

Debate Pack

Number CDP 2021/0159

By Sarah Barber,
Nikki Sutherland

28 October 2021

e-petition debate on endometriosis and polycystic ovary syndrome

1	Background	2
2	Parliamentary material	8
2.1	Statement	8
2.2	Debate	8
2.3	PQs	8
3	News items and useful links	13

1

Background

A debate will be held in Westminster Hall on Monday 1 November 2021 on an E-petition relating to endometriosis and polycystic ovary syndrome. The debate has been tabled by the Petitions Committee and will be led by Taiwo Owatemi MP.

Endometriosis

Endometriosis is a condition where tissue that is similar to the lining of the womb grows elsewhere in the body. Most commonly this is in the fallopian tubes and on the ovaries, but it can affect an individual's bowels, bladder and other parts of the body.

Symptoms of endometriosis are varied and may be worse during menstruation. The NHS website provides the following information about symptoms:

The main symptoms of endometriosis are:

- pain in your lower tummy or back ([pelvic pain](#)) – usually worse during your period
- [period pain](#) that stops you doing your normal activities
- pain during or after sex
- pain when peeing or pooing during your period
- feeling sick, constipation, diarrhoea, or blood in your pee during your period
- difficulty getting pregnant

You may also have heavy periods. You might use lots of pads or tampons, or you may bleed through your clothes.

For some women, endometriosis can have a big impact on their life and may sometimes lead to feelings of depression.¹

According to Endometriosis UK, endometriosis affects 10% of women and those assigned female at birth in the UK.²

¹ NHS, [Endometriosis](#), overview, January 2019

² DHSC, [More women urged to come forward to shape women's health strategy](#), May 2021. Those “assigned female at birth” may include trans men and non-binary individuals.

There is currently no cure for endometriosis but treatments that may be offered include painkillers, hormone treatments such as the contraceptive pill, and surgery.

More general information on endometriosis is provided in the following sources:

- NHS, [Endometriosis](#)
- Endometriosis UK, [Understanding Endometriosis](#)
- Royal College of Obstetricians and Gynaecologists, [Endometriosis](#), 2018

Polycystic ovary syndrome

The NHS website provides the following information about polycystic ovary syndrome:

Polycystic ovary syndrome (PCOS) is a common condition that affects how a woman's ovaries work.

The 3 main features of PCOS are:

- [irregular periods](#) – which means your ovaries do not regularly release eggs (ovulation)
- excess androgen – high levels of "male" hormones in your body, which may cause physical signs such as excess facial or body hair
- polycystic ovaries – your ovaries become enlarged and contain many fluid-filled sacs (follicles) that surround the eggs (but despite the name, you do not actually have cysts if you have PCOS)

If you have at least 2 of these features, you may be diagnosed with PCOS.³

Verity, the PCOS charity states that the condition is “very common, affecting 1 in 10 (10%) women and AFAB [assigned female at birth] individuals, although this can vary from country to country.”⁴

Symptoms of PCOS can include irregular periods, difficulties conceiving, excessive hair growth and weight gain. The cause of PCOS is unknown but it is associated with abnormal levels of hormones in the body.

³ NHS, Polycystic ovary syndrome, February 2019

⁴ Verity, [What is PCOS?](#) [accessed 15 October 2021] Those “assigned female at birth” may include trans men and non-binary individuals.

There is no cure for PCOS but treatments include lifestyle changes, medicines and in some cases, surgery:

If you have PCOS and you're overweight, [losing weight](#) and eating a [healthy, balanced diet](#) can make some symptoms better.

Medicines are also available to treat symptoms such as excessive hair growth, irregular periods and fertility problems.

If fertility medicines are not effective, a simple surgical procedure called laparoscopic ovarian drilling (LOD) may be recommended.

This involves using heat or a laser to destroy the tissue in the ovaries that's producing androgens, such as testosterone.

With treatment, most women with PCOS are able to get pregnant.⁵

More information on PCOS is provided in the following sources:

- NHS, [Polycystic ovary syndrome](#)
- Royal College of Obstetricians and Gynaecologists, [Polycystic ovary syndrome \(PCOS\): what it means for your long-term health](#), 2015
- Verity, [What is PCOS](#)

1.1

The petition

The petition states that both Endometriosis and PCOS affect around 10% of women worldwide, but these conditions are under prioritised in terms of research and funding. It calls for more funding to research the causes and potential treatments for the conditions:

Endometriosis and PCOS are two gynaecological conditions which both affect 10% of women worldwide, but both are, in terms of research and funding, incredibly under prioritised. This petition is calling for more funding, to enable for new, extensive and thorough research into female health issues.

Many women seldom get the medical attention they require, or frequently have their symptoms miscalculated.

Due to personal experience, we are aware that the average time taken for a full diagnosis for endometriosis is 7 1/2 years in the UK.

⁵ NHS, [Polycystic ovary syndrome](#), February 2019

A cure for these conditions has not yet been found. It is important to us to start a conversation, to hopefully achieve funding to eventually find a cure for these conditions, or find more legitimate ways of treating symptoms.⁶

The petition is now closed, it received 101,900 signatures. The charities Endometriosis UK and Verity have both expressed support for the aims of the petition and have encouraged people to ask their MP to attend the debate.⁷

The Department of Health and Social Care published a response to the petition in August:

The Government recognises the importance of research into endometriosis and polycystic ovary syndrome. The Government is funding a broad range of research through its funding organisations.

The Government is aware of and sympathises with the hardships faced by women who experience severe symptoms from conditions such as endometriosis and polycystic ovary syndrome. While treatment is available, NHS England highlight that symptoms for both conditions vary widely, including in terms of severity. It is therefore important to seek clinical advice if women notice symptoms about which they have concern.⁸

The response provides an overview on how medical research is funded in the UK, and provides examples of ongoing studies looking at these conditions:

The Government funds medical research through the National Institute for Health Research (NIHR) and UK Research Innovation (UKRI). In the last five financial years to 2019-20, the NIHR and UKRI have awarded £8.52m for research into endometriosis and £6.60m for research into polycystic ovary syndrome. This includes a wide range of projects from basic science through to applied health research into diagnosis, treatment and service delivery.

Examples of research includes: a project, hosted by the NIHR School for Primary Care Research, examining what happens in primary care when women consult with endometriosis-like symptoms in order to start addressing delays in diagnosis and treatment and lead to improvement in care for women; and a randomised controlled trial exploring the use of two different treatment options for women with polycystic ovary syndrome whose eggs do not release from their ovaries to determine the most effective drug, or combination of drugs, needed to ensure women are offered the best available

⁶ UK Government and Parliament Petitions, [Increase funding for research into Endometriosis and PCOS](#)

⁷ Endometriosis UK, [Endometriosis UK and Verity join force to increase research funding into endometriosis and PCOS](#), 4 October 2021

⁸ UK Government and Parliament Petitions, [Increase funding for research into Endometriosis and PCOS](#)

care with minimum side effects and spared the need for more invasive and costly fertility treatments. Other Government-funded research includes studies to investigate new therapeutics, the genetic basis for polycystic ovary syndrome, clinical prediction models of whether surgery will be successful for endometriosis, pain management trials and research to improve reproductive outcomes for women with these conditions.

The NIHR engages and involves patients, carers and the public in all the processes by which research is identified, prioritised, designed, conducted, evaluated and disseminated to improve the reach, quality and impact of the funded research. Women with endometriosis and polycystic ovary syndrome play a vital role in the research identified above.

The NIHR welcomes funding applications for research into any aspect of human health, including endometriosis and polycystic ovary syndrome; it is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.⁹

The response also sets out information on training and clinical guidance on these conditions:

To support women with endometriosis, all obstetricians and gynaecologists have been trained in the diagnosis, investigation and management of the condition, which is specifically listed as a topic in the core curriculum for obstetrics and gynaecology.

NHS England expects providers to adhere to NICE guidance regarding the diagnosis, management and treatment of endometriosis available at <https://www.nice.org.uk/guidance/NG73>. NHS England also recommends the European Society of Human Reproduction and Embryology (ESHRE) guidelines on the management of women with endometriosis <https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline.aspx>. The guidance offers best practice advice on the diagnosis and treatment of women with suspected endometriosis as well as the effectiveness of medically assisted reproduction for endometriosis-associated infertility. It also provides information on the management of patients in whom endometriosis is found incidentally (without pain or infertility).

Polycystic ovary syndrome is a multifaceted, polygenic condition that often starts in adolescence and may have lifelong effects - through

⁹ UK Government and Parliament Petitions, [Increase funding for research into Endometriosis and PCOS](#)

reproductive years to post-menopause. While there is currently no “cure”, there are several options for treatment and ways that individuals can alter lifestyle to ameliorate symptoms. Those who are overweight tend to have worse symptoms and long-term consequences and are less likely to respond to treatment.

There are many effective treatments and a large body of research looking at evidence-based therapy - whether for symptoms of hyperandrogenism, menstrual cycle disturbance or infertility. There are a number of consensus papers outlining the best approach for investigation and management.

NHS England advise that the UK patient support organisation Verity provides resources for patients as does the Women’s Network pages of the Royal College of Obstetricians and Gynaecologists’ website.¹⁰

The Government highlighted the development of a new Women’s Health Strategy in its response to the petition.

The Government launched a consultation on a future Women’s Health Strategy in March 2021. The consultation ended in June and received over 100,000 submissions. The Government is analysing the responses and has said it will publish a response to the consultation in the autumn and the strategy later this year.¹¹

¹⁰ UK Government and Parliament Petitions, [Increase funding for research into Endometriosis and PCOS](#)

¹¹ [PQ UIN 33936 Health services: females](#), 22 July 2021

2 Parliamentary material

2.1 Statement

Commons statement followed by questions: [Women's Health Strategy](#)

HC Deb 8 March 2021 | Vol 690 c535-

Repeated and followed by questions in the Lords: [Women's Health Strategy](#)

HL Deb 9 March 2021 | v810 c1476-

2.2 Debate

Lords debate: [Women's health outcomes](#)

HL Deb 8 July 2021 | Vol 813 c1490-

2.3 PQs

[Polycystic Ovary Syndrome](#)

Asked by: Robinson, Gavin

To ask the Secretary of State for Health and Social Care, pursuant to the Answer of 23 September 2021 to Question 44360, on Polycystic Ovary Syndrome, if he will provide the data requested in the context of the Answer of 7 November 2016 to Question 51291, on Polycystic Ovary Syndrome.

Answering member: Maria Caulfield | Department: Department of Health and Social Care

The information requested on the number of number of women diagnosed with polycystic ovary syndrome is not collected in the format requested. In our earlier answer of 7 November 2016, we provided the number of finished admission episodes (FAE) where the patient is female and a primary diagnosis for polycystic ovary syndrome was made in England. It should be noted that a FAE does not reflect the number of women who have had the syndrome as the same patient can be recorded on more than one occasion. In addition,

diagnoses for this condition can occur in non-hospital settings, which is not recorded in this data.

The following table shows FAE activity in English National Health Service hospitals and English NHS commissioned activity in the independent sector in each year from 2015-16 to 2019-2020.

Year	Admissions
2015-16	1,392
2016-17	1,297
2017-18	1,223
2018-19	1,254
2019-20	1,226

Source: Hospital Episode Statistics, NHS Digital

HC Deb 26 Oct 2021 | PQ 56682

[Endometriosis: Health Services](#)

Asked by: De Cordova, Marsha

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to help ensure women living with endometriosis are supported mentally and physically while they are on the waiting list for treatment.

Answering member: Maria Caulfield | Department: Department of Health and Social Care

To support women with endometriosis, all obstetricians and gynaecologists have been trained in the diagnosis, investigation, and management of the condition, which is within the core curriculum for obstetrics and gynaecology. Women with endometriosis or suspected endometriosis should receive good care in line with the National Institute for Health and Care Excellence's guideline 'Endometriosis: diagnosis and management'. Within the guideline, clinicians are advised to direct women to local support groups, online forums and national charities and how to access them and if the woman agrees, to involve people important to them in discussions.

HC Deb 25 Oct 2021 | PQ 57321

Endometriosis: Diagnosis

Asked by: Nichols, Charlotte

To ask the Secretary of State for Health and Social Care, if he will make it his policy to reduce the average diagnosis time for endometriosis patients to (a) four years or less by 2025 and (b) one year or less by 2030.

Answering member: Ms Nadine Dorries | Department: Department of Health and Social Care

The treatment and diagnosis of endometriosis which will be carefully considered as part of work on the Women's Health Strategy. A call for evidence was launched to inform the priorities, content and actions of the Strategy, which included questions on gynaecological conditions such as endometriosis. We are analysing the responses and we aim to publish the Strategy later this year.

Research exploring the experiences of women presenting with endometriosis-like symptoms in primary care hosted by the National Institute of Health Research, was published earlier this year, which will inform our understanding of delays in diagnosis.

HC Deb 27 July 2021 | PQ 35941

Asked by: Hayes, Helen

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to reduce waiting times for endometriosis screening and treatment.

Answering member: Ms Nadine Dorries | Department: Department of Health and Social Care

No estimate has been made.

There is no national screening programme for diagnosis of endometriosis. Women should consult their general practitioner in the first instance if they suspect symptoms. Clinicians should follow the National Institute for Health and Care Excellence's guideline on diagnosis and management of endometriosis. Diagnosis and treatment times for endometriosis this will be considered as part of the Women's Health Strategy.

Research to explore women's experiences in primary care when presenting with endometriosis-like symptoms is currently underway, hosted by the National Institute of Health Research. The results will be published later this year and will help us to understand delays in diagnosis.

HC Deb 18 June 2021 | PQ 10537

[Endometriosis: Research](#)

Asked by: Fletcher, Colleen

To ask the Secretary of State for Health and Social Care, what funding his Department has allocated for research into the (a) causes of and (b) treatment for endometriosis.

Answering member: Ms Nadine Dorries | Department: Department of Health and Social Care

In the last five financial years to 2019-20, the National Institute for Health Research and UK Research and Innovation have awarded £8.52 million for research into endometriosis.

HC Deb 20 April 2021 | PQ 180520

[Endometriosis: Diagnosis](#)

Asked by: Villiers, Theresa

To ask the Secretary of State for Health and Social Care, if he will take steps to improve the speed of diagnosis of endometriosis.

Answering member: Ms Nadine Dorries | Department: Department of Health and Social Care

Research exploring the experiences of women who present with endometriosis-like symptoms in primary care is currently underway, hosted by the National Institute of Health Research. The results will be published later this year and will help to understand delays in diagnosis.

On 8 March, we launched a 12-week call for evidence as part of the first Government-led Women's Health Strategy for England. The online survey within the call for evidence seeks information on gynaecological conditions, including endometriosis. The treatment and diagnosis of endometriosis will be carefully considered as part of the ongoing work on the Women's Health Strategy.

HC Deb 13 April 2021 | PQ 174751

[Endometriosis: Medical Treatments](#)

Asked by: Villiers, Theresa

To ask the Secretary of State for Health and Social Care, what steps he is taking to improve patient access to specialist treatment for endometriosis.

Answering member: Ms Nadine Dorries | Department: Department of Health and Social Care

Research exploring the experiences of women who present with endometriosis-like symptoms in primary care is currently underway, hosted by the National Institute of Health Research. The results will be published later this year and will help to understand delays in diagnosis.

On 8 March, we launched a 12-week call for evidence as part of the first Government-led Women's Health Strategy for England. The online survey within the call for evidence seeks information on gynaecological conditions, including endometriosis. The treatment and diagnosis of endometriosis will be carefully considered as part of the ongoing work on the Women's Health Strategy.

HC Deb 13 April 2021 | PQ 174750

[Endometriosis: Diagnosis](#)

Asked by: Huq, Dr Rupa

To ask the Secretary of State for Health and Social Care, what steps his Department is taking in response to the recommendations by the APPG on Endometriosis Inquiry Report 2020 entitled Endometriosis in the UK: to reduce diagnosis to four years or less by 2025, and a year or less by 2030.

Answering member: Ms Nadine Dorries | Department: Department of Health and Social Care

The report raises a number of important issues concerning the treatment and diagnosis of endometriosis which will be carefully considered as part of our ongoing work in women's health.

HC Deb 08 March 2021 | PQ 161819

3

News items and useful links

All-party Parliamentary Group on Endometriosis

<https://www.endometriosis-uk.org/endometriosis-appg>

APPG enquiry report, [Endometriosis in the UK: time for change](#), 2020

Endometriosis UK

<https://www.endometriosis-uk.org/>

Verity, the PCOS charity

<https://www.verity-pcos.org.uk/>

Endometriosis UK

4 October 2021

[Endometriosis UK and Verity join forces to increase research funding into endometriosis and PCOS](#)

Endometriosis UK

19 October 2020

[MP's call for urgent Government action to support 1.5 million with endometriosis, as new report shows no improvement in diagnosis in a decade](#)

PCOS (polycystic ovary syndrome) – [information links from the Royal College of Obstetricians and Gynaecologists](#)

Department of Health and Social Care press release

6 March 2021

[Government launches call for evidence to improve health and wellbeing of women in England](#)

Department of Health and Social Care press release

1 May 2021

[More women urged to come forward to shape women's health strategy](#)

House of Commons Library research briefing

5 August 2021

[Research and Development funding policy](#)

Scottish Government's Women's Health Plan 2021-24

<https://www.gov.scot/publications/womens-health-plan/>

iNews

27 September 2021

[Women diagnosed with PCOS told they can only access medication if they're 'trying for a baby'](#)

Telegraph

3 September 2021

['I practically had to beg to go for tests': why PCOS is often a 'hidden' condition](#)

Guardian

2 July 2021

[A common treatment for endometriosis could actually be making things worse](#)

Independent

30 March 2021

[Why hasn't endometriosis care improved?](#)

BMJ Opinion blog

12 March 2021

[Endometriosis should be considered a priority health issue](#)

BBC News Online

19 October 2020

[Endometriosis care needs urgent improvement, MPs say](#)

Disclaimer

The Commons Library does not intend the information in our research publications and briefings to address the specific circumstances of any particular individual. We have published it to support the work of MPs. You should not rely upon it as legal or professional advice, or as a substitute for it. We do not accept any liability whatsoever for any errors, omissions or misstatements contained herein. You should consult a suitably qualified professional if you require specific advice or information. Read our briefing '[Legal help: where to go and how to pay](#)' for further information about sources of legal advice and help. This information is provided subject to the conditions of the Open Parliament Licence.

Feedback

Every effort is made to ensure that the information contained in these publicly available briefings is correct at the time of publication. Readers should be aware however that briefings are not necessarily updated to reflect subsequent changes.

If you have any comments on our briefings please email papers@parliament.uk. Please note that authors are not always able to engage in discussions with members of the public who express opinions about the content of our research, although we will carefully consider and correct any factual errors.

You can read our feedback and complaints policy and our editorial policy at commonslibrary.parliament.uk. If you have general questions about the work of the House of Commons email hcenquiries@parliament.uk.

The House of Commons Library is a research and information service based in the UK Parliament. Our impartial analysis, statistical research and resources help MPs and their staff scrutinise legislation, develop policy, and support constituents.

Our published material is available to everyone on commonslibrary.parliament.uk.

Get our latest research delivered straight to your inbox. Subscribe at commonslibrary.parliament.uk/subscribe or scan the code below:



 commonslibrary.parliament.uk

 [@commonslibrary](https://twitter.com/commonslibrary)