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1 **Title**

2 Endometriosis and negative perception of the medical profession

3

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47 Abstract

48 Objective

49 To identify factors independently associated with a negative impression of the medical
50 profession in patients with endometriosis presenting to a tertiary referral centre.

51 Methods

52 A cross-sectional analysis was conducted on a prospective data registry between December 2013
53 to June 2017 at a tertiary referral centre for pelvic pain and endometriosis. The main outcome
54 variable, negative impression about the medical profession, was measured with the 4-item
55 subscale of the Endometriosis Health Profile-30 and divided into 3 groups: no (0), some (1-8),
56 and many (9-16) negative impressions. Patients with a surgical/histological diagnosis of
57 endometriosis were included. Postmenopausal women were excluded. Bivariate analyses
58 determined significant associations ($p < 0.05$) between variables from the registry and the main
59 outcome. Variables with significant association were put into ordinal logistic regression with
60 sequential backwards elimination.

61 Results

62 Negative impression of the medical profession was independently associated with a previous
63 surgery that did not help symptoms (aOR 1.77, 95% CI 1.09-2.87, $p = 0.021$), presentation to an
64 emergency room in the past 3 months (aOR 1.90, 95% CI 1.17-3.07, $p = 0.009$), and previous
65 visits to a complementary healthcare provider (aOR 2.16, 95% CI 1.42-3.29, $p < 0.0005$),
66 controlling for an endometriosis pain-related morbidity composite variable.

67 Conclusion

68 Negative perception of the medical profession in women with endometriosis was associated with
69 surgical treatment failure, emergency room utilization, and accessing complementary healthcare.

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70 Each identified factor offers an opportunity for intervention to improve endometriosis patients’
71 perception of the medical profession.

72 **Key words:** endometriosis, chronic_pelvic_pain, physician-patient_relationship,
73 emergency_medicine, complementary_medicine, laparoscopic_surgery

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93 Introduction

94 Endometriosis is a gynecological disorder that affects approximately 10% of reproductive-aged
95 females.[1] Endometriosis is characterized by the ectopic implantation of uterine endometrial
96 tissue and can lead to a myriad of symptoms including pelvic pain, infertility, pelvic masses,
97 and/or abnormal uterine bleeding. Living with the symptoms of endometriosis has been found to
98 negatively impact aspects of a patient’s life including their ability to work, maintain
99 relationships, and carry out day-to-day activities.[2]

100
101 There are multiple reasons why women with endometriosis may be dissatisfied with the medical
102 profession. Placebo controlled trials have shown that surgical treatment of endometriosis lesions
103 is associated with a reduction in pain on average, but some patients are surgical non-
104 responders.[3] Similarly, hormonally suppressive therapies are effective for some patients, but a
105 significant minority are either non-responders or cannot tolerate side-effects.[4] Non-responders
106 may resort to alternative/complementary care providers, or else end up going to the emergency
107 room (ER) when experiencing pain flares. Another factor is that the average delay in diagnosis of
108 endometriosis can range from 7-10 years from the onset of symptoms.[5,6] Previous qualitative
109 studies suggest that possible reasons may include delay in patient presentation to
110 physicians,[5,7,8] use of non-discriminating investigations,[7] difficulty accessing health
111 services such as for those residing outside metropolitan areas,[8] and/or dismissal of symptoms
112 by physicians.[5,7,8]

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114 The objective of this study was to identify factors that may be independently associated with a
115 negative view of the medical profession in women with endometriosis, measured using the

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116 Endometriosis Health Profile-30 (EHP-30). The EHP-30 is a validated quality of life
117 questionnaire developed to evaluate different areas of concern for women with endometriosis,
118 which has a subscale for negative impressions of the medical profession.[9,10]

119

Materials and Methods

Study Population

The study population consisted of patients enrolled in the prospective Endometriosis Pelvic Pain
Interdisciplinary Cohort (EPPIC) Data Registry (Clinicaltrials.gov, NCT02911090) based at a
tertiary referral centre for pelvic pain and endometriosis in British Columbia, Canada. The
EPPIC database contains baseline and prospective variables which include demographics,
physical exam findings, surgical findings, validated questionnaire scores, and pain severity
scores. Registry data collection methods and other information captured by the database have
been previously reported.[11]

129

Inclusion criteria were new or re-referral to the centre with prospective surgical excision of
endometriosis and histopathological confirmation in at least one excised specimen, from
December 1 2013 to June 30 2017. Excluded were patients who were spontaneously or
surgically postmenopausal, did not undergo a physical exam, or indicated that the primary
outcome (EHP-30 Section D, see below) was not applicable or did not complete the questions.

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Measures and analyses

A cross-sectional analysis of baseline data was conducted to investigate factors associated with
negative impressions of the medical profession. The main outcome measure was the baseline

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139 Section D of the EHP-30, a 4-item subscale which measures patient-reported negative feelings
140 towards the medical profession: feeling that doctors are not doing anything, feeling that doctors
141 think it's all in the mind, frustration regarding doctors' knowledge, and feeling that one is
142 wasting doctors' time. Each item is scored from 0 (never) to 4 (always) for a total sum of 16.[10]
143 The main outcome measure was divided into 3 groups: no (0), some (1-8), and many (9-16)
144 negative impressions.

145
146 The following variables from the registry were examined for an association with the main
147 outcome measure and have been previously described in a study of the contributors to the
148 severity of chronic pelvic pain in women[11]: 1) Demographic characteristics (Table 1) included
149 age, BMI, partner status, duration of symptoms (years) as a proxy for delay in diagnosis, and
150 staging of endometriosis at the time of surgery at the centre (Stage I/II vs. Stage III/IV); 2)
151 Patient-reported ineffectiveness or discontinuation due to side-effects of oral contraceptives; 3)
152 Patient-reported ineffectiveness of surgical treatment in the past; 4) Patient-reported
153 ineffectiveness or discontinuation due to side-effects of opioid therapy; 5) Seen a physician for
154 pelvic pain in last 3 months; 6) Seen in emergency room for pelvic pain in last 3 months; and 7)
155 Seen a complementary (alternative) care provider for pelvic pain including homeopaths,
156 naturopaths, massage therapists, physical therapists/physiotherapists, acupuncturists,
157 chiropractors, hypnotists, and biofeedback therapists. All these variables were from baseline,
158 except for Stage which was from the prospective surgery done at the centre.

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160 We developed an endometriosis composite variable to account for pain-related morbidity. The
161 composite variable was binary (yes/no) and participants were positive if they met at least four of

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4 162 the following eight criteria: irritable bowel syndrome (IBS) (using ROME III Criteria[12]);
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6 163 painful bladder syndrome (PBS) (using International Continence Society[13] or American
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9 164 Urological Association criteria[14]); pelvic pain scores $\geq 7/10$ for dysmenorrhea, deep
10
11 165 dyspareunia, or chronic pelvic pain (0=no pain, 10=worst pain imaginable)[15]; score of 10 or
12
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14 166 more on the Patient Health Quality-9 for moderate depression[16]; a score of 10 or more on the
15
16 167 Generalized Anxiety Disorder 7-item scale for moderate anxiety[17]; or a score of 30 or more
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19 168 (above the 75th percentile) on the 13-item Pain Catastrophizing Scale.[18] The reason for the
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21 169 composite variable was due to collinearity between these factors, while trying to control for pain-
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24 170 related morbidity when assessing the association between the variables above (e.g. demographic)
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26 171 and the main outcome measure.

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31 173 Bivariate analyses determined significant associations with the main outcome measure.
32
33 174 Spearman's rank correlation was used for continuous variables while the Mann-Whitney U test
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35
36 175 was used for categorical variables. Variables with significant association ($p < 0.05$) were put into
37
38 176 ordinal logistic regression with sequential backwards elimination based on $p < 0.05$. All analyses
39
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41 177 were done using IBM SPSS Statistics 25.

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44 45 179 **Results**

46
47
48 180 Three hundred eighty-four participants were included in the study sample (Figure 1).
49
50 181 Demographics of the study sample are shown in Table 1. We compared the study sample with
51
52
53 182 those who were excluded because they did not complete the main outcome measure (EHP-30
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55 183 Section D); there were no significant differences between the two groups, except the non-
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58 184 responders were less likely to identify as heterosexual (Table 2).

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In the study sample (n = 384), there were 75 individuals who had a EHP-30 Module D score of 0 (no negative impressions of the medical profession), 182 individuals who had a EHP-30 Module D score of 1-8 (some negative impressions), and 127 individuals who had a EHP-30 Module D score of 9-16 (many negative impressions).

190

Bivariate associations for the study sample are shown in Table 3. Factors associated with a negative perception of the medical profession were Stage I/II endometriosis, oral contraceptive ineffectiveness or discontinuation due to side-effects, previous ineffective surgery, opioid ineffectiveness or discontinuation due to side-effects, ER visit in the last 3 months for pelvic pain, and seen a complementary healthcare provider for pelvic pain. As expected, negative perception of the medical profession was also associated with the morbidity composite variable.

197

These variables were entered into an ordinal logistic regression model, and the following variables were found to be independently associated with negative perception of the medical profession, controlling for the morbidity composite variable (Table 4): previous ineffective surgery (aOR 1.77, 95% CI 1.09-2.87, p=0.021), ER visit in in the past 3 months for pelvic pain (OR 1.90, 95% CI 1.17-3.07, p=0.009), and seen a complementary healthcare provider for pelvic pain (aOR 2.16, 95% CI 1.42-3.29, p<0.0005).

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Discussion

In this cross-sectional analysis of a prospective registry of patients with surgically/histologically confirmed endometriosis, we found that a negative impression of the medical profession was

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208 independently associated with patient-reported ineffectiveness of previous surgery, having seen a
209 complementary healthcare provider for pelvic pain, and presentation to an ER in the past three
210 months for pelvic pain, controlling for a morbidity composite variable (involving pain severity,
211 psychological symptoms, and non-gynecologic pain diagnoses).

212
213 While randomized trials of conservative surgery for treatment of endometriosis have shown a
214 benefit for pain, an average of 20% of patients do not respond for reasons that may include
215 comorbid central nervous system sensitization, myofascial pain, or persistent dysmenorrhea.[3]

216 The association between patient satisfaction and surgical outcome is consistent across other
217 surgical disciplines such as general surgery[19] and orthopaedic surgery[20]. To address this
218 problem, the gynaecologic surgeon should ensure the patient is aware of the possibility of
219 surgical treatment failure due to multifactorial pain mechanisms and ensure patients'
220 expectations are congruent with the limitations of surgery in chronic pelvic pain.[20,21] [22]

221
222 The relationship between negative impressions of doctors and a history of seeing a
223 complementary healthcare provider may reflect either a subpopulation who prefer
224 complementary healthcare to Western medicine or those who feel they have exhausted
225 conventional Western treatment options.[23] Endometriosis patients have reported using
226 complementary/alternative medicine as a means to regain control over their own health after
227 being unheard and dismissed by the medical system.[23] A review of complementary and
228 alternative medicine in pain management suggested that certain treatments, such as acupuncture,
229 may have utility in chronic pain – even leading to a decrease in opioid dosages for patients.[24]

230 Thus, we suggest that physicians ask patients about their use of complementary/alternative

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231 treatments, explore the reasons why patients sought these treatments, and seek to find a balance
232 between respecting patient choice while promoting evidenced based care.

233
234 Presentation to ER for pelvic pain in the past three months was significantly associated with
235 negative perception of the medical profession, whereas seeing a physician in general about the
236 pain in the last three months was not. This difference may relate to the need for acute pain
237 management in the ER, versus chronic pain management in the primary care setting. A multisite
238 study of patients presenting with pain to ER found that an empathic staff response increased
239 patient satisfaction with care.[25] However, many patients only received analgesics after lengthy
240 delays, or not at all, and there was often a gap between patient and staff expectations of analgesic
241 treatment.[25] It may therefore be important for ER staff to establish protocols for patients
242 presenting with acute pain flares of chronic pain.[26,27] Alternatively, this finding may also
243 reflect inadequate primary care for endometriosis, leading patients to become reliant on the ER
244 for pain management.[5,7]

245
246 Strengths of this study include the analysis of a large prospective registry and the inclusion of
247 patients with the gold-standard diagnosis of endometriosis (surgical/histological). Limitations
248 may include recall bias for certain self-reported measures, inability to define temporal
249 relationships between variables due to the nature of the study design, and selection bias as the
250 study population consisted only of women that required presentation to a tertiary referral centre
251 to manage their disease.

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253 The findings of this study point to several new lines of research. Issues that warrant further
254 investigation include ER physicians’ knowledge of endometriosis, the nature of the interactions
255 between ER staff and patients with a known history of endometriosis, and management of acute-
256 on-chronic pain flares for endometriosis patients in the ER setting. Also of interest is research
257 into optimizing shared decision-making in the informed consent process for endometriosis
258 surgery, particularly in patients where chronic pain is the major symptom.

260 **Conclusion**

261 It has been reported that patients with positive, trusting relationships with their physicians are
262 more likely to adhere to treatment regimens, present earlier with additional concerns before
263 severe disease progression, and be more forthcoming with concerns to their physicians.[28-29]
264 Endometriosis is a complex chronic condition that may require lifelong patient-physician
265 relationships.[4] Thus, the factors identified in this study may be important indicators/predictors
266 of negative impressions of the medical profession that should be addressed as part of patient-
267 centred care for those with endometriosis over the lifespan.

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276 Author Contributions

277 PY and NN were involved with the conception and design of the study. PY, CA, CW, MB, and
278 HN acquired the data. PY, NN, KW, and NO were involved with the analysis of data. All
279 authors contributed to interpretation of data. PY and NN drafted the article, and CA, CW, MB,
280 HN, KW, and NO revised and approved the article.

281

282 Competing Interests

283 CA and MB have financial affiliations with Abbvie and Allergan, unrelated to the subject matter
284 of this study.

285

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389 **Tables**

390 **Table 1.** Demographics of the study sample (N = 384)

Variable	Mean ± SD / Percent (frequency)
Age (years)	34.0 ± 6.9
BMI (kg/m ²)	25.3 ± 5.7
Caucasian	70.1% (269)
Duration of symptoms (years)	14.6 ± 9.1
Endometriosis Stage	
I/II	62.6% (234)
III/IV	37.4% (140)
Smoker	13.5% (52)
Heterosexual	94.8% (364)
Nulliparous	64.3% (247)
Partnered	78.1% (300)
Education	
<High school	2.3% (9)
Completed high school or GED	10.4% (40)
Some college	22.4% (86)
Graduated 2 year college	14.1% (54)
Graduated 4 year college	27.3% (105)
Post-grad degree	20.1% (77)
Other	3.4% (13)

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Annual Household Income	
<\$20000	11.5% (44)
\$20000-\$39999	15.9% (61)
\$40000-\$59999	14.6% (56)
\$60000-\$79999	19.3% (74)
\$80000-\$99999	15.4% (59)
>\$100000	23.4% (90)

N = 374 for endometriosis stage and N = 375 for BMI

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406 **Table 2.** Comparison of demographics between the study sample and non-responders excluded
 407 because the main outcome measure (EHP-30 module D) was not completed.

Variable	Study Sample	Number (N)	No EHP-30 Module D n = 115	Number (N)	p-value
Age (years)	34.0 ± 6.9	384	35.4 ± 7.7	112	0.059
BMI (kg/m ²)	25.3 ± 5.7	375	25.1 ± 5.2	114	0.90
Caucasian	70.1% (269)	384	67.8% (78)	115	0.65
Duration of symptoms (years)	14.6 ± 9.1	384	15.7 ± 9.2	112	0.29
Endometriosis Stage					
I/II	62.6% (234)	374	60.4% (67)	111	0.67
III/IV	37.4% (140)		39.6% (44)		
Smoker	13.5% (52)	384	14.9% (15)	110	0.98
Heterosexual	94.8% (364)	384	86.1% (99)	115	0.002
Nulliparous	64.3% (247)	384	69.1% (76)	110	0.35
Partnered	78.1% (300)	384	88.5% (84)	115	0.26
Education					
<High school	2.3% (9)	384	6.4% (7)	110	0.12
Completed high school or GED	10.4% (40)		8.2% (9)		
Some college	22.4% (86)		31.8% (35)		
Graduated 2 year	14.1% (54)		10.0% (11)		

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College					
Graduated 4 year college	27.3% (105)		22.7% (25)		
Post-grad degree	20.1% (77)		18.2% (20)		
Other	3.4% (13)		2.7% (3)		
Annual Household Income					
<\$20000	11.5% (44)	384	10.0% (11)	110	0.91
\$20000-\$39999	15.9% (61)		21.8% (24)		
\$40000-\$59999	14.6% (56)		10.9% (12)		
\$60000-\$79999	19.3% (74)		17.3% (19)		
\$80000-\$99999	15.4% (59)		12.7% (14)		
>\$100000	23.4% (90)		27.3% (30)		

Variables reported as mean ± SD or percent (frequency).

417 **Table 3.** Continuous and binary/categorical factors associated with increased negative perception
 418 of medical profession (EHP-30 Module D).

Variable		Spearman rho for correlation with EHP-30 Module D Score			p-value	Number (N)
Age (years)		-0.07			0.16	384
BMI (kg/m ²)		0.04			0.44	375
Duration of symptoms (years)		0.06			0.23	384
		EHP Module D Score (0) N = 75	EHP Module D Score (1-8) N = 182	EHP Module D Score (9-16) N = 127	p-value	
Partnered	No N=84	11.9% (10)	54.8% (46)	33.3% (28)	0.30	384
	Yes N=300	21.7% (65)	45.3% (136)	33.0% (99)		
Stage of Endometriosis	I/II N=234	16.2% (38)	46.6% (109)	37.1% (87)	0.012	374
	III/IV N=140	25.7% (36)	47.1% (66)	27.1% (38)		
Previous ineffective oral contraceptive use	No N=138	22.5% (31)	55.1% (76)	22.5% (31)	0.004	384
	Yes	30.1% (44)	43.1% (106)	39.0% (96)		

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and/or discontinuation due to side effects	N=246					
Previous ineffective surgery	No N=297	20.9% (62)	48.8% (145)	30.3% (90)	0.027	381
	Yes N=84	14.3% (12)	42.9% (36)	42.9% (36)		
Previous ineffective opioid use and/or discontinuation due to side effects	No N=282	21.3% (60)	50.0% (141)	28.7% (81)	0.004	379
	Yes N=97	14.4% (14)	40.2% (39)	45.4% (44)		
Seen a physician in the past 3 months for pelvic pain	No N=81	25.9% (21)	42.0% (34)	32.1% (26)	0.26	341
	Yes N=260	15.4% (40)	51.9% (135)	32.7% (85)		
Presented in the emergency room (ER) in the last 3 months for pelvic pain	No N=287	22.0% (63)	49.1% (141)	28.9% (83)	0.001	373
	Yes N=86	10.5% (9)	44.2% (38)	45.3% (39)		
Seen a complementary	No N=133	30.1% (40)	46.6% (62)	23.3% (31)	<0.0005	384

healthcare provider for pelvic pain	Yes N=251	13.9% (35)	47.8% (120)	38.2% (96)		
Morbidity composite variable ≥ 4/8	No N=187	28.3% (53)	50.8% (95)	20.9% (39)	<0.0005	384
	Yes N=197	11.1% (22)	44.2% (87)	44.7% (88)		

Binary/categorical factors reported as percent (frequency).

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436 **Table 4.** Ordinal logistic regression model following backwards elimination

	Adjusted Odds Ratios (95% confidence interval)	p-value
Previous ineffective surgery	1.77 (1.09-2.87)	0.021
Presentation to ER in the past 3 months	1.90 (1.17-3.07)	0.009
Seen a complementary healthcare provider	2.16 (1.42-3.29)	<0.0005
Morbidity composite variable \geq 4/8	2.42 (1.60-3.66)	<0.0005

437 N = 357 due to missing values in the independent variables

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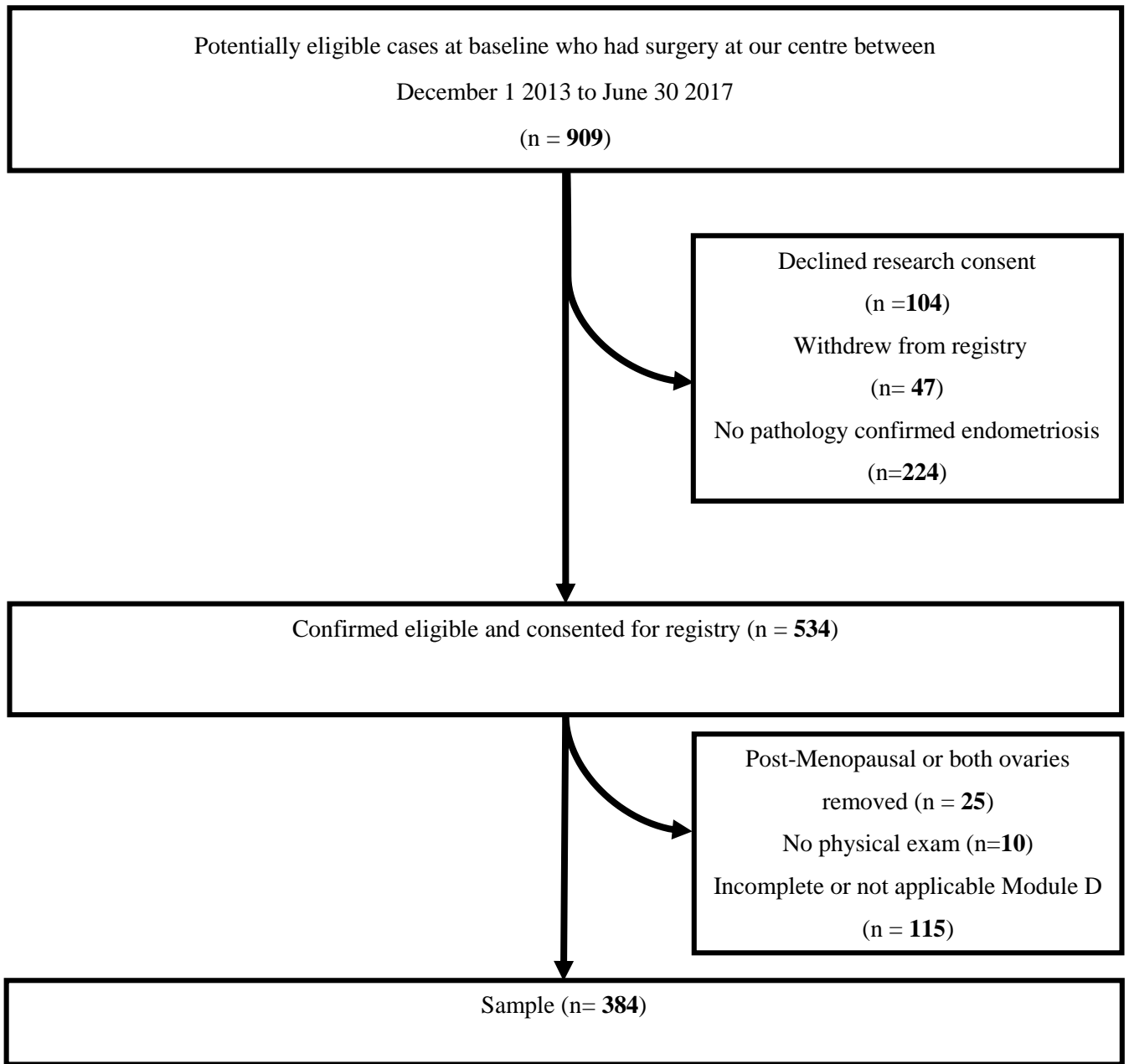


Figure 1. Flow chart of inclusion and exclusion criteria.