

# MEASURING THE QUALITY OF LIFE OF WOMEN & THOSE ASSIGNED FEMALE AT BIRTH LIVING WITH ENDOMETRIOSIS

**A survey commissioned by Endometriosis UK using the Endometriosis Health Profile-30 questionnaire**

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## **Background:**

The Endometriosis Health Profile-30 (EHP-30) was originally developed in English at the University of Oxford, working with Endometriosis UK (named the National Endometriosis Society at that time). The EHP-30 consists of a core instrument with five scale scores covering: Pain; Control and powerlessness; Social support; Emotional well-being, and Self-image. In addition, six (optional) supplementary modules can be deployed alongside the core instrument covering areas of health status that may not affect every endometriosis sufferer. These cover: Work; Relationship with child/children; Sexual intercourse/functioning; Feelings about medical profession; Feelings about treatment, and Feelings about infertility. Practitioners can choose these modules (in any combination) to assess specific areas of health-related quality of life (HRQoL) that are relevant to their research/clinical practice and the patient. The core section outcomes can be presented at an individual item level, domain level, or as an overall summary score (i.e. a total score which includes all 30 items). On the modular section, only the outcomes at an item level or domain level are appropriate. The EHP-30 Core and Modular sections combined take on average less than 15 minutes to complete (Nogueira-Silva et al, 2015).

The EHP-30 (and its briefer version, the EHP-5) provided the first psychometrically established instruments, designed specifically to evaluate the impact of endometriosis and its associated treatments, or other related interventions, from the woman's perspective.

This report provides an overview of the statistical and qualitative analyses conducted on an anonymised dataset collected by Endometriosis UK in 2023-2024. EHP-30 domain scores have also been compared with survey data collected in 1999-2000 to assess whether the HRQoL of those with endometriosis responding to an Endometriosis UK survey have changed since the development of the instrument over 20 years ago.

## **Aims:**

- To analyse an anonymised dataset collected by Endometriosis UK using the EHP-30.
- To conduct a qualitative analysis on the open-ended survey responses surrounding patients' experiences of endometriosis.
- To compare the 2023-2024 responses to a pre-existing dataset from 1999-2000.

## Methods:

- Anonymised survey data was collected by Endometriosis UK. The survey included the EHP-30, a validated measure of quality of life in patients with endometriosis (developed by Professor Georgina Jones, Professor Stephen Kennedy and Professor Crispin Jenkinson at the University of Oxford), as well as demographics and six open-ended questions surrounding patients' experiences of living with endometriosis. A copy of the survey (EHP-30 and open-ended questions) is presented at the end of this document.
- Anonymised survey data was shared by Endometriosis UK with the Leeds Beckett University (LBU) team via a OneDrive folder created by LBU.
- Statistical and qualitative analyses were carried out by the team at LBU. Analyses included basic descriptive statistics of demographic and quality of life scores, and qualitative analysis of the open-ended questions.
- EHP-30 scores were compared with data collected in 1999-2000. As the previous survey with Endometriosis UK (known then as the National Endometriosis Society) was analysed on those that had a surgically confirmed diagnosis of endometriosis, we have analysed the 2023-2024 data for A) the overall sample, and B) those that have been surgically confirmed only, to allow comparisons between the two datasets.
- Analyses of the survey data (statistical anonymised output and qualitative findings) were shared with the team at the University of Oxford and Endometriosis UK for discussion.
- Final analyses, including a brief report summarising the key findings (this document) were shared with Endometriosis UK via the OneDrive folder for public dissemination.

**Table 1: Demographics of the Endometriosis UK 2023-2024 survey sample**

<b>Demographic</b>	<b>Total sample (N = 1840)</b>		<b>Surgically diagnosed group (N = 1177)</b>	
	N	%	N	%
<b>Gender</b>				
Female	1816	98.7	1165	99.0
Male	4	.2	0	0
Non-binary	14	.8	10	.8
Other	3	.2	2	.2
Prefer not to say	3	.2	0	0
<b>Employment status</b>				
Full time employment	1212	65.9	792	67.3
Part time employment	310	16.8	199	16.9
Full time education	84	4.6	45	3.8
Unemployed	105	5.7	65	5.5
Retired	23	1.3	13	1.1
Other	78	4.2	48	4.1
Prefer not to say	28	1.5	15	1.3
<b>Educational status</b>				
Qualifications below A-level	128	7.0	88	7.5
A-levels, vocational or equivalent	341	18.5	218	18.5
Other higher education below degree	117	6.4	84	7.1
Degree or degree equivalent	654	35.5	413	35.1
Higher degree or postgraduate	509	27.7	309	26.3
No qualifications	14	.8	10	.8
Other	14	.8	12	1.0
Prefer not to say	63	3.4	43	3.7
<b>Ethnicity</b>				
White	1693	92.0	1100	93.5
Asian	67	3.6	33	2.8
Black	21	1.1	9	.8
Mixed descent	43	2.3	29	2.5
Other	13	.7	4	.3
Prefer not to say	3	.2	2	.2

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<b>Year born</b>				
1944-1953	1	.1	0	0
1954-1963	16	.9	9	.8
1964-1973	99	5.4	63	5.4
1974-1983	427	23.2	288	24.5
1984-1993	706	38.4	457	38.8
1994-2003	531	28.9	337	28.6
2004-2007	60	3.3	23	2.0

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<b>Location</b>				
England	1482	80.5	964	81.9
Scotland	182	9.9	121	10.3
Northern Ireland	40	2.2	19	1.6
Wales	93	5.1	55	4.7
Other	43	2.3	18	1.5

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**Table 2: EHP-30 core domain scores (total sample 2023-2024)**

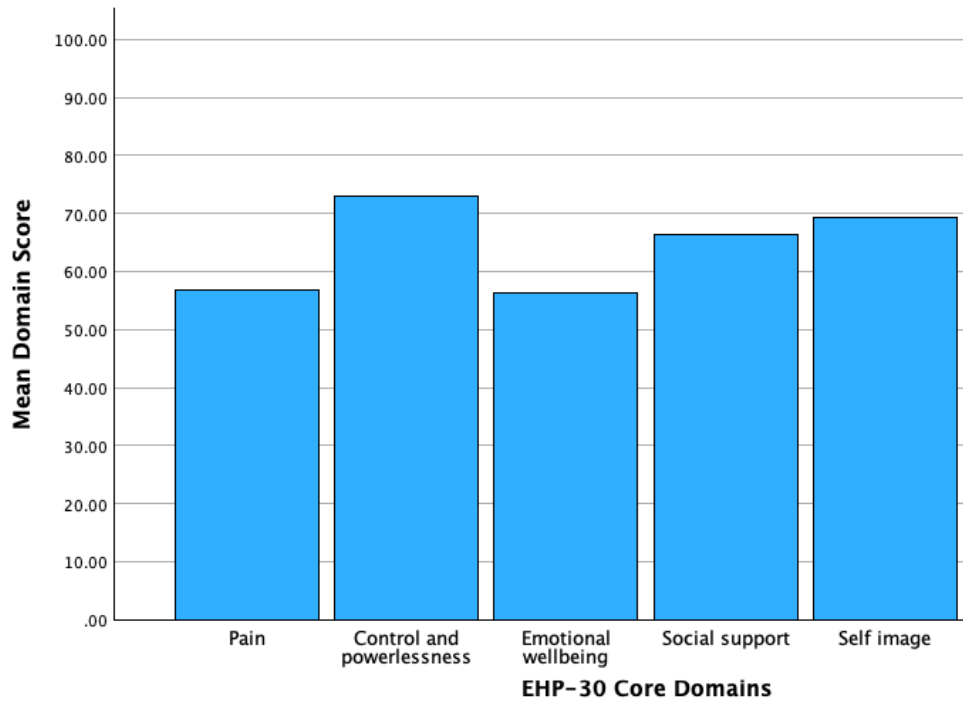
<b>Scale</b>		
<b>Pain</b>		
Mean	56.8	(% scoring min) 3.5
Median	61.4	(% scoring max) 1.3
SD	22.1	(25 <sup>th</sup> percentile) 45.5
Range of scores	0-100	(50 <sup>th</sup> percentile) 61.4
Number	1578	(75 <sup>th</sup> percentile) 72.7
<b>Control and powerlessness</b>		
Mean	72.9	(% scoring min) 2.6
Median	79.2	(% scoring max) 11.9
SD	24.2	(25 <sup>th</sup> percentile) 62.5
Range of scores	0-100	(50 <sup>th</sup> percentile) 79.2
Number	1578	(75 <sup>th</sup> percentile) 91.7
<b>Emotional well-being</b>		
Mean	56.3	(% scoring min) 2.2
Median	58.3	(% scoring max) 1.0
SD	20.7	(25 <sup>th</sup> percentile) 41.7
Range of scores	0-100	(50 <sup>th</sup> percentile) 58.3
Number	1573	(75 <sup>th</sup> percentile) 70.8
<b>Social support</b>		
Mean	66.4	(% scoring min) 2.5
Median	68.8	(% scoring max) 6.9
SD	23.3	(25 <sup>th</sup> percentile) 56.3
Range of scores	0-100	(50 <sup>th</sup> percentile) 68.8
Number	1574	(75 <sup>th</sup> percentile) 81.3
<b>Self-image</b>		
Mean	69.2	(% scoring min) 2.7
Median	75.0	(% scoring max) 17.3
SD	25.5	(25 <sup>th</sup> percentile) 50.0
Range of scores	0-100	(50 <sup>th</sup> percentile) 75.0
Number	1577	(75 <sup>th</sup> percentile) 91.7

Note: EHP-30 scores range from 0 (best possible health status) to 100 (worst possible health status).

#### Headlines:

- ‘Control and powerlessness’ is the worst HRQoL domain, followed by self-image. This information is presented graphically in figure 1.

**Figure 1: Mean EHP-30 core domain scores (total sample 2023-2024)**



**Table 3: Percentage of respondents scoring at each response category for the EHP-30 core items (total sample 2023-2024)**

Item N	N completed	Never	Rarely	Sometimes	Often	Always
P1	1590	13.3	10.9	36.1	32.6	7.1
P2	1588	7.9	7.9	35.1	41.7	7.4
P3	1588	9.2	12.7	36.2	34.5	7.4
P4	1588	10.8	18.1	36.1	28.7	6.2
P5	1587	9.5	12.5	38.6	32.1	7.2
P6	1588	6.0	6.2	24.9	42.8	20.1
P7	1587	14.2	18.2	33.1	27.2	7.3
P8	1584	7.2	9.8	30.6	39.1	13.3
P9	1585	8.5	7.7	30.2	41.9	11.7
P10	1583	6.7	5.6	31.8	43.6	12.3
P11	1582	9.9	12.1	31.1	35.1	11.8
C&P12	1584	3.8	5.3	21.8	43.2	25.9
C&P13	1585	4.8	5.3	14.3	33.6	42.0
C&P14	1584	4.5	4.2	14.0	33.3	44.0
C&P15	1584	5.2	5.4	15.3	36.0	38.1
C&P16	1581	6.1	6.5	18.9	30.5	38.0
EW17	1584	7.6	9.5	19.6	29.2	34.2
EW18	1582	7.3	11.9	32.3	33.8	14.7
EW19	1580	4.5	9.0	31.5	41.8	13.2
EW20	1581	4.7	9.2	30.4	40.9	14.8
EW21	1580	3.8	8.0	27.0	42.2	19.0
EW22	1579	4.6	11.7	32.2	38.1	13.4
EW23	1579	38.3	31.3	20.3	7.9	2.3
SS24	1581	8.7	10.8	33.7	33.1	13.7
SS25	1580	3.6	4.6	19.3	38.5	34.0
SS26	1580	6.2	7.0	19.9	33.9	33.1
SS27	1576	7.8	8.6	25.7	37.4	20.5
SI28	1578	7.2	8.9	20.4	35.2	28.3
SI29	1580	5.5	7.0	20.4	31.1	36.1
SI30	1580	4.5	7.6	24.2	33.9	29.7

\*Abbreviations: Pain (P); Control and Powerlessness (C&P); Emotional Well-being (EW); Social Support (SS); Self-image (SI)

#### Headlines:

- Notably, respondents had a poor HRQoL on the control and powerlessness items. For example, 77.3% reported 'often' or 'always' feeling frustrated due to not being able to control symptoms (C&P14)
- The worst area of 'pain' was difficulty exercising or engaging in leisure activity (P6) with 20.1% and 42.8% responding 'always' or 'often', respectively.
- For question 29, 'felt your appearance has been affected?', 36.1% responded always and 31.1% often.



**Table 4: EHP-30 modular domain scores (total sample 2023-2024)**

<b>Scale</b>		
<b>Work</b>		
Mean	51.4	(% scoring min) 6.5
Median	55.0	(% scoring max) 2.4
SD	26.9	(25 <sup>th</sup> percentile) 30.0
Range of scores	0-100	(50 <sup>th</sup> percentile) 55.0
Number	1332	(75 <sup>th</sup> percentile) 70.0
<b>Children</b>		
Mean	40.6	(% scoring min) 24.2
Median	50.0	(% scoring max) 2.4
SD	28.5	(25 <sup>th</sup> percentile) 12.5
Range of scores	0-100	(50 <sup>th</sup> percentile) 50.0
Number	509	(75 <sup>th</sup> percentile) 62.5
<b>Sex*</b>		
Mean	68.4	(% scoring min) 3.3
Median	75.0	(% scoring max) 13.6
SD	26.8	(25 <sup>th</sup> percentile) 55.0
Range of scores	0-100	(50 <sup>th</sup> percentile) 75.0
Number	1119	(75 <sup>th</sup> percentile) 90.0
<b>Medical</b>		
Mean	56.8	(% scoring min) 5.8
Median	62.5	(% scoring max) 6.6
SD	27.7	(25 <sup>th</sup> percentile) 37.5
Range of scores	0-100	(50 <sup>th</sup> percentile) 62.5
Number	1323	(75 <sup>th</sup> percentile) 75.0
<b>Treatment</b>		
Mean	63.9	(% scoring min) 2.3
Median	66.7	(% scoring max) 11.2
SD	24.7	(25 <sup>th</sup> percentile) 50.0
Range of scores	0-100	(50 <sup>th</sup> percentile) 66.7
Number	1231	(75 <sup>th</sup> percentile) 83.3
<b>Infertility</b>		
Mean	63.4	(% scoring min) 11.9
Median	68.8	(% scoring max) 24.5
SD	34.1	(25 <sup>th</sup> percentile) 37.5
Range of scores	0-100	(50 <sup>th</sup> percentile) 68.8
Number	793	(75 <sup>th</sup> percentile) 93.8

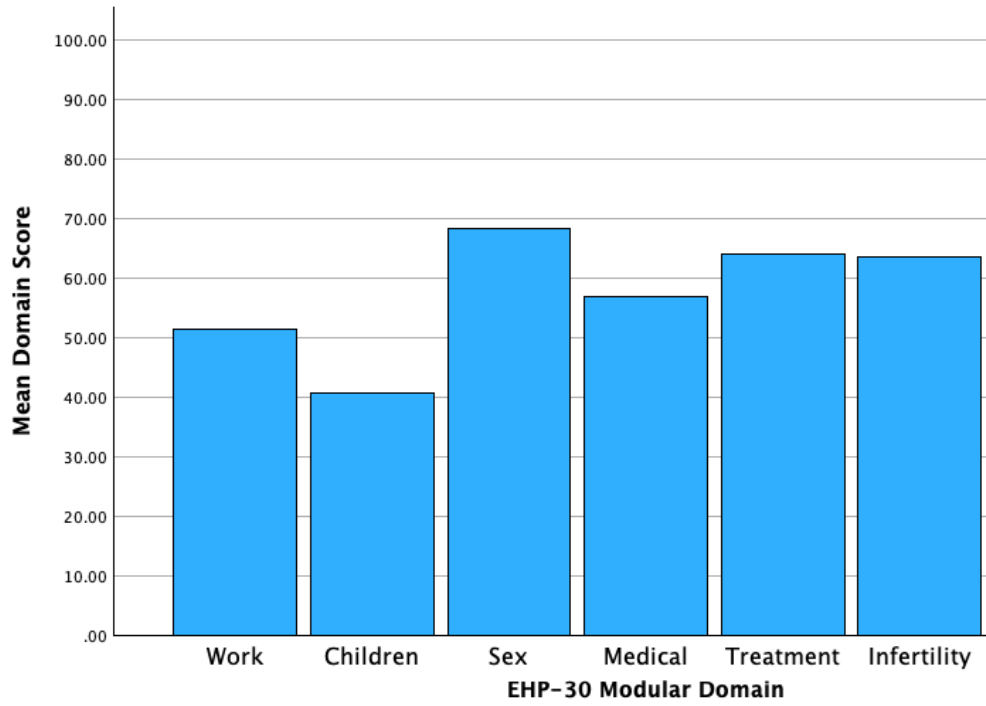
Note: EHP-30 scores range from 0 (best possible health status) to 100 (worst possible health status).

\*Domain scores were only calculated for respondents who answered all 5 items on the EHP-30 sexual relationships module

#### **Headlines:**

- *For the modular component, 'sexual intercourse/functioning' was the worst HRQoL domain, followed by treatment. This information is presented graphically in figure 2.*

**Figure 2: Mean EHP-30 modular domain scores (total sample 2023-2024)**



**Table 5: Percentage of respondents scoring at each response category for the EHP-30 modular items (total sample 2023-2024)**

Item N	N completed	Never	Rarely	Sometimes	Often	Always
W1	1342	33.7	16.8	30.0	14.4	5.2
W2	1339	19.6	18.5	36.8	19.5	5.6
W3	1337	13.6	11.1	28.6	30.2	16.4
W4	1336	20.3	6.9	14.1	22.1	36.6
W5	1340	12.1	9.8	27.9	24.0	26.2
C1	514	26.7	13.0	38.7	18.9	2.7
C2	513	26.1	12.9	34.5	22.2	4.3
S1	1152	6.9	5.7	21.6	30.2	35.6
S2	1284	6.8	6.6	20.3	24.1	42.1
S3	1290	8.4	8.8	26.3	30.9	25.6
S4	1282	8.8	5.7	17.4	24.9	43.2
S5	1283	8.0	7.0	20.7	27.0	37.3
MP1	1327	11.8	10.2	26.7	33.6	17.7
MP2	1329	20.0	14.8	28.3	23.9	12.9
MP3	1332	10.5	8.1	20.5	26.4	34.5
MP4	1335	21.9	11.2	22.1	23.2	21.5
T1	1254	5.8	7.5	26.7	34.2	25.8
T2	1239	9.3	9.2	28.2	32.0	21.3
T3	1244	10.8	10.4	23.6	25.7	29.5
F1	843	14.4	4.0	14.7	18.6	48.3
F2	822	16.4	5.5	15.8	18.5	43.8
F3	844	15.5	6.8	19.7	18.6	39.5
F4	816	26.6	11.2	21.4	12.4	28.4

\*Abbreviations: Work (W); Children (C); Sexual Intercourse (S); Relationship with the Medical Professional (MP); Treatment (T); Fertility (F)

#### Example headlines:

- 68.1% indicated that they 'always' or 'often' felt guilty about not wanting to have intercourse (S4)
- 65.8% reported 'always' or 'often' experiencing pain during or after sex (S1)
- 56.5% 'always' or 'often' avoided intercourse because of the pain (S3)
- 66.9% of respondents indicated that they 'always' or 'often' felt worried about the possibility of not having children/more children. (F1)
- 60.9% of participants responded 'always' or 'often' to 'felt frustrated at the doctors(s) lack of knowledge about endometriosis'. (MP3)
- 60% of participants responded 'always' or 'often' to 'felt frustrated because the treatment is not working' (T1)
- 58.7% indicated that they 'always' or 'often' felt guilty about taking time off work (W4)

**Table 6: EHP-30 core domain scores for participants with surgically diagnosed endometriosis (2023-2024).**

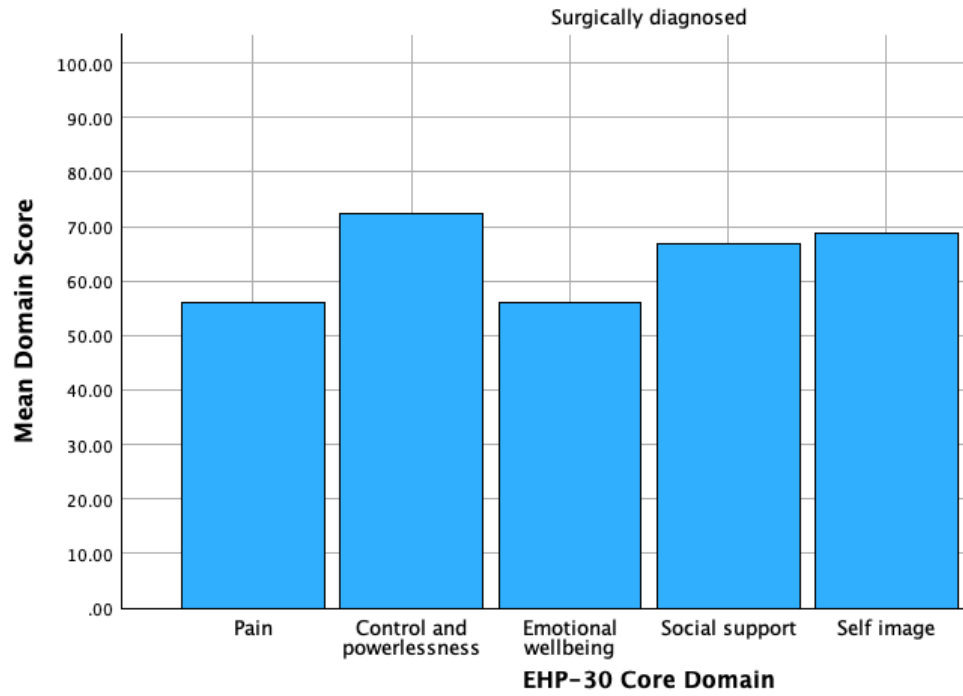
<b>Scale</b>		
<b>Pain</b>		
Mean	55.9	(% scoring min) 3.7
Median	59.1	(% scoring max) 1.1
SD	22.2	(25 <sup>th</sup> percentile) 45.5
Range of scores	0-100	(50 <sup>th</sup> percentile) 59.1
Number	1016	(75 <sup>th</sup> percentile) 70.5
<b>Control and powerlessness</b>		
Mean	72.3	(% scoring min) 2.9
Median	79.2	(% scoring max) 11.1
SD	24.7	(25 <sup>th</sup> percentile) 58.3
Range of scores	0-100	(50 <sup>th</sup> percentile) 79.2
Number	1014	(75 <sup>th</sup> percentile) 91.7
<b>Emotional well-being</b>		
Mean	56.0	(% scoring min) 2.4
Median	58.3	(% scoring max) 1.1
SD	20.9	(25 <sup>th</sup> percentile) 41.7
Range of scores	0-100	(50 <sup>th</sup> percentile) 58.3
Number	1012	(75 <sup>th</sup> percentile) 70.8
<b>Social support</b>		
Mean	66.9	(% scoring min)
Median	68.8	(% scoring max)
SD	23.4	(25 <sup>th</sup> percentile) 56.3
Range of scores	0-100	(50 <sup>th</sup> percentile) 68.8
Number	1014	(75 <sup>th</sup> percentile) 81.3
<b>Self-image</b>		
Mean	69.0	(% scoring min) 2.9
Median	75.0	(% scoring max) 16.4
SD	25.5	(25 <sup>th</sup> percentile) 50.0
Range of scores	0-100	(50 <sup>th</sup> percentile) 75.0
Number	1015	(75 <sup>th</sup> percentile) 91.7

Note: EHP-30 scores range from 0 (best possible health status) to 100 (worst possible health status).

#### Headlines:

- ‘Control and powerlessness’ continues to be the worst HRQoL domain when analysing the surgically confirmed group only. This data is presented graphically in figure 3.

**Figure 3: Mean EHP-30 core domain scores for patients with surgically diagnosed endometriosis (2023-2024).**



**Table 7: Percentage of respondents scoring at each response category for the EHP-30 core items (surgically confirmed sample 2023-2024)**

<b>Item N</b>	<b>N completed</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
<b>P1</b>	1023	13.4	11.1	37.5	31.2	6.7
<b>P2</b>	1023	8.3	7.9	36.7	41.0	6.2
<b>P3</b>	1023	9.6	13.0	36.5	33.9	7.0
<b>P4</b>	1023	10.9	17.9	36.9	28.3	6.0
<b>P5</b>	1023	10.3	13.1	38.5	31.0	7.1
<b>P6</b>	1023	6.2	6.7	25.9	41.5	19.6
<b>P7</b>	1023	15.3	18.6	32.3	27.1	6.7
<b>P8</b>	1020	7.5	10.1	31.2	38.4	12.7
<b>P9</b>	1021	9.2	7.5	31.9	40.5	10.8
<b>P10</b>	1020	7.5	5.7	33.5	41.9	11.5
<b>P11</b>	1018	10.7	10.8	33.7	34.6	10.2
<b>C&amp;P12</b>	1020	4.3	5.2	22.5	43.4	24.6
<b>C&amp;P13</b>	1021	5.3	5.3	13.8	33.8	41.8
<b>C&amp;P14</b>	1020	5.1	3.6	14.5	33.4	43.3
<b>C&amp;P15</b>	1020	6.2	5.3	15.2	35.1	38.2
<b>C&amp;P16</b>	1017	6.8	6.5	19.0	30.0	37.8
<b>EW17</b>	1020	8.2	9.7	19.8	28.3	33.9
<b>EW18</b>	1019	7.7	11.6	31.7	34.9	14.1
<b>EW19</b>	1016	4.8	9.4	31.5	41.1	13.1
<b>EW20</b>	1017	5.3	8.8	29.8	41.7	14.4
<b>EW21</b>	1016	3.9	8.6	25.7	42.4	19.4
<b>EW22</b>	1017	4.9	12.2	32.3	37.4	13.3
<b>EW23</b>	1015	40.0	30.7	19.2	8.1	2.0
<b>SS24</b>	1017	9.4	10.0	33.3	33.2	14.0
<b>SS25</b>	1016	3.6	3.9	18.8	38.3	35.3
<b>SS26</b>	1017	5.8	5.8	20.3	34.6	33.5
<b>SS27</b>	1015	7.9	8.0	26.0	36.7	21.4
<b>SI28</b>	1015	7.9	7.8	20.9	35.7	27.8
<b>SI29</b>	1016	5.6	6.8	21.4	30.7	35.5
<b>SI30</b>	1017	4.1	7.7	25.1	33.2	29.9

\*Abbreviations: Pain (P); Control and Powerlessness (C&P); Emotional Well-being (EW); Social Support (SS); Self-image (SI)

**Table 8: EHP-30 modular domain scores for participants with surgically diagnosed endometriosis (2023-2024).**

<b>Scale</b>		
<b>Work</b>		
Mean	50.9	(% scoring min) 7.0
Median	55.0	(% scoring max) 2.1
SD	26.6	(25 <sup>th</sup> percentile) 30.0
Range of scores	0-100	(50 <sup>th</sup> percentile) 55.0
Number	858	(75 <sup>th</sup> percentile) 70.0
<b>Children</b>		
Mean	40.0	(% scoring min) 24.6
Median	50.0	(% scoring max) 2.1
SD	28.2	(25 <sup>th</sup> percentile) 12.5
Range of scores	0-100	(50 <sup>th</sup> percentile) 50.0
Number	341	(75 <sup>th</sup> percentile) 62.5
<b>Sex*</b>		
Mean	68.8	(% scoring min) 3.5
Median	75.0	(% scoring max) 13.6
SD	26.9	(25 <sup>th</sup> percentile) 55.0
Range of scores	0-100	(50 <sup>th</sup> percentile) 75.0
Number	751	(75 <sup>th</sup> percentile) 90.0
<b>Medical</b>		
Mean	57.0	(% scoring min) 6.1
Median	62.5	(% scoring max) 6.4
SD	27.6	(25 <sup>th</sup> percentile) 37.5
Range of scores	0-100	(50 <sup>th</sup> percentile) 62.5
Number	838	(75 <sup>th</sup> percentile) 75.0
<b>Treatment</b>		
Mean	64.9	(% scoring min) 2.1
Median	66.7	(% scoring max) 11.6
SD	24.4	(25 <sup>th</sup> percentile) 50.0
Range of scores	0-100	(50 <sup>th</sup> percentile) 66.7
Number	821	(75 <sup>th</sup> percentile) 83.3
<b>Infertility</b>		
Mean	63.9	(% scoring min) 11.0
Median	75.0	(% scoring max) 24.5
SD	33.9	(25 <sup>th</sup> percentile) 37.5
Range of scores	0-100	(50 <sup>th</sup> percentile) 75.0
Number	510	(75 <sup>th</sup> percentile) 93.8

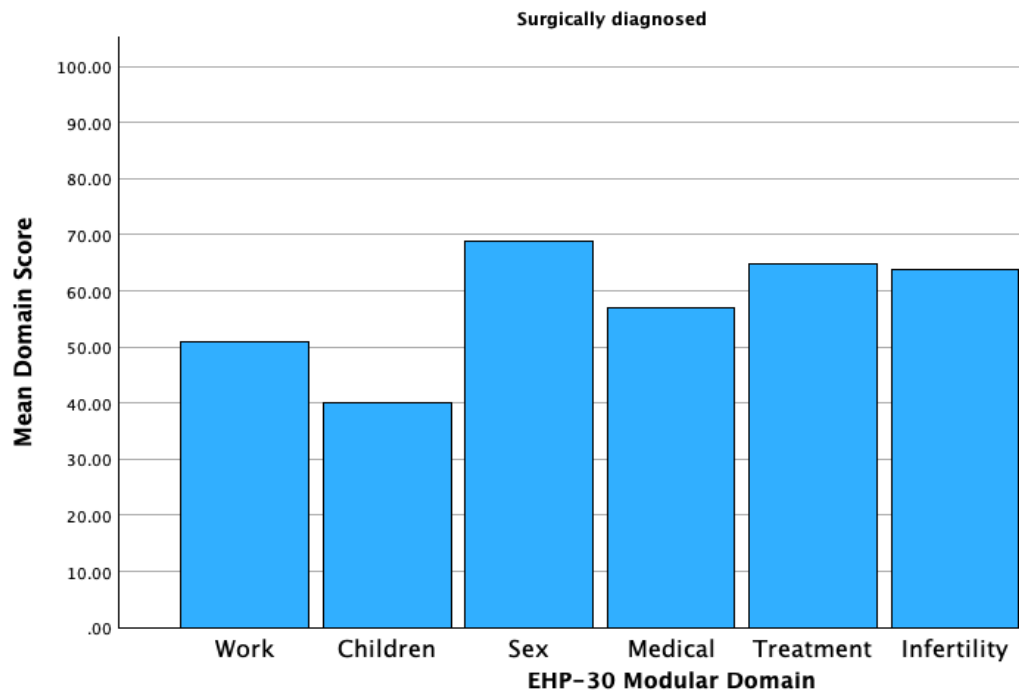
Note: EHP-30 scores range from 0 (best possible health status) to 100 (worst possible health status).

\*Domain scores were only calculated for respondents who answered all 5 items on the EHP-30 sexual relationships module.

**Headlines:**

- *Again, for the surgically confirmed group, 'sexual intercourse/functioning' was the worst HRQoL domain, followed by treatment. This information is presented graphically in figure 4.*

**Figure 4: Mean EHP-30 modular domain scores for patients with surgically diagnosed endometriosis (2023-2024).**





**Table 9: Percentage of respondents scoring at each response category for the EHP-30 modular items (surgically confirmed sample 2023-2024)**

<b>Item N</b>	<b>N completed</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
<b>W1</b>	864	34.6	17.0	30.8	12.5	5.1
<b>W2</b>	862	19.4	18.6	38.1	18.4	5.6
<b>W3</b>	862	14.2	10.7	28.8	30.5	15.8
<b>W4</b>	860	19.7	7.0	14.3	23.0	36.1
<b>W5</b>	862	12.6	8.6	29.1	24.5	25.2
<b>C1</b>	345	27.2	13.3	39.4	17.7	2.3
<b>C2</b>	344	25.9	13.1	35.5	21.5	4.1
<b>S1</b>	768	6.1	4.9	20.4	31.5	37.0
<b>S2</b>	843	6.8	6.6	19.5	24.7	42.5
<b>S3</b>	851	8.9	7.9	25.7	32.1	25.4
<b>S4</b>	853	8.3	5.7	18.2	24.2	43.6
<b>S5</b>	855	8.2	6.7	20.6	27.3	37.3
<b>MP1</b>	840	12.5	10.2	26.1	33.6	17.6
<b>MP2</b>	842	19.4	14.3	28.7	25.1	12.6
<b>MP3</b>	843	10.1	7.1	21.1	26.3	35.3
<b>MP4</b>	846	22.0	11.2	21.4	24.5	20.9
<b>T1</b>	836	5.4	6.9	26.9	33.3	27.5
<b>T2</b>	825	8.8	8.2	29.2	32.8	20.8
<b>T3</b>	831	9.7	8.8	24.4	25.9	31.2
<b>F1</b>	539	13.9	3.3	16.7	18.4	47.7
<b>F2</b>	526	16.0	5.5	14.6	19.4	44.5
<b>F3</b>	542	15.5	6.5	20.1	18.6	39.3
<b>F4</b>	529	25.9	11.0	20.4	14.2	28.5

*\*Abbreviations: Work (W); Children (C); Sexual Intercourse (S); Relationship with the Medical Professional (MP); Treatment (T); Fertility (F)*

**Table 10: Comparison of surgically confirmed EHP-30 core domain scores in 2000 versus 2024**

	<b>2023-2024</b>	<b>1999-2000</b>
<b>Pain</b>		
Mean	55.9	53.0
Median	59.1	54.6
SD	22.2	21.51
Range of scores	0-100	0-100
Number	1016	311
<b>Control and powerlessness</b>		
Mean	72.3	72.7
Median	79.2	75.0
SD	24.7	21.0
Range of scores	0-100	8-100
Number	1014	322
<b>Emotional well-being</b>		
Mean	56.0	55.2
Median	58.3	54.2
SD	20.9	20.3
Range of scores	0-100	0-100
Number	1012	318
<b>Social support</b>		
Mean	66.9	61.4
Median	68.8	62.5
SD	23.4	24.4
Range of scores	0-100	0-100
Number	1014	323
<b>Self-image</b>		
Mean	69.0	57.2
Median	75.0	58.3
SD	25.5	26.7
Range of scores	0-100	0-100
Number	1015	321

Note: EHP-30 scores range from 0 (best possible health status) to 100 (worst possible health status).

**Headlines:**

- ‘Control and powerlessness’ continues to be ‘worst’ domain, and there has been no improvement since 2000.
- Self-image is notably worse in 2024 than 2000.
- All other EHP-30 domain scores are similar, although slightly worse (may not be significantly so) than in the previous 1999-2000 survey.

**Table 11: Comparison of surgically confirmed EHP-30 modular domain scores in 2000 versus 2024**

<b>Work</b>	<b>2023-2024</b>	<b>1999-2000</b>
Mean	50.9	47.0
Median	55.0	50.0
SD	26.6	27.4
Range of scores	0-100	0-100
Number	858	264
<b>Children</b>		
Mean	40.0	47.5
Median	50.0	50.0
SD	28.2	24.5
Range of scores	0-100	0-100
Number	341	86
<b>Sex</b>		
Mean	68.8	61.3
Median	75.0	65.0
SD	27.0	29.3
Range of scores	0-100	0-100
Number	751	259
<b>Medical</b>		
Mean	57.0	41.5
Median	62.5	37.5
SD	27.6	27.6
Range of scores	0-100	0-100
Number	838	239
<b>Treatment</b>		
Mean	64.9	64.0
Median	66.7	66.7
SD	24.4	24.2
Range of scores	0-100	0-100
Number	821	247
<b>Infertility</b>		
Mean	63.9	67.1
Median	75.0	75.0
SD	34.0	27.8
Range of scores	0-100	0-100
Number	510	150

Note: EHP-30 scores range from 0 (best possible health status) to 100 (worst possible health status).

### Headlines:

- Most notable is that the 'relationship with medical profession' domain appears worse now, than in the previous 1999-2000 survey.
- However, 'relationship with children' and 'infertility' appear to better than the 1999-2000 survey.

## Education

The work module was modified to create a new ‘education’ domain to measure the impact of endometriosis upon schooling and education.

**Table 12: Total Sample**

Education		
Mean	54.8	(% scoring min) 17.7
Median	65.0	(% scoring max) 6.9
SD	33.2	(25 <sup>th</sup> percentile) 26.3
Range of scores	0-100	(50 <sup>th</sup> percentile) 65.0
Number	260	(75 <sup>th</sup> percentile) 80.0

*Note: EHP-30 scores range from 0 (best possible health status) to 100 (worst possible health status)*

**Table 13: Surgically Confirmed Sample**

Education		
Mean	51.8	(% scoring min) 19.0
Median	60.0	(% scoring max) 5.2
SD	33.0	(25 <sup>th</sup> percentile) 20.0
Range of scores	0-100	(50 <sup>th</sup> percentile) 60.0
Number	153	(75 <sup>th</sup> percentile) 77.5

*Note: EHP-30 scores range from 0 (best possible health status) to 100 (worst possible health status).*

**Table 14: Percentage of respondents scoring at each response category for the ‘education’ domain (total sample 2023-2024)**

Item N	N completed	Never	Rarely	Sometimes	Often	Always
E1	276	24.6	9.1	23.6	31.5	11.2
E2	272	22.4	6.6	27.9	31.3	11.8
E3	265	28.3	4.5	15.8	30.2	21.2
E4	263	24.0	3.0	15.6	27.4	30.0
E5	261	20.7	5.7	15.7	25.7	32.2

*\*Abbreviations: Education (E)*

## Headlines

- 42.7% reported that they ‘always’ or ‘often’ take time off school, college, or university because of the pain (E1)
- 57.4% reported that they always or often felt guilty for taking time off work (E4)
- 57.9% reported that they always or often felt worried about not being able to go to school, college or university (E5).

**Other Statistical Results**

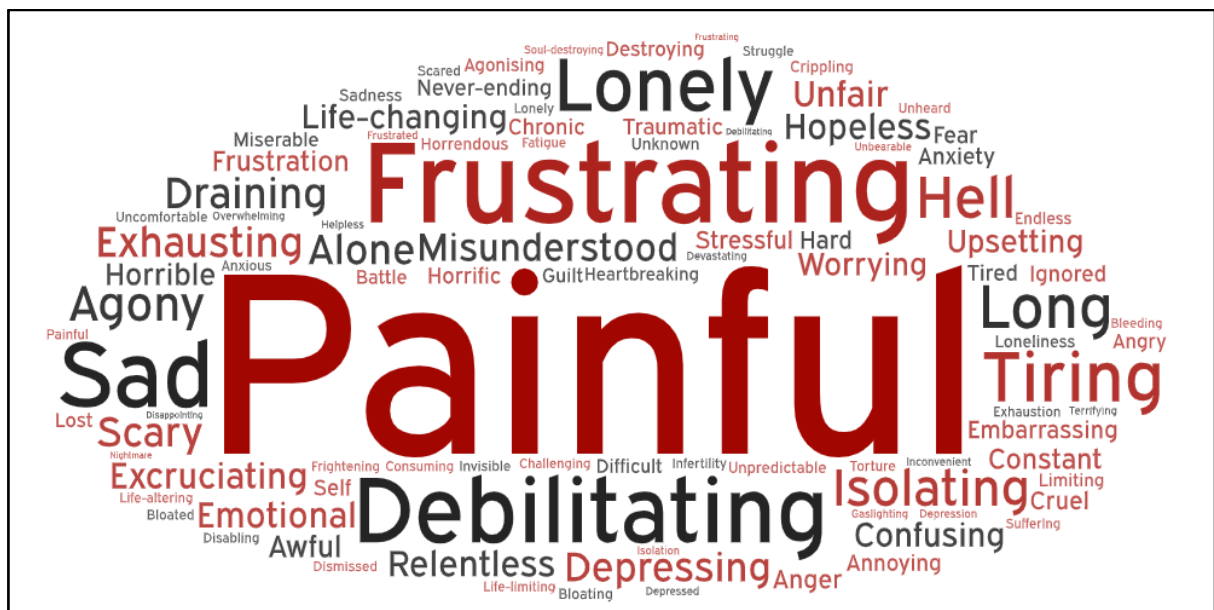
- Age: ANOVA suggests that younger participants have a worse HRQoL than older participants
- No differences in HRQoL scores were found by region (England, NI, Wales, Scotland)
- An analysis by ethnicity was not undertaken due to small sample sizes in non-white groups.
- An analysis by gender was not undertaken due to small sample sizes in non-female groups.
- Differences were observed according to employment group. Participants in the unemployed category scored significantly higher on the EHP-30 core scale (indicating worse health-related quality of life) than those in the ‘full time’, ‘full time education’, ‘part time’ and ‘other’ groups.
- Participants in ‘full time education’ scored significantly higher on the EHP-30 core scale (indicating worse health-related quality of life) than those in ‘full time employment’.

**Qualitative Results:**

**Question 6: What five words would you use to describe your experience of endometriosis?**

1157 participant completed this question. Most of the participants used 5 individual words to describe their experiences of endometriosis. Some participants used phrases such as “should be picked up earlier”. For the purposes of this analysis, the content of these phrases, some of which far exceeded 5 words, may not be represented in the results which are based on frequencies of explicit descriptors. Although no data was excluded during analyses, the implicit meanings of these extended phrases may not have been picked up. Such phrases have been flagged and will be explored and interpreted further during the next phases of qualitative analyses.

Commonly used words are represented in the word cloud below. The word cloud represents a crude analysis of the used words in the dataset.





Shown below are the results of a content analysis, during which words were grouped into 8 categories; (1) pain; (2) other physical impact; (3) Emotional/psychological impact; (4) Exhaustion/tiredness; (5) Impact on life; (6) Isolation/Loneliness; (7) Chronic nature of endometriosis; (8) Fertility. Categories were defined inductively based on common themes occurring within the data. Within categories, words have sometimes been grouped based on their root form e.g. depressed, depressing, depression, and depressive. Some synonyms have been grouped together to make the data concise and manageable, and as a means of ensuring that infrequently used words do not get 'lost' amongst their more frequently used synonyms. The categories represent broad themes within the data but do not contain every word used. Words (or concepts in cases of grouped synonyms) appearing less than 15 times in the data have not been included below. The words used were largely negative, highlighting the challenges associated with endometriosis. However, some participants did use positive descriptors, which have been included at the end of this section despite being infrequent.

### Categories and frequencies

#### Pain

Pain/Painful	651
Excruciating	86
Agony	38

#### Other physical impact

Debilitating	228
Crippling	22
Bloating/bloated/IBS/bowels	25
Uncomfortable/discomfort	22
Disabling/disability	16
Nausea/nauseous/nauseating/sickness	20
Heavy bleeding/blood/period	16

**Emotional/psychological experiences**

Frustrating/frustration	296
Depressed/depressing/depression/depressive	143
Sad/sadness	80
Scary/scared/fear/fearful/terrifying	79
Horrible/horrific/horrendous	70
Difficult/hard/challenging	59
Confusing/confused/confusion	54
Hopeless/hopelessness	51
Worried/worry/worrying	46
Emotional	46
Embarrassing/embarrassed/embarrassment/humiliating	46
Struggle/battle/fight	38
Upsetting/upset	37
Heartbreaking	37
Trauma/traumatising/traumatised	35
Anger/angry/infuriating	41
Anxiousness/anxious/anxiety	34
Hell	32
Unfair	30
Crying/tearful/tears/sad/sadness	27
Stressful	27
Agonising	27
Miserable/misery	26
Awful	25
Annoying/tiresome/irritating	35
Soul-destroying/crushing	21
Devastating	16
Helpless/powerless	15

**Exhaustion/tiredness**

Exhausting/exhaustion/exhausted	199
Tiring/tired/tiredness	109
Draining/drained	64
Fatigue/lethargic	17

**Impact on life**

Life-altering/changing/ruining/shattering	110
Unknown/uncertain/unpredictable	53
Life-limiting/limiting/restrictive	53
Consuming/all-encompassing/overwhelming	39
Uncontrollable/uncontrolled/controlling	15
Disruptive/inconvenient	18



**Lack of support/care/loneliness**

Lonely/loneliness	234
Isolating/isolated/isolation	135
Misunderstood	64
Ignored/unheard	38
Alone/alienated	28
Gaslighting/gaslit	26
Lost/Forgotten	16
Unsupported/no support	15
Lack of knowledge/awareness/education/under-funded	18
Dismissed/unimportant	18

**Chronic/never-ending**

Relentless/unrelenting	61
Never-ending/endless	55
Long/prolonged	46
Hopeless	45
Battle/fight	32
Constant	30
Chronic	24
Lifelong/life-sentence/long-term	15
Eternal/forever	8

**Fertility**

Infertility/infertile/worried about fertility	20
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**Some participants did respond with positive words. These words were not used frequently but do show some positive experiences.**

Community
Hope
Strong
Resilient/resilience
Brave
Positive
Prayerful
Acceptance
Learning
Liberating
Treatable
Lesson
Clarity
Strong
Relief
Lucky

## The EHP-30 CORE questionnaire:

P1	Been unable to go to social events because of the pain?
P2	Been unable to do jobs around the home because of the pain?
P3	Found it difficult to stand because of the pain?
P4	Found it difficult to sit because of the pain?
P5	Found it difficult to walk because of the pain?
P6	Found it difficult to exercise or do the leisure activities you would like to do because of the pain?
P7	Lost your appetite and/or been unable to eat because of the pain?
P8	Been unable to sleep properly because of the pain?
P9	Had to go to bed/lie down because of the pain?
P10	Been unable to do the things you want to do because of the pain?
P11	Felt unable to cope with the pain?
C&P12	Generally felt unwell?
C&P13	Felt frustrated because your symptoms are not getting better?
C&P14	Felt frustrated because you are not able to control your symptoms?
C&P15	Felt unable to forget your symptoms?
C&P16	Felt as though your symptoms are ruling your life?
C&P17	Felt your symptoms are taking away your life?
EW18	Felt depressed?
EW19	Felt weepy/tearful?
EW20	Felt miserable?
EW21	Had mood swings?
EW22	Felt bad tempered or short tempered?
EW23	Felt violent or aggressive?
SS24	Felt unable to tell people how you feel?
SS25	Felt others do not understand what you are going through?
SS26	Felt as though others think you are moaning?
SS27	Felt alone?
SI28	Felt frustrated as you cannot always wear the clothes you would choose?
SI29	Felt your appearance has been affected?
SI30	Lacked confidence?

## The EHP-30 Modular questions:

Work	
W1	Had to take time off work because of the pain?
W2	Been unable to carry out duties at work because of the pain?
W3	Felt embarrassed about symptoms at work?
W4	Felt guilty about taking time off work?
W5	Felt worried about not being able to do your job?
Children	
C1	Found it difficult to look after your child/children?
C2	Been unable to play with your child/children?
Sexual intercourse	
SI1	Experienced pain during or after intercourse?
SI2	Felt worried about having intercourse because of the pain?
SI3	Avoided intercourse because of the pain?

SI4	Felt guilty about not wanting to have intercourse?
SI5	Felt frustrated because you cannot enjoy intercourse?
Medical profession	
MP1	Felt the doctor(s) you have seen is (are) not doing anything for you
MP2	Felt the doctor(s) think it is all in your mind?
MP3	Felt frustrated at the doctor(s) lack of knowledge about endometriosis?
MP4	Felt like you are wasting doctor(s) time?
Treatment	
T1	Felt frustrated because treatment is not working?
T2	Found it difficult coping with the side effects of treatment?
T3	Felt annoyed at the amount of treatment you have had to have?
Fertility	
F1	Felt worries about the possibility of not having children/more children?
F2	Felt inadequate because you may not/have not been able to have children/more children?
F3	Felt depressed at the possibility of not having children/more children?
F4	Felt that the possibility of not conceiving/ not being able to conceive has put a strain on your personal relationship?

## Education questions:

Education	
E1	Had to take time off school/ college/ university because of the pain?
E2	Been unable to carry out activities at school/ college/ university because of the pain?
E3	Felt embarrassed about your symptoms at school/ college/ university?
E4	Felt guilty about taking time off school/ college / university?
E5	Felt worried about not being able to go to school/ college/ university?

## Open-ended survey questions:

Is there anything else you would like to tell us about the impact of endometriosis on your quality of life?
Have you tried to self-manage your symptoms of endometriosis? If yes, please use the box below to explain what you have tried.
What has been your experience of support with your endometriosis symptoms, from those around you?
Are there any additional healthcare services you feel would be useful to support you with your symptoms of endometriosis?
Have you received any psychological support with your endometriosis? For example, counselling or talking therapies (Yes/No) If yes, please use this space to tell us about your experience of this support?
What five words would you use to describe your experience of endometriosis?