

Statistical bulletin

# Characteristics of women with an endometriosis diagnosis in England: 27 March 2011 to 31 December 2021

A population-level analysis of the characteristics of women receiving an endometriosis diagnosis in an NHS hospital in England between 2011 and 2021.

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# 1 . Main points

- Endometriosis is a chronic gynaecological condition that has physical, psychological, social, and economic impacts; however, there has been no population-level analysis of the characteristics of women with endometriosis in England.
- Using 2011 Census data linked to hospital records from 2011 to 2021, we estimate the prevalence of an endometriosis diagnosis to be approximately 2% of reproductive age women in our linked population, with an average age at diagnosis of 35 years; this is likely an underestimate of the true prevalence, as many women will not have a diagnosis.
- The likelihood of receiving an endometriosis diagnosis was highest in the "White British", "Black Caribbean", and "Mixed White and Black Caribbean" ethnic groups, and lowest in the "Chinese", "Arab", and "Black African" ethnic groups.
- Women living in the most and least deprived areas were least likely to have an endometriosis diagnosis; this possibly reflects less access to healthcare services in the most deprived group and more use of private healthcare in the least deprived group.
- Women self-reporting to be in bad health or disabled were more likely to have an endometriosis diagnosis, compared with those who were in very good health or non-disabled, respectively.
- Differences in the likelihood of having an endometriosis diagnosis by sociodemographic characteristic reflect differences in the likelihood of having endometriosis, as well as the likelihood of receiving a diagnosis in an NHS hospital.

# 2 . Results of the analysis

We report rates of endometriosis by age group and age-standardised rates of receiving an endometriosis diagnosis by:

- ethnic group
- Index of Multiple Deprivation (IMD) decile group
- household National Statistics Socio-economic Classification (NS-SEC)
- highest educational qualification
- country of birth
- main language
- general health
- disability status
- rural/urban classification
- region
- upper tier local authority (UTLA)

All characteristics were self-reported from the 2011 Census. We used logistic regression models to estimate odds ratios of receiving an endometriosis diagnosis by each characteristic. Our models were first adjusted for age, and secondly for age and pre-existing health. Endometriosis diagnoses were identified using hospital admissions data between 2011 and 2021. Additional details can be found in [Section 5: Data sources and quality](#). Information on age standardisation, logistic regression, and odds ratios can be found in [Section 4: Glossary](#).

The likelihood of being diagnosed with endometriosis was significantly lower for all other ethnic groups, compared with the "White British" ethnic group. This is except for the "Black Caribbean", "Mixed White and Black Caribbean", "Other Mixed", and "White Gypsy or Irish Traveller" ethnic groups, which showed no evidence of a significant difference.

The groups with the lowest likelihood of diagnosis, compared with the "White" ethnic group, were:

- the "Chinese" ethnic group, with an odds ratio (OR) of 0.46, 95% confidence interval (CI) of 0.43 to 0.48
- the "Arab" ethnic group, with an OR of 0.52, 95% CI of 0.48 to 0.57
- the "Black African" ethnic group, with an OR of 0.61, 95% CI 0.59 to 0.64

Additional models using aggregated ethnic group breakdowns and adjusting for country of birth and main language can be found in our [accompanying dataset](#).

Women born outside the UK (OR of 0.72, 95% CI of 0.71 to 0.73) or whose main language was not English (OR of 0.67, 95% CI of 0.66 to 0.68) had significantly lower odds of being diagnosed, compared with those born in the UK or whose main language was English, respectively.

Analysis of socioeconomic factors, such as IMD, showed the odds were lowest for women living in the most deprived and least deprived areas of the country. Analysis of household NS-SEC showed the odds were lowest for women in households with the highest and lowest socio-economic classifications. When looking at education level, the odds ratios were lowest for women with "Other" (foreign or vocational) qualifications (OR of 0.87, 95% CI of 0.85 to 0.89) or no qualifications (OR of 0.96, 95% CI of 0.94 to 0.97), compared with "Level 4 and above" qualifications (for example, degree level).

Women reporting to be in bad health (OR of 2.04, 95% CI of 2.00 to 2.09) had the highest likelihood of a diagnosis, compared with those in very good health. Disabled women reporting to be limited a little (OR of 1.58, 95% CI of 1.55 to 1.60) or limited a lot (OR of 1.38, 95% CI of 1.36 to 1.40) in their day-to-day activities had significantly higher odds of diagnosis, compared with non-disabled women.

Additional results broken down by rural/urban classification, region, and UTLA can be found in our accompanying dataset. Further analysis, including our supplementary and sensitivity analyses, can also be found in our accompanying dataset.

### 3 . Data on the characteristics of women with an endometriosis diagnosis in England

[Characteristics of women with an endometriosis diagnosis in England](#)

Dataset | Released 10 December 2024

Population-level analysis of the characteristics of women receiving an endometriosis diagnosis in an NHS hospital in England between 2011 and 2021.

## 4 . Glossary

### Endometriosis

[Endometriosis](#) is a condition where endometrial tissue, similar to the lining of the uterus, grows in other places, such as the ovaries and fallopian tubes. Common symptoms include chronic pelvic pain, fatigue, heavy menstrual bleeding, pain during or after sex, painful urination and bowel movements, and reduced fertility, as described in the Nature Reviews [article on Endometriosis](#). Endometriosis usually affects women during their reproductive years (between menarche and menopause), but can affect women of any age, as described by the Royal College of Nursing in their [What is Endometriosis publication](#).

### 95% confidence intervals

A confidence interval (CI) is a measure of the uncertainty around a specific estimate. If a CI is calculated at the 95% level, it is expected that the interval will contain the true value on 95 occasions, if repeated 100 times. The level of uncertainty about where the true value lies increases as intervals around estimates widen. More information is available on our [Uncertainty and how we measure it for our surveys webpage](#).

## Age-standardised rates

Age-standardised rates are used to allow comparisons between populations that contain different proportions of people of different ages. Age-standardised rates were calculated as the weighted sum of age-specific rates in five-year age bands. The age-specific weights represent the overall age distribution in the observed study population.

## Odds ratio

Odds ratios quantify the strength of the association between an outcome (for example, receiving an endometriosis diagnosis) and a factor of interest (for example, ethnic group). Odds ratios compare the odds of experiencing an outcome for people in the presence of the factor of interest (for example, the "Black Caribbean" ethnic group) with a comparison group (for example, the "White British" ethnic group).

Odds ratios equal to 1 indicate that the odds in the group of interest is not significantly different to the comparison group. Odds ratios greater than 1 indicate that a particular group has higher odds, relative to people in the comparison group. Odds ratios less than 1 indicate the odds are lower, relative to people in the comparison group.

## Logistic regression

Logistic regression is a statistical technique for modelling the relationship between two characteristics of interest, such as ethnic group and receiving a diagnosis of endometriosis. The model can be used to understand the independent relationship between the two characteristics. This is while "adjusting" or "controlling" for other characteristics (such as age), which may be related to the group and outcome of interest.

# 5 . Data sources and quality

## Linked dataset

We used 2011 Census data linked to Hospital Episode Statistics (HES) Admitted Patient Care (APC) records from 1 April 2009 to 31 December 2022.

Data from the 2011 Census have been linked to the NHS Patient Registers from 2011 to 2013 to obtain NHS numbers, with a linkage rate of 94.6%, as described in this [International Journal of Epidemiology article](#).

## Data inclusion criteria

We defined two cohorts of women who:

- were counted in the 2011 Census
- were usual residents and living in England
- could be linked to an NHS number

All groups were filtered to restrict our cohort to people who self-reported as female in the 2011 Census. All sociodemographic variables included in the analyses were self-reported in the 2011 Census.

We used International Classification of Diseases, Tenth Revision (ICD-10) codes N80.0 to N80.9 to identify endometriosis diagnoses using the HES APC data. Each HES record includes up to 20 diagnosis values, as outlined in NHS England's [HES Data Dictionary](#). The first value (primary diagnosis) records the main condition being treated or investigated. The other values record any relevant secondary or subsidiary diagnoses.

For our main analysis, we identified women with any endometriosis diagnosis (recorded as a primary or secondary diagnosis) between 27 March 2011 and 31 December 2021. We also identified a control group of women counted in the 2011 Census with no evidence of endometriosis during the study period. The resulting cohort contained 24,560,795 women, with 262,065 having a diagnosis of endometriosis.

For our supplementary analysis, we identified a group of women with a primary endometriosis diagnosis only during our study period. We also used two additional years of HES APC data to exclude instances where women had a previous endometriosis diagnosis between 1 April 2009 and 26 March 2011. This excluded women who did not have their first diagnosis during our study period. The supplementary control group had no diagnosis of endometriosis during the study period, or in the two years prior. A total of 24,382,270 women were included in our supplementary analysis, with 120,515 having a primary diagnosis of endometriosis.

## Quality

Our prevalence estimate reflects the number of women who have been diagnosed with endometriosis in an NHS hospital in England between 2011 and 2021. It is important to note that this does not reflect the true prevalence of endometriosis, as not all women will have a diagnosis.

Our analysis only includes women whose 2011 Census response could be linked to an NHS number. It does not capture all women who have had a diagnosis in hospital. For our main analysis, our sample includes approximately 85% of all women who received an endometriosis diagnosis in hospital during this period. Additional information can be found in the sample flow in our [accompanying dataset](#).

All sociodemographic information was taken from the 2011 Census. This means that some characteristics that are more likely to change over time may be different at the time of diagnosis. We ran sensitivity analyses using two years of follow-up from the day of the 2011 Census to check the robustness of our findings. Additional information can be found in our accompanying dataset.

## Acknowledgements

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## 6 . Cite this statistical bulletin

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