as more difficult to access was gynaecology/endometriosis specialist centre appointments and surgery including laparoscopy.

NHS care	Much Easier/ Easier	No change	More difficult/ Much more difficult
Surgery including laparoscopy	4%	3%	91%
Gynaecology/specialist centre appointment	3%	6%	90%
GP appointment	5%	15%	80%
Test or scan appointment	4%	11%	84%
Fertility appointment	2%	3%	85%
Physiotherapy including pelvic physio	2%	6%	84%
Mental health support	2%	10%	83%
Prescription medicines	6%	6%	50%

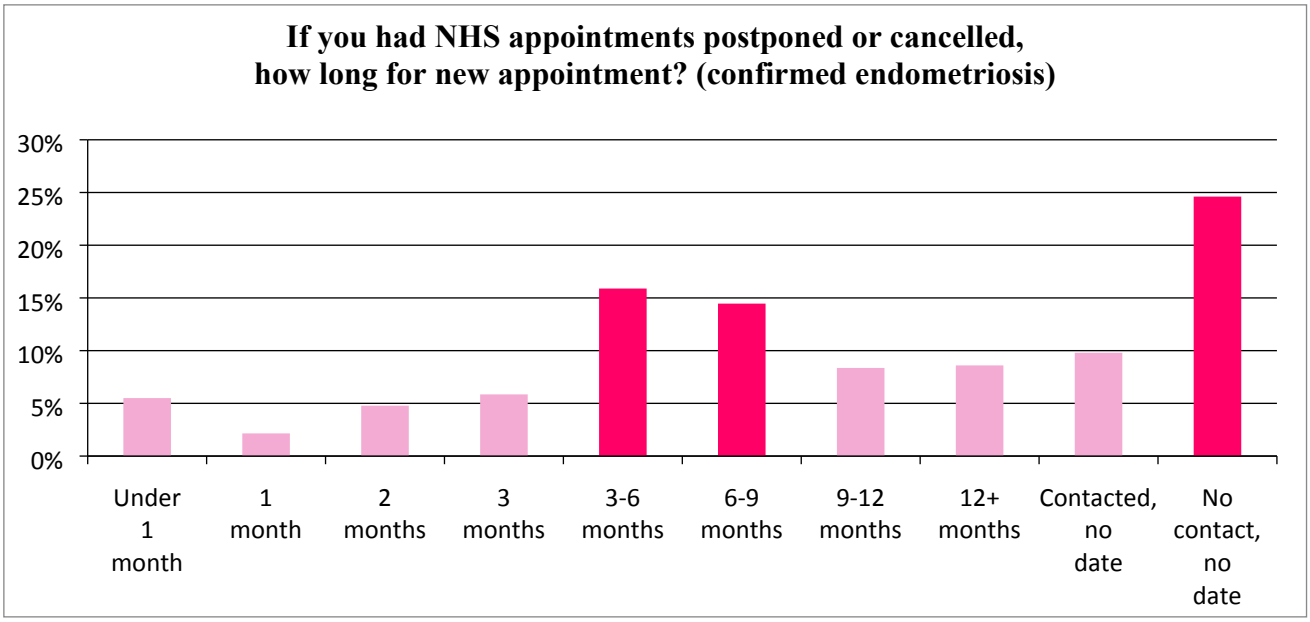
80% had NHS endometriosis appointments postponed or cancelled because of the pandemic. When those who had appointments cancelled or postponed were asked which type of appointments it was, the most commonly reported were:

- 56% - Gynaecology/endometriosis specialist centre appointments
- 39% - Surgery including laparoscopy
- 32% - Test or scan appointments

When NHS endometriosis appointments were cancelled or postponed, the wait for a new appointment was:

- 35% - No date yet, comprising
    - 25% had no date and had not been contacted
    - 10% had been contacted but had no date
- 18% - 3 months or less
- 17% - More than 9 months
- 16% - 3-6 months

[2] Further details of the England Covid impact survey can be found at the end of this submission.



When those who did not seek NHS care for their endometriosis during the pandemic (n= 129) were asked why, their answer were:

- 40% - Did not want to burden NHS/Thought it wouldn't be possible to get care
- 29% - Did not need any NHS care
- 32% - Other*

*Reasons given for other (n=41) include:

- having sought private care instead
- having given up on getting an appointment
- not wanting to go to hospital because of Covid-19

Over three quarters (79%) said the pandemic had made their mental health worse, compared to 18% who reported no change and 3% who said it had improved.

When asked to comment on the impact of the pandemic on their mental health, the following were commonly mentioned:

- Increased anxiety
- Difficulties in accessing NHS care for endometriosis including delays as a driver of worsened mental health
- Working from home, for some of those who did it, was said to contribute to improved mental health due to it enabling better management of symptoms and avoiding having to commute when experiencing painful symptoms

Most respondents (72%) who answered the questions on private care (n= 1,000) had not obtained private care for their endometriosis during the pandemic. Of those who said they had used private care for their endometriosis during the pandemic (n= 281), 65% had never done so pre-pandemic.

When private care was obtained, it was most commonly for:

- 39% - Gynaecology/endometriosis specialist centre appointments
- 26% - Surgery including laparoscopy

For those with suspected endometriosis:

60% were waiting for NHS referrals or appointments for their suspected endometriosis before the pandemic began, most commonly:

- 24% - GP referral to gynaecology/endometriosis specialist centre
- 15% - Gynaecology surgery referral
- 15% - Test or scan appointment

Of those who were waiting for an NHS referral or appointment date for their suspected endometriosis before the pandemic and are still waiting, total waiting times are:

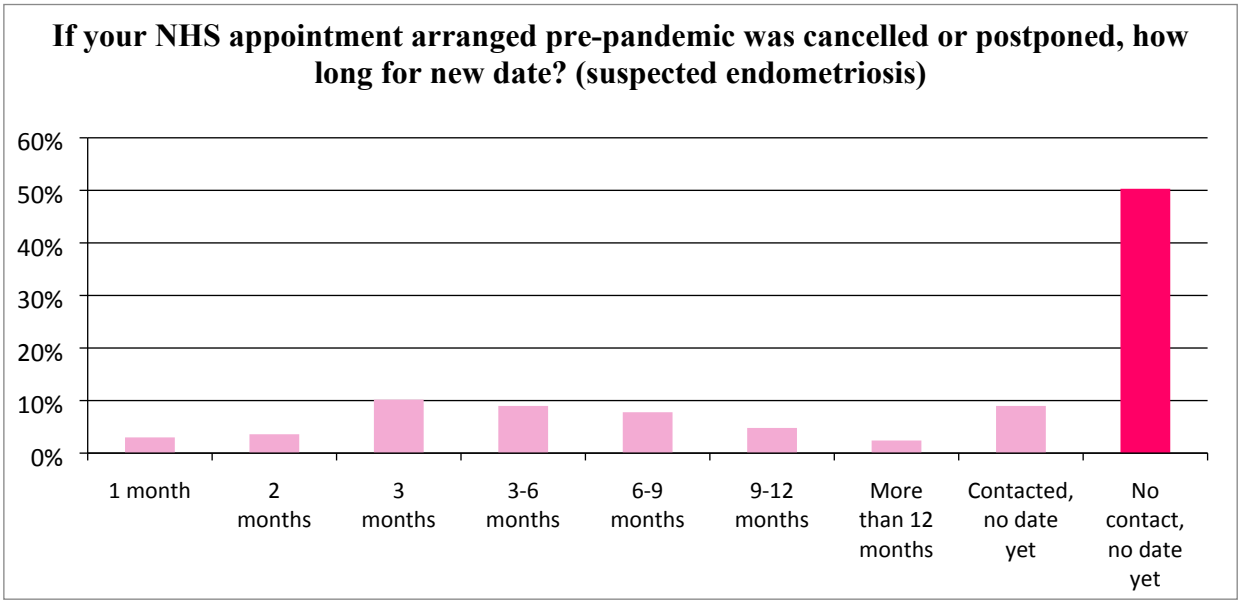
- 35% - 12-18 months
- 29% - 6-12 months
- 15% - 3-6 months
- 11% - 18 months to 2 years
- 5% - Less than 3 months

39% had NHS appointments (arranged pre-pandemic) for their suspected endometriosis cancelled or postponed due to the pandemic, most commonly:

- 35% - Gynaecology/endometriosis specialist centre appointment
- 22% - GP appointment
- 20% - Test or scan appointment

When NHS appointments for suspected endometriosis were postponed or cancelled the wait for a new appointment was:

- 50% - No date yet and no contact
- 17% - 3 months or less
- 15% - 6 or more months
- 7% - 9 or more months



Asked about the impact of the pandemic on their mental health:

- 73% said that it was worse or much worse
- 17% said there was no change
- 10% reported improvements

When asked to comment on the impact of the pandemic on their mental health, the most commonly mentioned were:

- Increased anxiety
- Worry or stress caused by difficulties including delays in accessing NHS care; this was said to be a driver in worsening mental health

The data generated from our England Covid impact survey showed that many with confirmed or suspected endometriosis found themselves unable to get the NHS care they needed during the pandemic or faced significant delays in getting that care. Shockingly, when appointments were postponed or cancelled a quarter of those with confirmed endometriosis and half of those with suspected endometriosis had received no new date and had not been contacted by the NHS about the rescheduling of their appointment.

There was also unmet demand for endometriosis care during the pandemic including:

- those who tried to get care and were unable to do so
- those who did not try to get care they needed because they thought it impossible or did not want to burden the NHS when it was fighting Covid-19

Tellingly, both those with confirmed and suspected endometriosis were most likely to have gynaecologist/endometriosis specialist centre appointments cancelled or postponed, which aligns with analysis of NHS England waiting list data showing that gynaecology services had the largest increase in backlog in recent years.

For those with suspected endometriosis, referral to gynaecology or endometriosis specialist centre is a crucial step in getting a diagnosis, without which they are unlikely to receive the right care and support. For both those with confirmed or suspected endometriosis, delays in getting the right care may result in the disease progressing.

NHS capacity

What capacity is available within the NHS to deal with the current backlog? To what extent are the required resources in place, including the right number of staff with the right skills mix, to address the backlog?

Whilst there is a NICE Guideline for endometriosis treatment and management outlining a baseline for care, this has not been fully implemented. Prior to the pandemic, there was no overall strategic planning within the NHS to measure and meet the demand for endometriosis care in England.

For example, an inquiry undertaken by the All Party Parliamentary Group (APPG) on Endometriosis in 2020[3] found that some with endometriosis in England experienced long waiting times for gynaecology or endometriosis specialist centre consultation or for surgery before the pandemic:

- 23% waited more than 6 months for a gynaecology/endometriosis specialist centre appointment after being referred, compared to 40% who got an appointment within 3 months and 26% who waited 4-6 months

[3] *Endometriosis in the UK – Time for Change*, Inquiry Report of APPG on Endometriosis, October 2020 https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf

- After being referred for surgery, while 40% had surgery within 3 months, 31% waited 4-6 months and 25% waited more than 6 months

Despite NICE guidance, the APPG report[3] found that patients with suspected or confirmed deep endometriosis were not always seen in an endometriosis specialist centre[4].

It takes on average 8 years to get a diagnosis of endometriosis in England[3] which means that those with the condition may 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.

The 2020 survey[3] found that prior to diagnosis, those with endometriosis in England:

- 62% visited their GP more than ten times with symptoms, 78% five or more times.
- 42% had more than 5 hospital appointments due to symptoms, 20% had ten or more appointments
- 49% went to A&E with symptoms, 20% went to A&E more than three times

Improving diagnosis requires improving GP awareness of endometriosis and referral options for suspected endometriosis including local gynaecology departments with relevant expertise and referral to a BSGE centre. The RCCP menstrual well-being toolkit and e-learning on endometriosis[5] developed with Endometriosis UK can be used in achieving this aim.

In relation to capacity and the staff and skills mix, fully implementing the NICE guidance on endometriosis must be the starting point. Fully implementing NICE Guideline NG 73[6] on endometriosis diagnosis and management and NICE Quality Standard QS 172[7] on endometriosis in England is essential to reduce diagnosis time, reduce unnecessary GP, hospital and A&E visits, and improve access to care. Fully implementing the relevant NICE guidance will include, but not be limited to:

- All areas to have managed clinical network to coordinate endometriosis 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 a with Special Interest in Endometriosis', working closely with BSGE and RCOG to define role and competencies
- Access to an endometriosis specialist nurse for all with endometriosis
- Access to pain management including pharmacological treatment and (not in NG 73) non-pharmacological services such as pelvic physiotherapy and psychological support, aligning with NICE chronic pain guideline[8]
- Prompt primary care onward referral of those for whom initial hormonal treatment is contraindicated or not effective/not tolerated after 6 months; no 'keeping' patients in primary care
- Ensuring access to BSGE centres, especially for those with suspected or confirmed deep endometriosis involving bowel, bladder or ureter

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[4] 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, please see: https://www.bsge.org.uk/endometriosis-centres/, for a list of centres please see: https://www.bsge.org.uk/centre/

[5] RCGP Menstrual Wellbeing Toolkit: https://www.rcgp.org.uk/menstrualwellbeingtoolkit

[6] *NICE Guideline on Endometriosis: Diagnosis and Management* (NG 73), 6 September 2017 https://www.nice.org.uk/guidance/NG73

[7] *NICE Quality Standards on Endometriosis* (QS 172), 6 August 2018 https://www.nice.org.uk/guidance/QS172

[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, https://www.nice.org.uk/guidance/ng193

In addition, there are some gaps in the NICE guidance that need to be addressed including:

- Care pathways recognising endometriosis as a chronic condition and treating it holistically, not as a series of unconnected incidents with referral separate from surgery
- Establishing care pathways for estimated 10% of people with non-pelvic endometriosis starting with thoracic
- Appropriate post-surgery care including consultant follow up, other care for example pelvic physiotherapy, and support for post-operative complications
- Post hysterectomy care –women are generally discharged from gynaecology post hysterectomy so if any issues arise, there are no care pathways available
- Access to pharmacological and non-pharmacological pain management for endometriosis, recognised as a chronic pain condition in NICE chronic pain guideline[9]; the 2020 survey found many (58%) wanted but were not offered this[3]
- Integrating mental health support into care pathways which currently have few mental health service links, despite 81% of respondents to the 2020 survey saying it negatively affects their mental health and 90% wanting mental health support[3]
- Updating NICE guideline NG 73 on pain management including aligning with NICE guideline NG 193 on chronic pain

There has thus far been no England-wide, or regional planning for the care provision required by those with endometriosis, including in relation to the number and capacity of BSGE accredited endometriosis specialist centres[10].

BSGE centres are not physical centres, but multi-disciplinary groups of clinicians in a hospital. Centre capacity varies including for surgery; there is a minimum requirement of 12 rectovaginal surgeries per gynaecological surgeon per year. As many BSGE centres were set up by individual clinicians interested in endometriosis, the continued functioning of those centres may be at risk should those clinicians leave or retire.

In order to ensure the NHS capacity needed to meet the demand for endometriosis care in England including the additional demand due to the pandemic backlog, the first step should be a service audit of endometriosis care in England. Once services have been audited, a gap analysis should be undertaken to identify the barriers to implementing the relevant NICE guidance to ensure that all those with endometriosis can access the care and support they need in a timely fashion.

Financial investment

How much financial investment will be needed to tackle the backlog over the short, medium, and long-term; and how should such investment be distributed? To what extent is the financial investment received to date adequate to manage the backlog?

From our understanding, there has not been financial investment in the recommencement of gynaecology services, with some benign gynaecology services apparently being assigned a lower priority than other specialities.

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[9] *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, https://www.nice.org.uk/guidance/ng193

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Service organisation and reform

How might the organisation and work of the NHS and care services be reformed in order to effectively deal with the backlog, in the short-term, medium-term, and long-term?

Reform to ensure the NHS can deal with the endometriosis care backlog requires:

- The introduction of managed clinical networks for endometriosis across all areas England linking gynaecology departments with endometriosis specialist centres to help tackle the backlog.

- Implementing NICE guideline NG73 on endometriosis diagnosis and management and NICE quality standards QS 172 on endometriosis including but not limited to:
  - 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 a with Special Interest in Endometriosis', working closely with BSGE and RCOG to define role and competencies
  - Access to an endometriosis specialist nurse for all with endometriosis
  - Access to pain management including pharmacological treatment and (not in NG 73) non-pharmacological services such as pelvic physiotherapy and psychological support, aligning with NICE chronic pain guideline[11]
  - Prompt primary care onward referral of those for whom initial hormonal treatment is contraindicated or not effective/not tolerated after 6 months; no 'keeping' patients in primary care
  - Ensuring access to BSGE centres, especially for those with suspected or confirmed deep endometriosis involving bowel, bladder or ureter

- Streamlining 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
  - Ensuring gynaecology departments and BSGE centre capacity meets demand
  - Identifying learning from Cancer Rapid Diagnostic Centres to help reduce endometriosis diagnosis time

Undertaking a service audit of endometriosis care in England followed by a gap analysis to identify the barriers to implementing NICE Guideline NG 73 and ensure services are available to all irrespective of postcode.

Our research over the last two years[12] has revealed:

- Failure of some NHS trusts to contact patients waiting for new dates for appointments postponed or cancelled due to the pandemic
- Difficulties in accessing NHS care for endometriosis during the pandemic including delays being reported as having a negative impact on mental health
- Virtual or phone appointments sometimes getting cancelled or rescheduled at the last minute, increasing patient stress and leading to patients missing appointments through no fault of their own

[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, https://www.nice.org.uk/guidance/ng193

[12] *Endometriosis UK England Covid Impact Survey* (2021) unpublished, *Endometriosis UK – UK Wide Covid Impact Survey*, (2021) unpublished and *Endometriosis in the UK – Time for Change*, Inquiry Report of APPG on Endometriosis, October 2020 https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf

- Comments from members of the endometriosis community highlighting the need to be assertive and/or know how to "navigate" the NHS to get the care they needed

This indicates a need for reform to improve patient liaison from some gynaecology departments, so that patients are not left waiting in uncertainty. In addition, those without the confidence and/or knowledge to push for new or rescheduled appointments should not lose out. This could involve the identification and spread of best practice in patient liaison both in terms of working practices and IT tools/apps from those NHS trusts which do it well.

Learning from pandemic service re-design

What positive lessons can be learnt from how healthcare services have been redesigned during the pandemic? How could this support the future work of the NHS and care services?

The introduction of virtual and/or telephone appointments during the pandemic has enabled learning about how and when such appointments are suitable. From our own research[12] and from speaking to the endometriosis community, we would note the following:

Virtual and telephone appointments can be a positive development:

- They can be more convenient for patients due to not having to travel and taking up less time
- They use less NHS resources due to reducing the need for hospital based appointment especially in relation to monitoring/check-up type appointments where physical examinations would not usually be required or could be done through patient devices

However there are also disadvantages associated with them including:

- Personal choice – not everyone wants or feels comfortable with a virtual or phone appointment
- Those with disabilities such as visual or hearing impairment or neurodevelopmental conditions like autism may find them difficult to undertake
- Many from black, Asian, and minority ethnic backgrounds can find virtual or phone appointments unsuitable including due to cultural reasons and/or finding it difficult to speak with healthcare practitioners due to the presence of their husband or other family members in the home
- Members of the endometriosis community told us that they did not consider virtual or phone appointments suitable for first gynaecology appointments, pre-op assessments and any appointments where physical examinations would usually be required

We would recommend:

- Individual choice and capacity including disabilities must be taken into account when deciding to use virtual or telephone appointments
- Care must be taken in relation to those from ethnic minority communities who may find virtual or telephone appointments unsuitable
- Those not wanting a virtual or telephone appointment for any reason should be offered a face-to-face alternative, and making this choice should not delay their care unnecessarily

111 call-first service

How effectively has the 111 call-first system for A&E Departments been? What can be done to improve this?

Endometriosis UK has no research evidence on this.

Service innovation
What can the Department of Health & Social Care, national bodies and local systems do to facilitate innovation as services evolve to meet emerging challenges?

It is necessary to:

- Undertake strategic planning to ensure appropriate resources so that NHS capacity meets demand for endometriosis care
- Implement NICE guidance including managed clinical networks linking GPs, gynaecology departments and BSGE accredited endometriosis specialist centres
- Identify learning from Cancer Rapid Diagnostic Centres that could help reduce the average time it takes to get a diagnosis of endometriosis in England

Long Covid
To what extent is long-covid contributing to the backlog of healthcare services? How can individuals suffering from long-covid be better supported?

Endometriosis UK has no comments on this.

ABOUT ENGLAND COVID IMPACT SURVEY

Endometriosis UK undertook a survey on the impact of Covid on those with endometriosis living in England. The online survey using Survey Monkey was open for responses from 17 – 31 May 2021. Respondents were self-selecting, not a representative sample. The survey was promoted on social media, via our mailing lists and through our support groups.

1,580 responses were received, 85% from those with confirmed endometriosis (n= 1,243) and 15% from those with suspected endometriosis (n= 235).

The survey has not been published, but a summary report of some of the data was submitted to the DHSC Women's Health Strategy – Call for Evidence as an annex to the Endometriosis UK response to the call.

ABOUT US

Endometriosis UK is the UK's largest charity supporting those affected by endometriosis in the UK. We support those with the condition through the provision of information through our website and information leaflets, and direct support through a helpline, support groups, and an online forum. We also raise awareness 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 the Royal College of Obstetricians and Gynaecologists.

Endometriosis UK would be happy to discuss our submission to the Health and Social Care Select Committee's Inquiry in further detail or to answer any questions arising. Please contact us on policy@endometriosis-uk.org.

Sept 2021