“IMPROVING THE DIAGNOSIS AND TREATMENT OF ENDOMETRIOSIS” RESEARCH GROUP

# BASELINE PATIENT QUESTIONNAIRE

(BASED OFF THE NECST DATA DICTIONARY)

This questionnaire is to be read with reference to the accompanying “road map” which demonstrates which subset of questions in this document will be asked of participants each particular study. Some participants may take part in multiple studies but overlapping questions will only be asked once.

- Aim 1 = Predicting absence of endometriosis
- Aim 2 = Predicting recurrence of endometriosis
- Aim 3 = Epithelial somatic mutations in endometriosis recurrence
- Aim 4 = Endometriosis lesion biomarkers
- Aim 5 = PEA/PLD treatment for endometriosis
- Aim 6 = Cellular mechanisms of PEA/PLD
- Aim 7 = Pelvic floor muscle tenderness and endometriosis surgery
- Aim 8 = Endometrioma and AMH study
- Aim 9 = Endometriosis Longitudinal Fertility Study

## 1. Demographics and consent

**Date questionnaire completed**

Coding: DDMMYYYY

**Study ID Number**

**PATIENT DETAILS**

**Given name**

Definition: Patient’s first name. Person and provider identification in healthcare NBPDS. (METeOR ID: 529511)

Coding: Free text field.

**Last name**

Definition: Patient’s surname or family name. (METeOR ID: 529511)

Coding: Free text field.

**Date of birth**

Definition: Date of birth of the patient. (METeOR ID: 529511)

Coding: DDMMYYYY

**Gender**

Definition: The gender/sex of the patient. (METeOR ID 635994; ABS 2016. Standard for Sex and Gender Variables, 1200.055.012)

Coding: (1 is not being used as 1 = Male in accordance to the above metadata guidance)

2: Female

3: Other (please specify) (Free text to be enabled)

4: Indeterminate/intersex/unspecified

**What was your sex assigned at birth?**

Coding: (Drop down list)

1: Male

2: Female

3: Other (please specify) (Free text to be enabled)

4: Indeterminate/intersex/unspecified

**What is your gender identity?**

Coding: (Drop down list)

1: Male

2: Female

3: Other (please specify) (Free text to be enabled)

4: Indeterminate/intersex/unspecified

**Address**

Definition: The referential description of a location where an entity is located or can be otherwise reached or found. (METeOR ID 529511, 327278, 594217)

Coding: Free text fields for the following attributes used in the formation of a full address.

- Address line (unit number/building number/house number, road name, road type, suburb/town/locality, postcode or postal delivery point identifier, State/Territory)

**State**

Definition: The Australian state or Territory where a person can be located, as represented by a code. (METeOR ID 529511, 327278, 594217, 286620)

Coding: (Drop down list)

1: NSW

2: VIC

3: QLD

4: SA

5: WA

6: TAS

7: NT

8: ACT

9: Other (please specify) (free text field enabled; e.g. other territories (Cocos (Keeling) Islands, Christmas Island and Jervis Bay Territory))

**Postcode**

Definition: The numeric descriptor for a postal delivery area, aligned with locality, suburb or place for the address of a person. (METeOR ID 529511, 327278, 594217, 286620)

Coding: A NNNN(4) representing the suburb area. To have "0000" allowed for the localities that do not have a postcode (e.g. some rural localities).

**Contact number**

Definition: The information of patient to enable contact via their telephone or mobile number. (METeOR ID 529511, 611164)

Coding: A 10 digit, free number/text field for entering phone number.

**Email**

Definition: The information of patient to enable contact via electronic mail. (METeOR ID 529511, 611164)

Coding: Free number/text field for entering email address.

**Preferred contact method**

Definition: The means by which the patient prefers to be contacted by. (Modelled against METeOR ID 323145)

Coding: (Drop down list)

1: Email

2: Phone

3: Post

88: Other (please specify) (free text field enabled)

**Medicare number (with reference number)**

Definition: Person identifier, allocated by the Health Insurance Commission to eligible persons under the Medicare scheme that appears on a Medicare card. (METeOR ID 270101)

Coding:

Medicare no: A N(10) number representing the Medicare number.

Reference no: A N(1) number representing their position with the Medicare number.

Expiry date: MMYYYY

**Secondary contact**

**Given name**

Definition: Secondary contact's first name. (METeOR ID: 529511)

Coding: Free text field.

**Last name**

Definition: Secondary contact's surname or family name. (METeOR ID: 529511)

Coding: Free text field.

**Contact number**

Definition: The information of secondary contact to enable contact via their telephone or mobile number. (METeOR ID 529511, 611164)

Coding: A 10 digit, free number/text field for entering phone number.

**Email**

Definition: The information of secondary contact to enable contact via electronic mail. (METeOR ID 529511, 611164)

Coding: Free number/text field for entering email address.

**Relationship to patient**

Definition: Interpersonal relation of secondary contact to patient. (Modelled against METeOR ID 680219)

Coding: (Drop down list)

1: Spouse/partner
2: Mother
3: Father
4: Daughter
5: Son
6: Sister
7: Brother
8: Other female relative
9: Other male relative
10: Friend/neighbor
88: Other (please specify) (free text field enabled)

**ETHNICITY AND LANGUAGE**

**Country of birth?**

Definition: The country in which the patient was born. (METeOR ID: 659454; ABS 2016b, Standard Australian Classification of Countries (SACC), 1269.0)

Coding: NNNN(4) (Drop down list, with 'Other' to enable free text field)

1101: Australia
2102: England
1201: New Zealand
7103: India
3104: Italy
5105: Vietnam
5204: Philippines
9225: South Africa
2105: Scotland
5203: Malaysia
8102: Canada
6101: China (excludes SARs and Taiwan)
2304: Germany
3207: Greece
6102: Hong Kong (SAR of China)
2201: Ireland
8104: United States of America

4205: Israel

9: Other (please specify) (Free text field to enter alternative not included in the list above)

**What is your ethnicity? With which ethnic group(s) do you identify your ancestry and culture?**
**Please tick all that apply**

Coding: N (tick box)

1: Oceanian

2: Aboriginal and Torres Strait Islander

3: North-west European

4: Southern and eastern european

5: North African and middle eastern

6: South-east Asian

7: North-east Asian

8: Southern and Central Asian

9: People's of the Americas

10: Sub-saharan African

11: Prefer not to answer

12: Other specify (Free text field enabled when this option is selected to allow for reason to be entered)

**How well do you speak English?**

Definition: Proficiency in spoken English. This metadata item is only intended to be collected if a person has a main language other than English spoken at home; and/or first language spoken is not English. (METeOR ID 270203)

Coding: N (Tick box)

0: Not applicable (persons under 5 year of age and people who speak only English)

1: Very well

2: Well

3: Not well

4: Not at all

9: Not stated/inadequately described (not for use, for administrative purposes when this data item has not been collected)

**Which language did you first speak as a child?**

Definition: Which languages other than English are spoken by people at home. (METeOR ID 460120 and 460125; ABS 2016, Australian Standard Classification of Languages (ASCL), 1267.0)

Coding: NNNN(4)

1201: English

7104: Mandarin

2401: Italian

4202: Arabic
7101: Cantonese
2201: Greek
6302: Vietnamese
2303: Spanish
5203: Hindi
6511: Tagalog
99: Other (please specify) (Free text field)

**Do you speak a language other than English at home?** (To bring this question up when a language selection is made)

Definition: The language reported by a person as the main language other than English spoken by that person in his/her home (or most recent private residential setting occupied by the person) to communicate with other residents of the home or setting and regular visitors. (METeOR ID 460120 and 460125; ABS 2016, Australian Standard Classification of Languages (ASCL), 1267.0)

Coding: NNNN(4)

1201: No, English only
7104: Yes, Mandarin
2401: Yes, Italian
4202: Yes, Arabic
7101: Yes, Cantonese
2201: Yes, Greek
6302: Yes, Vietnamese
2303: Yes, Spanish
5203: Yes, Hindi
6511: Yes, Tagalog
88: Other (please specify) (Free text field)

**Indigenous status**

Definition: Whether a person identifies as being of Aboriginal or Torres Strait Islander origin. (METeOR ID 602543; ABS National Health Survey 2014-2015, item 4363.0, released 2018)

Coding: Drop down list

0: Not applicable
1: Aboriginal but not Torres Strait Islander origin
2: Torres Strait Islander but not Aboriginal origin
3: Both Aboriginal and Torres Strait Islander origin
4: Neither Aboriginal nor Torres Strait Islander origin
99: Not stated/Inadequately described (not for use, for administrative purposes only when this data item has not been collected in other datasets)

**EDUCATION, EMPLOYMENT AND OCCUPATION STATUS**

**Highest education level completed**

Definition: The highest level of education achieved by a person in relation to completed education. (METeOR ID 321069)

Coding: (Drop down list)

99: Not stated/inadequately described (not for use, for administrative purposes only when this data item has not been collected in other datasets)

88: No education

1: Postgraduate degree

2: Graduate diploma and graduate certificate

3: Bachelor degree

4: Advanced diploma and diploma

5: Certificate (includes Certificate I-IV, Statement of Attainment, Bridging and Enabling Course I-IV)

6: Senior secondary education

7: Junior secondary education

8: Primary education

9: Pre-primary education

10: Other education (please specify) (Free text field)

**Are you currently studying?**

Coding: (Drop down list)

1: Yes

2: No

**Current employment status**

Definition: The person's position in relation to their employment, whether a person in paid employment is employed full-time or part-time, the nature of a person's employment in relation to her expected continuity of employment and eligibility for basic leave entitlements. (METeOR ID 269951, 269950, 314867)

Coding: (Drop down list)

99: Not stated/inadequately described (not for use, for administrative purposes only when this data item has not been collected in other datasets)

88: Other (please specify) (free text field for entering reason, to be situated after "***Employment type***")

***Status in employment***

1: Employee

2: Employer

3: Own account worker (a person who operates his or her own unincorporated economic enterprise or engages independently in a profession or trade, and hires no employees.)

4: Contributing family worker (a person who works without pay in an economic enterprise operated by a relative.)

XX: Unemployed

***Full-time/part-time status***

1: Full-time (35 or more hours per week)

2: Part-time (less than 35 hours per week)

***Employment type***

1: Permanent

2: Fixed term contract

3: Casual

**Occupation**

Definition: The person's primary job in which they are principally engaged. (METeOR ID 350899 and ABS ANZSCO Cat. No. 1220.0)

Coding: N (Drop down list)

1: Managers (e.g. chief executives, general managers, legislators, farmers and farm managers, specialist managers, hospitality, retail and service)

2: Professionals (e.g. engineering, transport, scientist, doctor, registered nurse, allied health professional, education, artists and media, human resources, legal, social and welfare)

3: Technicians and trade workers (e.g. automatic and engineering, construction, food trades, electrotechnology and telecommunications, skilled animal and horticultural)

4: Community and personal service workers (e.g. health and welfare support, carers and aides, hospitality, protective services, sports and personal service)

5: Clerical and administrative workers (e.g. office managers and program administrators, personal assistants and secretaries, general clerical, inquiry clerks and receptionists, numerical clerks, clerical and office support)

6: Sales worker (e.g. sales representatives and agents, sales assistants and salespersons, sales support workers)

7: Machinery operators and drivers (e.g. machine and stationary plant operators, mobile plant operators, road and rail drivers, storepersons)

8: Labourers (e.g. cleaners and laundry, construction and mining, factory process, farm, forestry and garden, food preparation assistants, other)

88: Other (please specify) (Free text field enabled when this option is selected to allow for reason to be entered)

**MARITAL STATUS AND GENERAL HEALTH**

**Current registered marital status**

Definition: The civil status of each individual in relation to the marriage laws or customs of the country. (METeOR ID 291045; ABS National Health Survey 2014-2015, item 4363.0, released 2018)

Coding: (Drop down list)

1: Never married

2: Widowed

3: Divorced

4: Separated

5: Married (registered and de facto)

6: Other (please specify) (Free text field enabled when this option is selected to allow for reason to be entered)

What is your current relationship status?

Coding: (Drop down list)

1: Single

2: Relationship <6 months

3: Relationship >6 months (ie de facto or married)

(If 1, skip next question to Height)

**What type of relationship (if any) are you currently part of?**

Coding: (Drop down list)

1: Single

2: Heterosexual

3: Same sex

4: Other (please explain) (Free text field enabled when this option is selected to allow for reason to be entered)

(If 1, skip next question to Height)

**What was your current partner's sex assigned at birth?**

Coding: (Drop down list)

1: Male

2: Female

3: Other – please specify (Free text field enabled when this option is selected to allow for reason to be entered)

4: Indeterminate/intersex/unspecified

**What is your current partner's gender identity?**

Coding: (Drop down list)

1: Male

2: Female

3: Other – please specify (Free text field enabled when this option is selected to allow for reason to be entered)

4: Indeterminate/intersex/unspecified

**Height**

Definition: A person's self-reported height, measured in centimetres (measurement from head to toe). (METeOR ID 270365)

Coding: A 3 digit number [NNN] representing height in centimeters.

888: Unknown

999: Not stated/inadequately described

**Weight**

Definition: A person's self-reported weight (body mass). (METeOR ID: 302365)

Coding: A 3 digit number [NNN] representing weight in kilograms.

888: Unknown

999: Not stated/inadequately described

**BMI**

Definition: A measure of an adult's weight (body mass) relative to height used to assess the extent of weight deficit or excess where at least one of the measures is self reported. (METeOR ID 270086)

Coding: (Auto-calculate from height and weight), Ratio number, NN[N].N[N], equation = weight (kgs)/ height^2(meters)

888.8: Unknown

999.9: Not stated/inadequately described

**At age 21, what would you say your natural skin colour was?**

Coding: (Drop down list)

1: Dark

2: Olive

3: Medium

4: Fair/pale

5: No answer

**At age 21, what would you say your natural eye colour was?**

Coding: (Drop down list)

1: Blue/grey

2: Hazel/green

3: Brown

4: No answer

**At age 21, what would you say your natural hair colour was?**

Coding: (Drop down list)

1: Fair/blonde

2: Light brown

3: Light red/ginger

4: Dark red/auburn

5: Dark brown

6: Black

7: No answer

**Tobacco smoking status**

Definition: The patient's current and past smoking behavior. (METeOR ID 270311)

Coding: (Drop down list)

99: Unknown

0: Never smoked

1: Daily smoker

2: Weekly smoker

3: Irregular smoker

4: Ex-smoker

(If 99 or 0, skip to question “Alcohol Use”. If 4, skip to “Time since quitting”)

**How many cigarettes per day do you currently smoke?**

Coding: (Drop down list)

1: 1-5

2: 6-10

3: 11-15

4: 16-20

5: More than 20

**How many years have you smoked for in total?**

Coding: (Drop down list)

1: 1-5

2: 6-10

3: 11-15

4: 16-20

5: More than 20

**What is the average number of cigarettes you would have smoked per day over this time?**

Coding: (Drop down list)

1: 1-5

2: 6-10

3: 11-15

4: 16-20

5: More than 20

**Time since stopping smoking**

**How many years or months has it been since you stopped smoking? [text response so can take range]**

Coding: Free text field.

**Alcohol use**

Definition: The patient’s current and past alcohol use behavior. (no specific METeOR item, based on METeOR ID 691052, female alcohol consumption frequency in the first 20 wks of pregnancy)

Coding: (Drop down list)

0: Never consumed alcohol

1: Monthly or less
2 2 – 4 times a month
3 2 – 3 times a week
4 4 or more times a week
(If 0, skip to question “Do you smoke cannabis?”)

**Alcohol consumption**

**How many standard drinks do you have per week?**

A standard drink is 10gm = 12.5 ml of pure alcohol – some examples of this would be:
White wine (11.5%) – ½ glass (300 ml glass) = 1.4 standard drinks
Red wine (13%) – ½ glass (300 ml glass) = 1.5 standard drinks
Full strength beer – 1 glass (middy – 285 ml) = 1.1 standard drinks
Full strength beer – 1 glass (schooner – 425 ml) = 1.6 standard drinks
High strength spirits - Nip (30 ml in shot glass) = 1 standard drink
Premixed spirits – 1 can (375 ml can) = 1.5 standard drinks
Coding: (Drop down list)
1: 1-5
2: 6-10
3: 11-15
4: 16-20
5: More than 20

**Cannabis use**

**Do you smoke cannabis?**

Coding: (Drop down list)
1: Yes
2: No
3: Prefer not to answer

**Recreational drug use**

**Do you use recreational drugs?**

Coding: (Drop down list)
1: Yes
2: No
3: Prefer not to answer

**Exercise**

**Do you do a minimum of 150 minutes per week of moderate intensity exercise (e.g. brisk walking, dancing) OR a minimum of 75 minutes per week of vigorous intensity exercise (e.g. running, fast cycling, aerobics)?**

Coding: (Drop down list)

1: Yes

2: No

**Do you do at least 2 sessions of muscle strengthening exercises per week (e.g. resistance exercises, weight training, push-ups)?**

Coding: (Drop down list)

1: Yes

2: No

## 2. Clinical presentation and medical history

**Date questionnaire was completed**

Definition: The date this questionnaire was completed by patient prior to medical consultation with clinician (usually gynaecologist).

Coding: DD/MM/YYYY

**Who referred you to this service?**

Definition: The source of referral to the gynaecological treatment service. (Modelled against METeOR ID 269946, 607130, 607133 and 424298)

Coding: (Only single selection allowed from drop down menu, if "Other" is selected then free text field to be enabled)

0104: General practitioner

0222: Gynaecologist (including gynaecological sonographer, fertility specialist)

1: Other medical specialist (e.g. bowel or bladder specialist, emergency care doctor, pelvic pain specialist, etc.)

  1a: Please specify (Free text enabled if this option is selected)

88: Other (please specify) (Free text field enabled) (e.g. nurse, physiotherapist, naturopath, yoga instructor or online patient forum)

**PRESENTING SYMPTOMS**

**Primary presenting symptom**

Definition: The main reason for patient presenting to the clinician for review and management of symptoms.

Coding: (ICD-10 diagnosis codes. Only single selection allowed from drop down menu, if "Other" is selected then free text field to be enabled)

N92.0: Heavy menstrual bleeding with regular cycle

N92.1: Heavy menstrual bleeding with irregular cycle

N92.2: Heavy menstrual bleeding at puberty

N92.3: Regular intermenstrual bleeding

N92.4: Heavy menstrual bleeding in the premenopausal period

N92.5: Other specified irregular menstruation

N92.6: Irregular menstruation

N93.9: Abnormal uterine and vaginal bleeding

N94.1: Pain with sexual intercourse (dyspareunia)

N94.4: Monthly pain/cramps with menstruation without underlying gynaecological reason/pathology (primary dysmenorrhoea)

N94.5: Monthly pain/cramps with menstruation from an underlying gynaecological reason/pathology (secondary dysmenorrhoea)

N94.6: Monthly pain/cramps with menstruation (dysmenorrhoea)

N97.9: Female infertility

R10.2: Pelvic pain

R19.8: Pain with bowel motions (dyschezia)

R30.0: Pain with urination (dysuria)

R53: Fatigue
R79.9: Abnormal finding of blood chemistry
R93.8: Abnormal findings on diagnostic imaging of other specified body structures (Drop down, select all that apply)

1: Left ovary
2: Right ovary
3: Both ovaries
4: Uterus/womb
5: Cervix
6: Large bowel
7: Rectum
8: Diaphragm
9: Other location (please specify) (free text field enabled)

88: Other symptom (please specify) (Free text field enabled to only one, with text/word limit)

**Secondary symptoms** (you can choose as many as appropriate)
Definition: Any additional reasons for the patient presenting to the clinician for review of their symptoms and for management of said symptoms.
Coding: (ICD-10 diagnosis codes. Multi-selection available from drop down menu)
N97.9: Female infertility
N92.0: Heavy menstrual bleeding with regular cycle
N92.1: Heavy menstrual bleeding with irregular cycle
N92.2: Heavy menstrual bleeding at puberty
N92.3: Regular intermenstrual bleeding (bleeding between periods)
N92.4: Heavy menstrual bleeding in the premenopausal period
N92.5: Other specified irregular menstruation
N92.6: Irregular menstruation/periods
N93.9: Abnormal uterine and vaginal bleeding (e.g. bleeding or spotting between periods or after sexual intercourse or after menopause)
N94.1: Pain with sexual intercourse (dyspareunia)
N94.4: Monthly pain/cramps with menstruation without underlying gynaecological reason/pathology (primary dysmenorrhoea)
N94.5: Monthly pain/cramps with menstruation from an underlying gynaecological reason/pathology (secondary dysmenorrhoea)
N94.6: Monthly pain/cramps with menstruation (dysmenorrhoea)
R10.2: Pelvic pain
R19.8: Pain with bowel motions (dyschezia)
R30.0: Pain with urination (dysuria)
R53: Fatigue
R79.9: Abnormal finding of blood chemistry
R93.8: Abnormal findings on diagnostic imaging of other specified body structures (Drop down, select all that apply)

1: Left ovary

2: Right ovary
3: Both ovaries
4: Uterus/womb
5: Cervix
6: Large bowel
7: Rectum
8: Diaphragm
9: Other location (please specify) (free text field enabled)

88: Other symptoms (please specify) (free text field enabled)

**MENSTRUAL SYMPTOMS**

**Age of first menstrual period**

Definition: How old were you when you first started to have your periods? The age, in total years, of a female at the time of her first menstrual period. (Modelled against METeOR ID: 399602)

Coding:

1: NN(2) (Ability to enter age, whole years only)
2: Periods have not started yet
88: Don't remember

(If 2, skip to "Are you taking hormone medication(s) to prevent your period")

**Have you had a period in the last three months?**

Coding: (Drop down list)

1: Yes
2: No
88: Don't know

**Last menstrual period**

Coding: (Drop down list)

1: Recent menstrual period
1a: First day of last menstrual period (LMP) (Free text field enabled when this option is selected)
2: I am currently pregnant.
2a: Estimated due date (Free text field enabled when this option is selected)
3: I do not have periods.

**Are you taking hormone medication(s) to prevent your period?**

Coding: (Drop down list)

1: Yes
2: No
88: Unsure

**How old were you when you started to experience substantial period pain?**

Coding:

1: Periods have not started yet

2: I do not have substantial pain with my periods
3: < 10 years
    3a: Please specify (NN(2), text enable, branching logic)
4: 10 – 14 years old
5: 15 – 19 years old
6: 20 – 24 years old
7: 25 – 29 years old
8: 30 – 34 years old
9: 35 – 39 years old
10: 40 – 44 years old
11: 45 – 49 years old
12: 50 – 54 years old
13: > 55 years
(Skip logic: if 1, skip to *The following questions ask about different types of pain at times other than with your periods.* Do you experience pain when you have sexual intercourse?")

**How long do your periods usually last for (in days)?**
Coding: NN(2) – NN(2) (shortest number of days – longest number of days in whole days)
Guide for use: e.g. 2 – 6 means you may bleed as few as 2 days or as many as 6 days in your period.

**What is the usual time between the first day of one period to the first day of the next period**
Coding: NN(2) – NN(2) (shortest number of days to the first day of your next period – longest number of days to the first day of your next period in whole days)
Guide for use: e.g. 24 – 36 means sometimes you may have 24 days between the first day of one period to the first day of your next period or sometimes you may have 36 days between the first day of one period to the first day of your next period.

**Do you experience any spotting outside of your periods?**
Coding: (modelled against METeOR ID: 638745)
1: Yes
2: No
88: Don't know

**Do you experience vaginal spotting before your period starts?**
Coding: (Drop down list)
1: Yes
2: No
88: Don't know

**When you are not using hormone medications, how regular are your periods?**
Coding: (Drop down list)
1: Extremely regular (period starts 1−2 days before or after it is expected)

2: Very regular (period starts 3−4 days before or after it is expected)

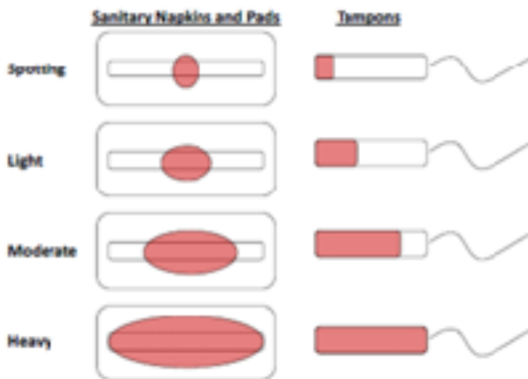
3: Regular (period starts 5−7 days before or after it is expected)

4: Somewhat irregular (period starts 8−20 days before or after it is expected)

5: Irregular (period starts more than 20 days before or after it is expected)

6: I don't know

**The figure below shows examples of the amount of bleeding you can experience every four hours during your period.**




Please describe the amount of bleeding you typically experience four-hourly during your period at its heaviest, and on average (when you are not using hormone medications).

**Heaviest**

Coding: (Drop down list)

1: Spotting

2: Light

3: Moderate

4: Heavy

**On average**

Coding: (Drop down list)

1: Spotting

2: Light

3: Moderate

4: Heavy

**PAIN HISTORY AND SYMPTOMS** (Matrix style, similar to EHP-30 PROMs questionnaire)

**Do you experience pain with your periods?**

Coding: (Matrix tick boxes and the VAS scale for all the questions below) (modelled against METeOR ID: 638745)

1: Yes (if this option is selected, show the additional questions below)

1a: On the scale of 0 to 10, please rate the level of pain you experience with your periods. Where 0 = no pain and 10 = worst imaginable pain. (To have VAS scale if “Yes” is selected for any question)

2: No

***The following questions ask about different types of pain felt during your periods (including irregular bleeding or bleeding while on hormonal treatments, but not spotting)***

**Do you experience pain when you have sexual intercourse during your period?**

Coding: (Matrix tick boxes and the VAS scale for all the questions below)

1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain)

1a: On the scale of 0 to 10 below, please rate the level of pain you experience having sexual intercourse

2: No

(If 2, skip to question “Do you experience pain when you open your bowels?”)

**Where is the pain during intercourse felt during your period?**

Coding: (Drop down list)

1: Entrance

2: Deep

3: Both

**Do you experience pain when you open your bowels (passing stool/bowel motions) during your period?**

Coding: (Drop down list)

1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain)

1a: On the scale of 0 to 10 below, please rate the level of pain you experience when you open your bowels

2: No

**Is your pain with passing a bowel motion worse (or only present) at the time of your period?**

Coding: (Drop down list)

1: Usually only present with periods

2: Worse with periods

3: No different with periods

**Do your bowel motions become soft/loose during your period?**

Coding: (Drop down list)

1: Yes

2: No

**Do you experience pain when your bladder is full during your period?**

Coding: (Drop down list)

1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain)

1a: On the scale of 0 to 10 below, please rate the level of pain you experience when your bladder is full)

2: No

**Do you experience pain when you urinate (passing urine/urination) during your period?**

Coding: (Drop down list)

1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain)

1a: On the scale of 0 to 10 below, please rate the level of pain you experience when you urinate)

2: No

**How many times do you need to go to the bathroom in a 24-hour period to pass urine during your periods?**

Coding: (Drop down list)

1: 3-6

2: 7-10

3: 11-14

4: 15-19

5: 20+

**Does the frequency you need to pass urine during your periods bother you?**

Coding: (Drop down list)

1: Never

2: Rarely

3: Sometimes

4: Often

5: Always

**Do you experience back pain during your period?**

Coding: (Drop down list)

1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain)

1a: On the scale of 0 to 10 below, please rate the level of back pain you experience)

2: No

**Do you experience any other type of pain symptoms not already mentioned during your period?**

Coding: (Drop down list)

1: Yes (Free text field enabled when this option is selected to allow for description) (if this option is selected, VAS scale to show and ask question for patient to rate her pain)

1a: On the scale of 0 to 10 below, please rate the level of other type of pain you experience

2: No

**Were your periods painful when they first started as a teenager?**

Coding: (Drop down menu)

1: Yes

2: No

**Has your period pain become worse over the last 6 months?**

Coding: (Drop down menu)

1: Yes

2: No

**Do you experience sharp pelvic pains during your period?**

Coding: (Drop down menu)

1: Yes

2: No

**Do you experience cramping pelvic pain during your period?**

Coding: (Drop down menu)

1: Yes

2: No

**Do you experience a dull constant pelvic ache during your period?**

Coding: (Drop down menu)

1: Yes

2: No

**Do you experience period pain which is worse on the left than the right?**

Coding: (Drop down menu)

1: Yes

2: No

**Do you experience period pain which is worse on the right than the left?**

Coding: (Drop down menu)

1: Yes

2: No

**Do you experience period pain which is worst in the middle low down?**

Coding: (Drop down menu)

1: Yes

2: No

**Do you get pain in your low back with your periods?**

Coding: (Drop down menu)

1: Yes

2: No

**Do you get pain in your thighs with your periods?**

Coding: (Drop down menu)

1: Yes

2: No

**Do you experience pelvic period-like-pain before your period begins?**

Coding: (Drop down menu)

1: Yes

2: No

**In the last 12 months, how often have you had pelvic pain during your period?**

Coding: (Drop down list)

0: Never

1: Occasionally (less than a quarter of my periods)

2: Often (a quarter to half of my periods)

3: Usually (more than half of my periods)

4: Always (every period)

**Please rate how severe your pelvic pain during your period was at its worst in the last 12 months using a scale from 0 to 10 where 0 = no pain and 10 = worst imaginable pain.**

Coding: VAS

No pain Worst pain imaginable

0 1 2 3 4 5 6 7 8 9 10

**Do you experience pain at times other than with your periods?**

Coding: (Matrix tick boxes and the VAS scale for all the questions below) (modelled against METeOR ID: 638745)

1: Yes (if this option is selected, show the additional questions below)

1a: On the scale of 0 to 10, please rate the level of pain you experience at other times than with your periods. Where 0 = no pain and 10 = worst imaginable pain. (To show VAS scale if "Yes" is selected for any question)

2: No

**At what age did this pain at times other than with your periods (non-menstrual pain) start?**

Coding: Drop down menu

1: < 10 years

1a: Please specify (NN(2), text enable, branching logic)

2: 10 – 14 years old

3: 15 – 19 years old

4: 20 – 24 years old

5: 25 – 29 years old
6: 30 – 34 years old
7: 35 – 39 years old
8: 40 – 44 years old
9: 45 – 49 years old
10: 50 – 54 years old
11: > 55 years

**How often do you experience pain at times other than with your periods (non-menstrual pain)?**

Coding: drop down

1: Every day
2: Multiple days per month
  2a: Please specify (NN(2), text enable, branching logic)
3: Multiple days per week
  3a: Please specify (NN(2), text enable, branching logic)

*The following questions ask about different types of pain at times other than with your periods*

**Do you experience pain when you have sexual intercourse at other times than with your periods?**

Coding: (Matrix tick boxes and the VAS scale for all the questions below)

1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain)
  1a: On the scale of 0 to 10 below, please rate the level of pain you experience having sexual intercourse
2: No

(If 2, skip to question "Do you experience pain when you open your bowels at other times than with your periods?")

**Where is the pain during intercourse felt at times other than with your periods?**

Coding: (Drop down list)

1: Entrance
2: Deep
3: Both

**Do you experience pain when you open your bowels (passing stool/bowel motions) at other times than with your periods?**

Coding: (Drop down list)

1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain)
  1a: On the scale of 0 to 10 below, please rate the level of pain you experience when you open your bowels)
2: No

**Do you experience pain when your bladder is full at other times than with your periods?**

Coding: (Drop down list)

1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain)

1a: On the scale of 0 to 10 below, please rate the level of pain you experience when your bladder is full)

2: No

**Do you experience pain when you urinate (passing urine/urination) at other times than with your periods?**

Coding: (Drop down list)

1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain)

1a: On the scale of 0 to 10 below, please rate the level of pain you experience when you urinate)

2: No

**Do you experience back pain at other times than with your periods?**

Coding: (Drop down list)

1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain)

1a: On the scale of 0 to 10 below, please rate the level of back pain you experience)

2: No

**Do you experience any other type of pain symptoms not already mentioned at other times than with your periods?**

Coding: (Drop down list)

1: Yes (Free text field enabled when this option is selected to allow for description) (if this option is selected, VAS scale to show and ask question for patient to rate her pain)

1a: On the scale of 0 to 10 below, please rate the level of other type of pain you experience

2: No

(NB: for this last question, free text to be enabled to allow for additions of other pain symptoms)

**When did your pelvic/period pain start?**

Coding: Drop down list

1: Within the first year after periods started

2: 2-3 years after periods started

3: More than 3 years after periods started

3a: Please specify (NN(2), text enable, branching logic)

4: After a trigger event (e.g infection, illness, miscarriage, stressful event)

5: Last 6-12 months

6: Last 18-24 months

7: Last 5 years

**When does your pelvic pain occur?**

Coding: N (Tick box)

1: Just with periods

2: Just with ovulation

3: Just with both periods and ovulation

4: Not with periods or ovulation

5: Randomly on any day
6: All the time
7: More than one type of pain
8: After eating
9: With exercise
10: With sexual activity
11: Other
    11a: Please specify (Text enable)

**<u>At any time, not just during your period</u>, do you experience pain when you have sexual intercourse?**

Coding: (Matrix tick boxes and the VAS scale for all the questions below)

4: Never had sexual intercourse
3: Prefer not to answer
0: No
1: Yes (if this option is selected, VAS scale to show and ask question for patient to rate her pain
    1a: On the scale of 0 to 10 below, please rate the level of pain you experience have sexual intercourse.

(If 4, 3 or 0, skip to “Are orgasms in general painful?”)

**Where is this pain during intercourse felt?**

Coding: (Drop down list)

1: Entrance
2: Deep
3: Both

**Do you experience burning, stinging pain at the entrance of the vagina during sex?**

Coding: Drop down list

1: Yes
2: No
3: I do not wish to answer this question

**Do you feel pain at the entrance of the vagina with sex/penetration?**

Coding: Drop down list

1: Yes
2: No
3: I do not wish to answer this question

**What happens when you try to have penetration?**

Coding: Drop down list

1: Too tight to have penetrative sex
2: Tight at the beginning but can relax and continue
3: Tightens up as sex progress and sometimes have to stop
4: I do not wish to answer this question

**Do you feel pain inside your body during sexual intercourse?**

Coding: Drop down list

1: Yes

2: No

3: I do not wish to answer this question

**Is there deep, dull, pressure pain during sex (and can get worse as sex continues)?**

Coding: Drop down list

1: Yes

2: No

3: I do not wish to answer this question

**Is there deep, sharp pain during sex (and can get worse as sex continues)?**

Coding: Drop down list

1: Yes

2: No

3: I do not wish to answer this question

**Is there deep, dull, pressure pain after sex that lasts for hours or days?**

Coding: Drop down list

1: Yes

2: No

3: I do not wish to answer this question

**Are orgasms in general painful?**

Coding: Drop down list

1: Yes

2: No

3: I do not wish to answer this question

**At any time, do you experience pain when your bladder is full?**

Coding: (Matrix tick boxes and the VAS scale for all the questions below)

1: Yes (if this option is selected, show the additional questions below)

1a: On the scale of 0 to 10, please rate the level of pain you experience at other times than with your periods. Where 0 = no pain and 10 = worst imaginable pain. (To show VAS scale if "Yes" is selected for any question)

2: No

**At any time, do you experience pain when you urinate?**

Coding: (Matrix tick boxes and the VAS scale for all the questions below)

1: Yes (if this option is selected, show the additional questions below)

1a: On the scale of 0 to 10, please rate the level of pain you experience at other times than with your periods. Where 0 = no pain and 10 = worst imaginable pain. (To show VAS scale if "Yes" is selected for any question)

2: No

**At any time, do you have a strong urge to pass urine just <u>after</u> going to the bathroom?**

Coding: (Drop down list)

1: Never

2: Rarely

3: Sometimes

4: Often

5: Always

**At any time, do your back, hip and abdominal muscles sometimes feel tight or go into spasm?**

Coding: (drop down list)

1: Yes

2: No

**Have you needed to seek emergency treatment because of the menstrual and / or pelvic pain?**

Coding: (drop down list)

1: Yes

2: No

**How often are you missing work/school/study due to your pelvic pain?**

Coding: (drop down list)

1: Never

2: 1-2 times per year

3: 3-6 times per year

4: Nearly every month or monthly

5: Multiple times per month

6: I am unable to work/study/go to school because of my pelvic pain

**Do you experience any other type of pain symptoms not already mentioned?**

(NB: for this last question, free text to be enabled to allow for additions of other pain symptoms)

**Do you also experience any of these other symptoms listed below <u>with your periods</u>?**

R51: Headache

G43.9: Migraine

R53: Fatigue
R11: Nausea/vomiting
99: Others (please specify) (Free text field to be enabled if this option is selected)

Coding: For all options of other symptoms, they are to be answered by selecting one of the options below (Matrix tick boxes)

1: Never
2: Rarely
3: Sometimes
4: Often
5: Always

**What makes your pelvic and / or period pain WORSE? (check box, tick all that apply)**

Coding: Multiple selection/checkboxes/drop down menu

1: Sitting
2: Stress
3: Full bladder or urinating
4: Bowel movement
5: Constipation
6: Intercourse or orgasm
7: Standing
8: Walking
9: Cardio / aerobic with moderate high-impact exercise
10: Cardio / aerobic with low impact exercise
11: Weight lifting / muscle strengthening exercise
12: Time of day
13: Full meal
14: Weather
15: Contact with clothing
16: Coughing/sneezing
17: Nothing
18: Other (please specify) (Free text field to be enabled if this option is selected)

**What HELPS your pelvic and / or period pain? (check box, tick all that apply)**

Coding: Multiple selection/checkboxes/drop down menu

1: Pain medication
2: Relaxation
3: Yoga
4: Lying down
5: Music
6: Massage
7: Ice
8: Heating pad

9: Bowel movement
10: Hot bath or shower
11: Meditation
12: Laxatives / enema
13: TENS machine
14: Emptying bladder
15: Cardio / aerobic with moderate high-impact exercise
16: Cardio / aerobic with low impact exercise
17: Weight lifting / muscle strengthening exercise
18: Nothing,
19: Other (please specify) (Free text field to be enabled if this option is selected)

**Overall do you feel your pain is worse on one side or the other?**

Coding: Drop down list

1. Yes
   1a: Left
   1b: Right
2. No

**Have you ever received a diagnosis for the pain from a doctor?**

Coding: Please tick all that apply

2: No
K58.9: Irritable bowel syndrome
K50.9: Crohn's Disease
K51.9: Ulcerative Colitis
N80.9: Endometriosis
D25.9: Fibroid(s)
N83.2: Ovarian cyst
M79.7: Fibromyalgia
N73.9: Pelvic inflammatory disease/infection
R39.8: Painful bladder syndrome
N30.9: Interstitial cystitis
Z73.3: Stress
99: Other (please specify) (Free text field enabled)
**xxxx:** Adenomyosis

**ENDOMETRIOSIS HISTORY** (only available to complete if patient selects they have been diagnosed with endometriosis, if not, skip to question "Have you ever had surgery to look for endometriosis and none was found?")

**Has a doctor or other health care provider ever diagnosed you with endometriosis?**

Coding: (modelled against METeOR ID: [638745])

1: Yes

  1a: YYYY (4 digit number representing year of diagnosis, branching logic for this and for the questions below)

2: No

(If 2, skip to "Have you had any previous laparoscopies for pelvic abdominal or pelvic issues?" – surgical tables)

**How old were you when you were first diagnosed with endometriosis?**

Coding: 2-digit unit of measure by total number of completed years.

1: NN(2) years old

2: Can't remember

**Have you been diagnosed with endometriosis in the last 5 years?**

Coding: drop down list

1: Yes

2: No

3: Unsure

**If yes, how was the diagnosis made?** (modelled against METeOR ID: [431754])

Coding: Please tick all that apply

1: Laparoscopy

2: Ultrasound pelvis

3: MRI pelvis

4: CT pelvis

5: Based on symptoms

88: Other (please specify) (Free text field)

**xxxx**: Laparotomy (*addition to NECST*)

(If anyone selects 2, answer the next question about ultrasound, if not, skip)

**When you had your ultrasound that diagnosed endometriosis please answer the following questions**

Coding: (free text field)

1: What month and year was this ultrasound performed? (free text enabled)

2: Which ultrasound or radiology group performed this ultrasound? (free text enabled)

3: Where was this ultrasound performed (road and/or suburb)? (free text enabled)

**What stage of endometriosis have you been told you have?**

Coding: Drop down list

1: Stage 1/minimal
2: Stage 2/mild
3: Stage 3/moderate
4: Stage 4/severe
5: Other, please specify (Free text field enabled)
6: Unsure/can't remember

**Have you had previous surgery for endometriosis?**

1: Yes
2: No

(If 2, skip to Have you had any other surgery on your pelvic floor or anal surgery?)

**Have you had a laparoscopy for endometriosis?**

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)
1a: Number of laparoscopies? (Free text field)
2: No

**Have you had a laparotomy for endometriosis?**

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)
1a: Number of laparotomies? (Free text field)
2: No

**Have you had a bowel resection for endometriosis?**

1: Yes
2: No

**Have you had any other surgery on your pelvic floor or anal surgery?**

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)
1a: Please specify details (Free text field)
2: No

**Have you been diagnosed as having adenomyosis on ultrasound (s) Y/N**

Coding: (drop down list)

1: Yes
2: No

**If you had surgery for endometriosis, during your most recent surgery, was your endometriosis treated (i.e. was it removed or burnt away)**

Coding:

1: Yes
2: No
3: Surgery scheduled
4: No surgery scheduled
99: Unsure

**How old were you when you first had symptoms?** (modelled against METeOR ID: 270843)
Coding: 2-digit unit of measure by total number of completed years.
1: NN(2) years old
2: No, you have never had symptoms (tick box)

**What symptoms, if any, prompted you to see a health care provider before your diagnosis with endometriosis?**
Coding: Please tick all that apply
R10.2: Pelvic pain
N97.9: Female infertility
2: No symptoms
88: Other (please specify) (Free text field)

**Have you had any previous laparoscopies for abdominal or pelvic issues?**
Coding:
1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)
  1a: How many of these procedures have you had? (Free text field)
  1b: Please fill out the table for each of these procedures (Populates table below, Table 1, using a "subform")
2: No
(If 2, skip to "Have you had any open abdominal or pelvic operations (e.g surgery resulting in a large scar on the abdomen)?")

**Table 1:**

| | **Please fill out table with each column corresponding to 1 procedure** | | | |
|---|---|---|---|---|
| **Month/Year** | | | | |
| **Hospital** | | | | |
| **State** | | | | |
| **Country** | | | | |
| **Public or Private** | | | | |

| | | | | |
|---|---|---|---|---|
| **Gynaecologist and/or surgeon name** | | | | |
| **Adhesions? Y/N** | | | | |
| **Treatment for adhesions? Y/N (do not fill out if no adhesions)** | | | | |
| **Endometriosis? Y/N** | | | | |
| **Treatment for endometriosis? Y/N (do not fill out if no endometriosis)** | | | | |

**Do you give us permission to obtain copies of your operation notes and pathology reports from your laparoscopies?**

Coding: (drop down list)

1: Yes

2: No

**Have you had any open abdominal or pelvic operations (e.g surgery resulting in a large scar on the abdomen)?**

Coding: (drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: How many of these procedures have you had? (Free text field)

1b: Please fill out the table for each of these procedures (Populates table below, Table 2, using a "subform")

2: No

**Table 2**

| | **Please fill out table with each column corresponding to 1 procedure** | | | |
|---|---|---|---|---|
| **Month/Year** | | | | |
| **Hospital** | | | | |
| **State** | | | | |
| **Country** | | | | |
| **Public or Private** | | | | |

| **Gynaecologist and/or surgeon name** | | | | |
|---|---|---|---|---|
| **Adhesions? Y/N** | | | | |
| **Treatment for adhesions? Y/N (do not fill out if no adhesions)** | | | | |
| **Endometriosis? Y/N** | | | | |
| **Treatment for endometriosis? Y/N (do not fill out if no endometriosis)** | | | | |

**Do you give us permission to obtain copies of your operation notes and pathology reports from your abdominal or pelvic operations?**

Coding: (drop down list)

1: Yes

2: No

**Have you had a hysterectomy?**

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: What year was this (Free text field)

2: No

**Have you ever had surgery to look for endometriosis and none was found?**

Coding: (modelled against METeOR ID: 638745)

1: Yes

1a: **If yes, what are the symptoms prompted the surgery?**

Coding: Please tick all that apply (branching logic)

R10.2: Pelvic pain (branching logic to ask the below)

1a-1: **If yes, did your symptoms improve after surgery?**

1a-1a: Yes (branching logic to ask the below, can be in matrix form)

1a-1a-1: **For how long did your symptoms improve after surgery?**

1a-1a-1a: < 6 months

1a-1a-1b: 6 – 12 months

1a-1a-1c: 1 – 2 years

1a-1a-1d: 2 – 5 years

1a-1a-1e: > 5 years

1a-1a-2: **By approximately how much did your pain symptoms improve?** (options below can be in matrix form)

1a-1a-2a: < 25 % improvement

1a-1a-2b: 25 – 50 % improvement

1a1a-2c: 50 - 75 % improvement

1a-1a-2d: > 75 % improvement

2: No

99: Don't know

N97.9: Female infertility

88: Other (please specify) (Free text field)

2: No

**Have any of your female blood relatives been diagnosed with endometriosis?**

1: Yes

2: No

(If 2, skip to "Have any of your female blood relatives suffered from chronic pelvic pain")

**Which of your female blood relatives have been diagnosed with endometrioses (select all that apply)?**

Coding: (for the question above, matrix tick box of the options below, select all that apply)

1: Mother

2: Sister

3: Grandmother

4: Aunt

5: Cousin

6: Child

**Have any of your female blood relatives suffered from chronic pelvic pain (i.e. "bad periods" or "periods that required some form of rest", etc)?**

Coding: (for the question above, matrix tick box of the options below, select all that apply)

1: Mother

2: Sister

3: Grandmother, aunt or cousin on mother's side

4: Grandmother, aunt or cousin on father's side

88: Unknown

**PREGNANCY, OBSTETRIC AND FERTILITY HISTORY**

**Obstetric history**

Definition: Patient's previous pregnancies and outcomes history.

Coding: A 1 – 2 digit number representing the patient's previous obstetric history.

G (Gravidity): Total number of confirmed pregnancies.

P (Parity): Number of births you have had after 20 weeks of gestation.

(If Parity = 0, skip to "Have you had any pregnancies with your current partner?". If Gravidity = 0, skip to "Current partner" section)

**Have you ever breastfed?**
Coding: (drop down list)
1: Yes
2: No
(If 2, skip to Have any of your pregnancies resulted in a caesarean?

**Are you currently breastfeeding?**
Coding: (drop down list)
1: Yes
2: No

**Have any of your pregnancies resulted in a caesarean?**
Coding:
1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: How many caesareans have you had? (Free text field)

2: No

**Have any of your pregnancies resulted in vaginal delivery?**
Coding:
1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: How many vaginal deliveries have you had? (Free text field)

1b: Have any of these resulted in vaginal tears (Yes or No)? (Free text field)

2: No

**Have you had any pregnancies with your current partner?**

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: How many? (Free text field)

1b: Please fill out the table for each of these procedures (Populates table below, Table 3, using a "subform")

2: No

3: No current partner

**Table 3**

| **Pregnancy number** | | | | |
|---|---|---|---|---|
| **Your age during the pregnancy** | | | | |
| **Conception Method (Spontaneous, OI, OI+IUI or IVF)** | | | | |
| **Pregnancy outcome (miscarriage, TOP, ectopic, stillbirth, livebirth)** | | | | |
| **Number of weeks pregnant at end of pregnancy** | | | | |
| **Pregnancy complications (Preeclampsia, PIH, GDM, IUGR, pre-term delivery)** | | | | |
| **Was this pregnancy using your own eggs? Y/N** | | | | |
| **Was this pregnancy using sperm from a male partner or donor sperm?** | | | | |
| **Key:** | OI: Ovulation Induction<br>IUI: Intrauterine Insemination<br>IVF: In-vitro fertilization<br>PIH: Pregnancy-Induced Hypertension<br>GDM: Gestational Diabetes<br>IUGR: Intrauterine Growth Restriction<br>TOP: Termination of Pregnancy (medical or surgical) | | | |

**Do you give us permission to obtain copies of your operation notes and/or pathology reports from your pregnancies?**

Coding: (drop down list)

1: Yes

2: No

**Have you had any pregnancies with previous partner(s)?**

Coding: (Drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

- 1a: How many? (Free text field)
- 1b: Please fill out the table for each of these procedures (Populates table below, Table 4, using a "subform")

2: No

3: No previous partner(s)

**Table 4**

| **Pregnancy number** | | | | |
|---|---|---|---|---|
| **Year of pregnancy** | | | | |
| **Conception Method (Spontaneous, OI, OI+IUI or IVF)** | | | | |
| **Pregnancy outcome (miscarriage, TOP, ectopic, stillbirth, livebirth)** | | | | |
| **Number of weeks pregnant at end of pregnancy** | | | | |
| **Pregnancy complications (Preeclampsia, PIH, GDM, IUGR, pre-term delivery)** | | | | |
| **Was this pregnancy using your own eggs? Y/N** | | | | |
| **Was this pregnancy using sperm with a male partner or donor sperm?** | | | | |
| **Key:** | OI: Ovulation Induction<br>IUI: Intrauterine Insemination<br>IVF: In-vitro fertilization<br>PIH: Pregnancy-Induced Hypertension<br>GDM: Gestational Diabetes<br>IUGR: Intrauterine Growth Restriction<br>TOP: Termination of Pregnancy (medical or surgical) | | | |

**Do you give us permission to obtain copies of your operation notes and/or pathology reports from your pregnancies?**

Coding: (drop down list)

1: Yes

2: No

**CURRENT PARTNER**

**Do you have a current partner?**

Coding: (drop down list)

1: Yes

2: No

(If 2, skip to "Difficulty conceiving")

**What is your partner's date of birth?**

Coding: DDMMYYYY

**What is your partner's height?**

Coding: A 3 digit number [NNN] representing height in centimeters.

888: Unknown

999: Not stated/inadequately described

**What is your partner's weight?**

Coding: A 3 digit number [NNN] representing weight in kilograms.

888: Unknown

999: Not stated/inadequately described

**Does your partner currently smoke?**

Coding: (Drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

  1a: How many cigarettes per week does your partner smoke? (Free text field)

2: No

**Does your partner drink alcohol?**

Coding: (Drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

  1a: How many drinks does your partner consume a week? (Free text field)

2: No

**Does your partner smoke cannabis?**

Coding: (Drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

  1a: How many days per week does your partner smoke cannabis? (Free text field)

2: No

**What sex was your current partner assigned at birth**

Coding: (drop down list)

1: Male

2: Female

3: Other (please specify) (Free text field)

(If 2, skip to "Have you had problems conceiving" as the questions in between are relevant for partners assigned as "male" at birth)

**Has your partner had any pregnancies with previous partner(s)?**

Coding: (drop down list)

1: Yes

2: No

3: Unsure

**Has your partner ever had a semen analysis? (NB: question applies for partners assigned as "male" at birth)**

Coding: (drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: Were the results normal or abnormal? (Free text field)

2: No

**Has your partner been diagnosed with any of the following? (NB: question applies for partners assigned as "male" at birth)**

Coding: (for the question above, matrix tick box of the options below, select all that apply)

1: Cancer requiring chemotherapy or radiotherapy

2: Varicocoele of the testis

3: Undescended testis

4: Mumps infection as an adult

5: Surgery on the testes

6: Erection problems

7: Ejaculation problems

8: Testicular torsion

9: Testicular trauma

10: Vasectomy

11: Absence of vas deferens

12: Klinefelter syndrome

13: Other problem causing abnormal sperm count

**Does your partner have any other problems or diagnoses causing an abnormal sperm count? (NB: question applies for partners assigned as "male" at birth)**

Coding: (drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: Please specify. (Free text field)

2: No

**DIFFICULTY CONCEIVING**

**Have you ever had problems conceiving (getting pregnant)?**

Coding: (drop down list)

1: Yes

2: No

3: Never tried

(If 3, skip to "Are you currently/actively trying to get pregnant")

**Have you ever tried to get pregnant for more than 12 months in a row without succeeding?**

Coding: (modelled against METeOR ID: 638745)

1: Yes (branching logic)

1a: **If yes, what was the longest amount of time that you tried, whether or not you actually got pregnant?**

Coding: NNN(3) (numerical value in months)

2: No

**Have you or your partner ever had any tests/investigations to find out why you were not getting pregnant?**

Coding: (modelled against METeOR ID: 638745)

1: Yes

1a: **If yes, what were the results of these tests?**

Coding: Tick boxes (select all that apply)

N80.9: Endometriosis

N73.6: Pelvic peritoneal adhesions

N99.4: Postprocedural pelvic peritoneal adhesions

N97.1: Infertility due to blocked tubes

E28.2: Polycystic ovary syndrome

N73.9: Pelvic inflammatory disease

N97.0: Infertility due to no/irregular ovulation

N46: Poor sperm count/quality

D25.9: Fibroids

2: No cause was found

88: Other (please specify) (free text field)

Xx: Premature ovarian insufficiency (premature menopause)

Xx: Low ovarian reserve (or low Anti Mullerian Hormone, AMH)

Xx: Uterine adhesions (Asherman's Syndrome)

2: No

**Did you ever seek treatment for infertility in any clinic?**

Coding: (modelled against METeOR ID: 638745)

1: Yes

1a: **If yes, please tell us about any fertility treatment you have used.**

Coding: Tick boxes (select all that apply)

1: Intercourse timed specifically to conceive

2: Fertility drugs by pills to stimulate ovulation (e.g. clomid, clomiphene or any other drug in pill form)

3: Fertility drugs by injection (e.g. gonadotrophin, HCG or any other drug by injection)

4: Progesterone (vaginal or intramuscular injection)
5: Insemination with your partner's semen
6: Intrauterine insemination with a donor's sperm
7: In vitro fertilization (IVF)
8: In vitro fertilization with intracytoplasmic sperm injection (ICSI)
9: In vitro fertilization with eggs from a donor

2: No

Are you currently actively trying to get pregnant?

Coding: (drop down list)

1: Yes

2: No

(If 2, skip to "What is your current method of contraception?")

**How long have you currently actively been trying to get pregnant?**

Coding: (drop down list)

1: less than 6 months

2: 6-12 months

3: 12-18 months

4: 18 months – 2 years

5: 2-3 years

6: 3-4 years

7: 4-5 years

8: more than 5 years

**How many cycles/months have you been actively trying to become pregnant?**

Coding: a 1, 2 or 3 digit number representing the number of cycles

888: Unknown

999: Not stated/inadequately described

**How many cycles/months have you been having unprotected sex (ie no contraception)?**

Coding: a 1, 2 or 3 digit number representing the number of cycles

888: Unknown

999: Not stated/inadequately described

**What is your current method of contraception? (Tick all that apply)**

Coding: (for the question above, matrix tick box of the options below, select all that apply)

1: Abstinence

2: Withdrawal

3: Rhythm or timing

4: Condoms
5: Female condoms
6: Diaphragm
7: Minipill
8: Combined oral contraceptive pill
9: NuvaRing
10: Implanon
11: Copper IUD
12: Mirena IUD
13: Kyleena IUD
14: Tubal ligation or removal
15: Vasectomy
16: None
17: Other, please describe (free text field)

**Have you been doing any of the following (pick all that applies):**

Coding: (for the question above, matrix tick box of the options below, select all that apply)

1: Timing sex on cycle length
2: Monitoring temp
3: Monitoring cervical mucus
4: urine/saliva testing for ovulation
5: blood testing for ovulation

**Have you had any cycles/months where you had drugs to stimulate ovulation (ovulation induction)?**

Coding: (drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: What type of medication did you use out of the following: Clomid, Letrozole, Gonal F injections or Puregon injections? (free text field)

1b: How many cycles? (Free text field)

2: No

**Have you had any cycles/months where you had artificial insemination (also called intrauterine insemination)?**

Coding: (drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: How many cycles? (Free text field)

2: No

**Have you had any cycles/months where you had an IVF stimulation cycle?**

Coding: (drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: How many cycles? (Free text field)

2: No

(If 2, skip to "Have you had a test to check if you are ovulating")

**Have you had any cycles/months where you had an IVF frozen embryo(s) transfer?**

Coding: (drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: How many cycles and embryos? (Free text field)

2: No

**Have you had a test to check if you are ovulating (releasing an egg each month)?**

Coding: (drop down list)

1: Yes

2: No.

(if 2, skip to "Have you had a test to check if your fallopian tube(s) are open")

**What was the result of this ovulation test?**

Coding: (drop down list)

1: Ovulating normally

2: Ovulating irregularly

3: Not ovulating

4: Unsure

**Have you had a test to check if your fallopian tube(s) are open?**

Coding: (drop down list)

1: Yes

2: No

(if 2, skip to Medication History section)

**What was the result of the fallopian tube test?**

Coding: (drop down list)

1: Both open

2: 1 tube blocked

3: Both tubes blockes

4: Unsure

**MEDICATION HISTORY**

**Hormonal medication(s) used** (to be in a table form and date logged, current/new medications at the top, with reason for using medication and adverse/side effect(s), to have their own column or ability to be grouped with the medication being used) – **NB: please see Module 5 – Medical management for data dictionary, groupings and options**.

**Pain medication(s) used** (to be in a table form and date logged, current/new medications at the top, with reason for using medication and adverse/side effect(s), to have their own column or ability to be grouped with the medication being used) – **NB: please see Module 5 – Medical management for data dictionary, groupings and options.**

**Other medication(s) used** (to be in a table form and date logged, current/new medications at the top, with reason for using medication and adverse/side effect(s), to have their own column or ability to be grouped with the medication being used) – **NB: please see Module 5 – Medical management for data dictionary, groupings and options.**

**Are you using any of these medications or contraceptives currently?**

Code: multiple selection/check boxes

1: Oral Contraceptive Pill
2: Progesterone only Pill / Mini Pill
3: Depo-Provera 3 monthly injection (Depot)
4: Implanon implant
5: Mirena intra-uterine device
6: Zoladex monthly implants
7: Synarel nasal spray
8: Danazol tablets
9: Visanne (dienogest)
10: Non-hormonal intra-uterine device
11: Condoms
12: Tubal ligation
13: Other (please specify): (free text field)

**Have you used any of these medications or contraceptives in the last 6 months? Please select all that apply**

Coding: (for the question above, matrix tick box of the options below, select all that apply)

1: Oral Contraceptive Pill
2: Progesterone only Pill / Mini Pill
3: Depo-Provera 3 monthly injection (Depot)
4: Implanon implant
5: Mirena intra-uterine device
6: Zoladex monthly implants

7: Synarel nasal spray

8: Danazol tablets

9: Visanne (dienogest)

10: Non-hormonal intra-uterine device

11: Condoms

12: Tubal ligation

13: Other (please specify): (free text field)

**Are you taking ANY other medications including vitamins and complementary medicines?**

Coding: drop down list

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

 1a: Please fill out the table for each of these vitamins/ medicines (Populates table below, Table 5, using a “subform”)

2: No

**Table 5**

| Medicine name (as on the label) | Medicine strength (as on the label) | How many do you take per day? | How many days per week do you take this medicine? | Start date or year |
|---|---|---|---|---|
| | | | | |
| | | | | |
| | | | | |

**MEDICAL HISTORY**

**Do you have any clinically relevant/significant conditions that exist prior to signing informed consent and any pre-planned hospitalisations or procedures.**

Coding: (drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

 1a: Please fill out the table for each of these procedures (Populates table below, Table 6, using a “subform”)

2: No

**Table 6: Record the diagnosis and procedure as separate records (and on separate lines) if both are relevant.**

| **Medical Condition(s) and/or Surgical Procedure(s)** | **Start Date:** | **Stop Date :** | **Current:** |
|---|---|---|---|
| | | | |
| | | | |
| | | | |

**Have you had ANY previous surgeries?**

Coding: (drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

1a: Please fill out the table for each of these procedures (Populates table below, Table 7, using a "subform")

2: No

**Table 7**

| Year | Procedure |
|---|---|
| | |
| | |
| | |

**Have you ever been diagnosed by a doctor with cancer or a malignancy of any kind?**

Coding: (modelled against METeOR ID: 638745)

1: Yes (branching logic)

1a: **If yes, what type(s) of cancer (primary location) have you been diagnosed with, and when were you first diagnosed?**

Coding: Free text fields

1a-1: "Type of cancer"

1a-2: "Age first diagnosed (years)"

2: No

(if 2, skip to "Have you ever had any of the following medical conditions diagnosed by a doctor?")

**Have you ever been diagnosed with any of the following forms of cancer? Please select all that apply.**

Coding: (for the question above, matrix tick box of the options below, select all that apply)

1: Ovarian Cancer

2: Cervical Cancer or pre-cancer (CIN)

3: Breast Cancer

4: Hodgkin's disease

5: Non-hodgkin's lymphoma

6: Leukemia

7: Endometrial cancer

8: Melanoma or any other forms of skin cancer. If yes what type? (enable free text)
9: Have you been diagnosed with any other forms of cancer? (free text)

**Have you ever had any of the following medical conditions diagnosed by a doctor?**

F41.9: Anxiety disorder
J45.9: Asthma
I51.5: Cardiovascular disease
K50.9: Crohn's Disease
G93.3: Chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME)
H91.9: Deafness/difficulty hearing
F32.9: Depression
L20.9: Eczema/dermatitis
D25.9: Fibroids
M79.7: Fibromyalgia
O24.4: Gestational diabetes mellitus
B27.9: Glandular fever
E05.0: Graves' Disease
E06.3: Hashimoto's disease
I10: High blood pressure
N30.9: Interstitial cystitis
K58.9: Irritable bowel syndrome
G43.9: Migraine
I34.1: Mitral valve prolapse
G35: Multiple sclerosis
R39.8: Painful bladder syndrome
N94.8: Pelvic congestion syndrome
N73.9: Pelvic inflammatory disease/infection
E28.2: Polycystic ovary syndrome (PCOS)
I49.8: Postural orthostatic tachycardia syndrome (POTS)/Neurocardiogenic syncope
M06.9: Rheumatoid arthritis
M41.9: Scoliosis (curvature of the spine)
M53.9: Spine problems (excluding scoliosis)
M35.0: Sjogren's syndrome
M32.9: Systemic lupus erythematous (SLE; Lupus)
E07.9: Thyroid disease
E10.9: Type I diabetes mellitus
E11.9: Type II diabetes mellitus
K51.9: Ulcerative Colitis
Acne
Disturbance or taste or smell
Food allergies (please specify wheat, nuts, soy, fish, dairy, eggs),
Food intolerances (please specify)
Hay fever

Inflammatory bowel disease
Recurrent upper respiratory infections
Recurrent vaginal infections
Scleroderma
Allergies to anything else (please specify)
Deep vein thrombosis
Pulmonary embolism
Pelvic infection
Anal fissures
Recurrent thrush
Haemorrhoids
Vulval skin problems
Temporo-mandibular joint dysfunction

Recurrent UTI
Overactive thyroid
Viral infections (please specify, chicken pox, shingles, measles, mumps, rubella, hpv, hiv, hepb, flu, covid, other)
Ovarian cysts
Fibrocystic breast disease
Adenomyosis
Low blood pressure
Have you fainted in the past? *(green: added to NECST questions)*
88: Other (please specify) (Free text box)
2: No

**VACCINATION HISTORY**

**Have you been vaccinated for MMR (Measles, Mumps and Rubella)?**

Coding: (drop down list)
1: Yes
2: No
3: Unsure

**Have you been vaccinated for whooping cough?**

Coding: (drop down list)
1: Yes
2: No

3: Unsure

**Have you been vaccinated for chickenpox?**

Coding: (drop down list)

1: Yes

2: No

3: Unsure

**Have you been vaccinated for tuberculosis?**

Coding: (drop down list)

1: Yes

2: No

3: Unsure

**Have you been vaccinated for polio?**

Coding: (drop down list)

1: Yes

2: No

3: Unsure

**Have you been vaccinated for hepatitis B?**

Coding: (drop down list)

1: Yes

2: No

3: Unsure

**Have you been vaccinated for hepatitis C?**

Coding: (drop down list)

1: Yes

2: No

3: Unsure

**Have you been vaccinated for hepatitis A?**

Coding: (drop down list)

1: Yes

2: No

3: Unsure

**Have you been vaccinated for typhoid fever?**

Coding: (drop down list)

1: Yes

2: No

3: Unsure

**Have you had any other vaccinations?**

Coding: (drop down list)

1: Yes (if this option is selected, allow the below to be shown and free text field enabled to allow details to be entered)

  1a: Please specify: (free text field)

2: No

3: Unsure

**Have you been told that you were born with a structural problem/birth defect of your uterus, cervix or vagina?**

Coding: (modelled against METeOR ID 638745)

1: Yes (branching logic)

  1a: **If yes, did you have surgery for this issue?**

  Coding: (modelled against METeOR ID 638745)

    1: Yes

    2: No

2: No

**In the last 3 months, have you had any of the following in relation to your bowel movements?**

Coding: Please tick all that apply

1: Rectal bleeding or blood in your stool

2: Less than 3 bowel movements per week

3: More than 3 bowel movements per day

4: Nausea and/or vomiting

5: Intestinal cramping

6: Straining during a bowel movement

7: Urgent need to have a bowel movement

8: Feeling of incomplete emptying with bowel movements

9: Passing mucus at the time of bowel movements

10: Abdominal fullness, bloating or swelling

11: None of the above

**In the last 3 months, have you experienced any of the following in relation to urination?**

Coding: Please tick all that apply

1: Loss of urine when coughing, sneezing or laughing

2: Difficulty passing urine

3: Frequent bladder infections

4: Blood in the urine

5: Still feeling full after urination

6: Having to urinate again within minutes of urinating

7: None of the above

**Have you experienced sexual or physical abuse?**

Coding: (drop down list)

1: Yes

2: No

3: Prefer not to answer

**Please indicate if you would like to be contacted to discuss this further**

Coding: (drop down list)

1: Yes

2: No

**In the past 2 years, have you received treatment for your pelvic pain from a non-medical clinician, e.g. an allied health clinician?**

Coding: (drop down list)

1: Yes

2: No

(If 2, skip next questions about non-medical clinicians, to **EQ-5D 5L**)

**Which of the following allied health clinicians have you received treatment from? (tick all that apply**)

Coding: multiple selection/check boxes

1: Physiotherapist

2: Psychologist / counsellor

3: Dietitian

4: Chiropractor

5: Osteopath

6: Myotherapist / massage therapist

7: Other therapist (free text field)

**If you have received treatment from a physiotherapist, please mark off all the statements that apply to you.**

Coding: multiple selection/check boxes

1: I have not seen a physiotherapist

2: Physiotherapy treatment focussed on my pelvic pain (pain with periods, pain with sex, pain with emptying bladder or bowels?)

3: Physiotherapy treatment focussed on other pelvic floor problems (related to bladder or bowel control or emptying, or a feeling of prolapse)

4: Physiotherapy treatment focussed on my pelvic problems other than my pelvic floor (such as joint pain or buttock pain).

5: Physiotherapy treatment focussed on other problems not related to my pelvis

(If 1, skip next question)

**How often have you received physiotherapy treatment focussing on pelvic pain?**

Coding: (drop down list)

1: Once or twice

2: 3 or more times

## 3. Patient reported outcome measures (PROMs)

Note on the patient groups that will complete either the EQ-5D and/or EHP-30

- All patients will complete the EQ-5D, regardless their presenting symptoms and diagnosis.
- Patients who answer to having had a diagnosis of endometriosis in Module 2. Clinical Presentation and Medical History will complete the EHP-30.
- Ongoing PROMs follow up schedule post initial visit and registration to the Registry
  - 6 months → 12 month → 24 months → annually
- Patients who then undergo surgery and have endometriosis confirmed by laparoscopy and histopathology will also then start completing the EHP-30 questionnaire, in addition to the EQ-5D.
- Ongoing PROMs follow up schedule, new schedule will initiated
  - 6 months → 12 month → 24 months → annually

**Date of completion of this questionnaire**

Definition: The date that the patient completed this questionnaire. (METeOR ID: 338737)

Coding: DD/MM/YYYY (electronic capture)

**EQ-5D 5L** (to be completed by all patients, i.e. new patients, returning patients, etc.)

Definition: Standardized instrument developed by the EuroQol Group. Measures of health-related quality of life across a wide range of health conditions and treatments.

**Please click the ONE box that best describes your health TODAY.**

MOBILITY

I have no problems in walking about q

I have slight problems in walking about q

I have moderate problems in walking about q

I have severe problems in walking about q

I am unable to walk about q

SELF-CARE

I have no problems washing or dressing myself q

I have slight problems washing or dressing myself q

I have moderate problems washing or dressing myself q

I have severe problems washing or dressing myself q

I am unable to wash or dress myself q

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems doing my usual activities q

I have slight problems doing my usual activities q

I have moderate problems doing my usual activities q

I have severe problems doing my usual activities q

I am unable to do my usual activities q

PAIN / DISCOMFORT

| | |
|---|---|
| I have no pain or discomfort | q |
| I have slight pain or discomfort | q |
| I have moderate pain or discomfort | q |
| I have severe pain or discomfort | q |
| I have extreme pain or discomfort | q |

ANXIETY / DEPRESSION

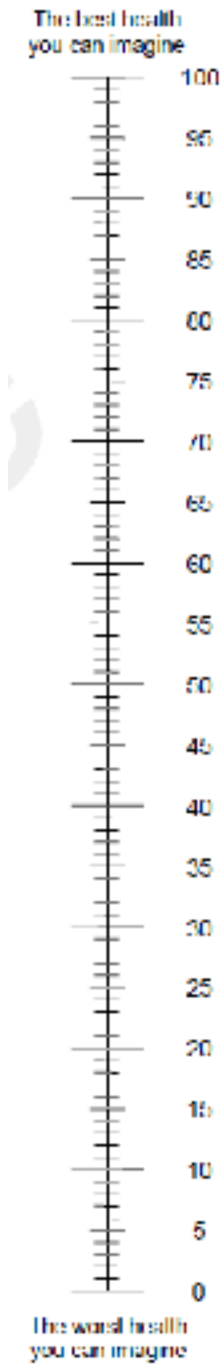
| | |
|---|---|
| I am not anxious or depressed | q |
| I am slightly anxious or depressed | q |
| I am moderately anxious or depressed | q |
| I am severely anxious or depressed | q |
| I am extremely anxious or depressed | q |

Coding: Tick/check box of the questions above, select the most representative answer to your situation from each category.

**EQ-5D-5L Visual analogue scale (VAS)**

Definition: EQ VAS records the patient's self-rated health on a vertical visual analogue scale.

Coding: (IT – To be a sliding scale, and allow selecting along the scale)




Guide for use: "**We would like to know how good or bad your health is TODAY. This scale is numbered from 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine. Mark an X on the scale to indicate how your health is TODAY. Now, please write the number you marked on the scale in the box below.**"

CENTRAL SENSITIZATION INVENTORY

Name:_______________________________________ Date: __________________

Please circle the best response to the right of each statement.

| 1 | I feel tired and unrefreshed when I wake from sleeping. | Never | Rarely | Sometimes | Often | Always |
|---|---|---|---|---|---|---|
| 2 | My muscles feel stiff and achy. | Never | Rarely | Sometimes | Often | Always |
| 3 | I have anxiety attacks. | Never | Rarely | Sometimes | Often | Always |
| 4 | I grind or clench my teeth. | Never | Rarely | Sometimes | Often | Always |
| 5 | I have problems with diarrhea and/or constipation. | Never | Rarely | Sometimes | Often | Always |
| 6 | I need help in performing my daily activities. | Never | Rarely | Sometimes | Often | Always |
| 7 | I am sensitive to bright lights. | Never | Rarely | Sometimes | Often | Always |
| 8 | I get tired very easily when I am physically active. | Never | Rarely | Sometimes | Often | Always |
| 9 | I feel pain all over my body. | Never | Rarely | Sometimes | Often | Always |
| 10 | I have headaches. | Never | Rarely | Sometimes | Often | Always |
| 11 | I feel discomfort in my bladder and/or burning when I urinate. | Never | Rarely | Sometimes | Often | Always |
| 12 | I do not sleep well. | Never | Rarely | Sometimes | Often | Always |
| 13 | I have difficulty concentrating. | Never | Rarely | Sometimes | Often | Always |
| 14 | I have skin problems such as dryness, itchiness, or rashes. | Never | Rarely | Sometimes | Often | Always |
| 15 | Stress makes my physical symptoms get worse. | Never | Rarely | Sometimes | Often | Always |
| 16 | I feel sad or depressed. | Never | Rarely | Sometimes | Often | Always |
| 17 | I have low energy. | Never | Rarely | Sometimes | Often | Always |
| 18 | I have muscle tension in my neck and shoulders. | Never | Rarely | Sometimes | Often | Always |
| 19 | I have pain in my jaw. | Never | Rarely | Sometimes | Often | Always |
| 20 | Certain smells, such as perfumes, make me feel dizzy and nauseated. | Never | Rarely | Sometimes | Often | Always |

| | | | | | | |
|---|---|---|---|---|---|---|
| 21 | I have to urinate frequently. | Never | Rarely | Sometimes | Often | Always |
| 22 | My legs feel uncomfortable and restless when I am trying to go to sleep at night. | Never | Rarely | Sometimes | Often | Always |
| 23 | I have difficulty remembering things. | Never | Rarely | Sometimes | Often | Always |
| 24 | I suffered trauma as a child. | Never | Rarely | Sometimes | Often | Always |
| 25 | I have pain in my pelvic area. | Never | Rarely | Sometimes | Often | Always |
| | | | | | | |
| | | | | | **Total=** | |

# AUSTRALIAN PELVIC FLOOR QUESTIONNAIRE

Patient's Name: ______________________

Date of Birth: ______________________

Date completed: ______________________

*Please circle your most applicable answer. Consider your experience during the last month*

## BLADDER FUNCTION (___ /45)

**Q1. How many times do you pass urine in a day?**
0 Up to 7
1 Between 8-10
2 Between 11-15
3 More than 15

**Q2. How many times do you get up at night to pass urine?**
0 0-1
1 2
2 3
3 More than 3 times

**Q3. Do you wet the bed before you wake up at night?**
0 Never
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Always - every night

**Q4. Do you need to rush/hurry to pass urine when you get the urge?**
0 Can hold on
1 Occasionally have to rush - less than once/week
2 Frequently have to rush - once or more/week
3 Daily

**Q5. Does urine leak when you rush or hurry to the toilet or can't you make it in time?**
0 Not at all
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Daily

**Q6. Do you leak with coughing, sneezing, laughing or exercising?**
0 Not at all
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Daily

**Q7. Is your urinary stream (urine flow) weak, prolonged or slow?**
0 Never
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Daily

**Q8. Do you have a feeling of incomplete bladder emptying?**
0 Never
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Daily

**Q9. Do you need to strain to empty your bladder?**
0 Never
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Daily

**Q10. Do you have to wear pads because of urinary leakage?**
0 None - Never
1 As a precaution
2 When exercising / during a cold
3 Daily

**Q11. Do you limit your fluid intake to decrease urinary leakage?**
0 Never
1 Before going out
2 Moderately
3 Always

**Q12. Do you have frequent bladder infections?**
0 No
1 1-3 per year
2 4-12 per year
3 More than one per month

**Q13. Do you have pain in your bladder or urethra when you empty your bladder?**
0 Never
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Daily

**Q14. Does urine leakage affect your routine activities like recreation, socializing, sleeping, shopping etc?**
0 Not at all
1 Slightly
2 Moderately
3 Greatly

**Q15. How much does your bladder problem bother you?**
0 Not at all
1 Slightly
2 Moderately
3 Greatly

Other symptoms (haematuria, pain etc.)

______________________________________________

## BOWEL FUNCTION (___ /30)

**Q16. How often do you usually open your bowels?**
0 Every other day or daily
1 Less than every 3 days
2 Less than once a week
0 More than once per day

**Q17. How is the consistency of your usual stool?**
0 Soft
0 Firm
0 Hard (pebbles)
1 Variable
2 Watery

**Q18. Do you have to strain to empty your bowels?**
0 Never
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Daily

**Q19. Do you use laxatives to empty your bowels?**
0 Never
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Daily

**Q20. Do you feel constipated?**
0 Never
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Daily

**Q21. When you get wind or flatus, can you control it, or does wind leak?**
0 Never
1 Occasionally - less than once per week
2 Frequently - once or more per week
3 Daily

AUSTRALIAN PELVIC FLOOR QUESTIONNAIRE

# AUSTRALIAN PELVIC FLOOR QUESTIONNAIRE

Patient's Name: ____________________

Date of Birth: ____________________

Date completed: ____________________

**Q22. Do you get an overwhelming sense of urgency to empty bowels?**
0 Never
1 Occasionally – less than once per week
2 Frequently – once or more per week
3 Daily

**Q23. Do you leak watery stool when you don't mean to?**
0 Never
1 Occasionally – less than once per week
2 Frequently – once or more per week
3 Daily

**Q24. Do you leak normal stool when you don't mean to?**
0 Never
1 Occasionally – less than once per week
2 Frequently – once or more per week
3 Daily

**Q25. Do you have a feeling of incomplete bowel emptying?**
0 Never
1 Occasionally – less than once per week
2 Frequently – once or more per week
3 Daily

**Q26. Do you use finger pressure to help empty your bowel?**
0 Never
1 Occasionally – less than once per week
2 Frequently – once or more per week
3 Daily

**Q27. How much does your bowel problem bother you?**
0 Not at all
1 Slightly
2 Moderately
3 Greatly

## PROLAPSE SYMPTOMS (____/15)

**Q28. Do you have a sensation of tissue protrusion/lump/bulging in your vagina?**
0 Never
1 Occasionally – less than once per week
2 Frequently – once or more per week
3 Daily

**Q29. Do you experience vaginal pressure or heaviness or a dragging sensation?**
0 Never
1 Occasionally – less than once per week
2 Frequently – once or more per week
3 Daily

**Q30. Do you have to push back your prolapse in order to void?**
0 Never
1 Occasionally – less than once per week
2 Frequently – once or more per week
3 Daily

**Q31. Do you have to push back your prolapse to empty your bowels?**
0 Never
1 Occasionally – less than once per week
2 Frequently – once or more per week
3 Daily

**Q32. How much does your prolapse bother you?**
0 Not at all
1 Slightly
2 Moderately
3 Greatly

**Other Symptoms:** (problems walking / sitting, pain, vaginal bleeding)

______________________

______________________

______________________

## SEXUAL FUNCTION (____/21)

**Q33. Are you sexually active?**
□ No
□ Less than once per week
□ Once or more per week
□ Daily or most days

*If you are not sexually active, please continue to answer questions 34 & 42*

**Q34. If you are not sexually active, please tell us why?**
□ Do not have a partner
□ I am not interested
□ My partner is unable
□ Vaginal dryness
□ Too painful
□ Embarrassment due to the prolapse/incontinence
□ Other reasons: ____________

**Q35. Do you have sufficient vaginal lubrication during intercourse?**
0 Yes
1 No

**Q36. During intercourse vaginal sensation is:**
0 Normal / pleasant
1 Minimal
1 Painful
3 None

**Q37. Do you feel that your vagina is too loose or lax?**
0 Never
1 Occasionally
2 Frequently
3 Always

**Q38. Do you feel that your vagina is too tight?**
0 Never
1 Occasionally
2 Frequently
3 Always

**Q39. Do you experience pain with sexual intercourse?**
0 Never
1 Occasionally
2 Frequently
3 Always

**Q40. Where does the pain during intercourse occur?**
0 Not applicable, I do not have pain
1 At the entrance to the vagina
1 Deep inside, in the pelvis
2 Both at the entrance & in the pelvis

**Q41. Do you leak urine during sexual intercourse?**
0 Never
1 Occasionally
2 Frequently
3 Always

**Q42. How much do these sexual issues bother you?**
□ Not applicable
0 Not at all
1 Slightly
2 Moderately
3 Greatly

**Q43. Other symptoms?**
(faecal incontinence, vag [illegible] etc)

Page 2 of 2

# The Pelvic Pain Impact Questionnaire

Name: ______________________________ Date: ______________

**Directions:**
For each of the following 8 questions, tick the box that best indicates how much your pelvic pain has affected these aspects of your life during the past month. Your answers to these questions can then be summed to give you a final score.

| In the past month, how much has your pelvic pain affected your: | Not at all (0) | A little bit (1) | Somewhat (2) | Quite a bit (3) | A great deal (4) |
|---|---|---|---|---|---|
| energy levels? | ☐ | ☐ | ☐ | ☐ | ☐ |
| mood? | ☐ | ☐ | ☐ | ☐ | ☐ |
| sleep? | ☐ | ☐ | ☐ | ☐ | ☐ |
| stomach and intestinal function? | ☐ | ☐ | ☐ | ☐ | ☐ |
| ability to sit for longer than 20 minutes? | ☐ | ☐ | ☐ | ☐ | ☐ |
| ability to perform and function normally at home/work/school/university? | ☐ | ☐ | ☐ | ☐ | ☐ |
| ability to take part in physical activity? (e.g. jogging, yoga, bicycling) | ☐ | ☐ | ☐ | ☐ | ☐ |
| ability to wear certain clothes? (e.g. underwear, tight fitting clothes) | ☐ | ☐ | ☐ | ☐ | ☐ |
| | | | | Total: | |

**If the following questions apply to you, please answer. If not, please leave these blank. These questions will not be added to your summed score.**

| | | | | | |
|---|---|---|---|---|---|
| During your last period, how much did your pelvic pain affect your ability to use tampons? | ☐ | ☐ | ☐ | ☐ | ☐ |
| In the past month, how much has your pelvic pain affected your levels of intimacy or sexual relationships? (e.g. having sex, masturbating) | ☐ | ☐ | ☐ | ☐ | ☐ |

**Endometriosis-specific questionnaire – ENDOMETRIOSIS HEALTH PROFILE (EHP)-30** (Only for patients that have a "diagnosis of endometriosis". Surgical patients easily identifiable. Will need to define the group of patients that will have a clinical diagnosis of endometriosis, e.g. based on their symptom profile, with/without imaging assessment)

Definition: A health related quality-of-life (HRQoL) questionnaire specifically addressing the impact of endometriosis on the physical, psychologic, and social aspects of patients' lives.

During the **last 4 weeks**, how often, because of your endometriosis, have you

1: Been unable to go to social events because of the pain?
2: Been unable to do jobs around the home because of the pain?
3: Found it difficult to stand because of the pain?
4: Found it difficult to sit because of the pain?
5: Found it difficult to walk because of the pain?
6: Found it difficult to exercise or do the leisure activities you would like to do because of the pain?
7: Lost your appetite and/or been unable to eat because of the pain?
8: Been unable to sleep properly because of the pain?
9: Had to go to bed/lie down because of the pain?
10: Been unable to do the things you want to do because of the pain?
11: Felt unable to cope with the pain?
12: Generally felt unwell?
13: Felt frustrated because your symptoms are not getting better?
14: Felt frustrated because you are not able to control your symptoms?
15: Felt unable to forget your symptoms?
16: Felt as though your symptoms are ruling your life?
17: Felt your symptoms are taking away your life?
18: Felt depressed?
19: Felt weepy/tearful?
20: Felt miserable?
21: Had mood swings?
22: Felt bad tempered or short tempered?
23: Felt violent or aggressive?
24: Felt unable to tell people how you feel?
25: Felt others do not understand what you are going through?
26: Felt as though others think you are moaning?
27: Felt alone?
28: Felt frustrated as you cannot always wear the clothes you would choose?
29: Felt your appearance has been affected?
30: Lacked confidence?

Coding: All 30 questions are to be answered by selecting one of the options (Tick boxes)

1: Never
2: Rarely
3: Sometimes
4: Often
5: Always

PART 2: MODULAR QUESTIONS

Section A:

These questions concern the effect endometriosis has had on your work during the last 4 weeks. If you have not been in paid or voluntary employment during the last 4 weeks, please tick here and move onto Section B.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1. Had to take time off work because of the pain?
2. Been unable to complete tasks at work because of the pain?
3. Felt embarrassed about symptoms at work?
4. Felt guilty about taking time off work?
5. Felt worried about not being able to do your job?

Section B:

These questions concern the effect endometriosis has had on your relationship with your child/children during the last 4 weeks. If you do not have any children, please tick here and move onto Section C.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1. Found it difficult to look after your child/children?
2. Been unable to play with your child/children?

Section C:

These questions concern the effect endometriosis has had on your sexual relationships during the last 4 weeks.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1. Experienced pain during or after intercourse?
   If not relevant, please tick here
2. Felt worried about having intercourse because of the pain?
   If not relevant, please tick here
3. Avoided intercourse because of the pain?
   If not relevant, please tick here
4. Felt guilty about not wanting to have intercourse?
   If not relevant, please tick here
5. Felt frustrated because you cannot enjoy intercourse?
   If not relevant, please tick here

Section D:

These questions concern your feelings during the last 4 weeks about the medical profession.

If this section is not relevant to you, please tick here  and move onto Section E.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1. Felt the doctor(s) you have seen is (are) not doing anything for you?
2. Felt the doctor(s) thinks (think) it is all in your mind?
3. Felt frustrated at the doctor's/doctors' lack of knowledge about endometriosis?
4. Felt like you are wasting the doctor's/doctors' time?

Section E:

These questions concern your feelings during the last 4 weeks about your treatment for endometriosis. Treatment means any surgery or prescribed medication for your endometriosis.

If this section is not relevant to you, please tick here  and move onto Section F.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1. Felt frustrated because treatment is not working?
2. Found it difficult coping with the side effects of treatment?
3. Felt annoyed at the amount of treatment you have had to have?

Section F:

These questions concern your problems conceiving during the last 4 weeks.

If this section is not relevant to you, please tick here .

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1. Felt worried about the possibility of not having children/more children?
2. Felt inadequate because you may not/have not been able to have children/more children?
3. Felt depressed at the possibility of not having children/more children?
4. Felt that the possibility of not conceiving/not being able to conceive has put a strain upon your personal relationship?

Coding: All Part 2 Modular Questions (Sections A – F) are to be answered by selecting one of the options (Tick boxes)

1: Never
2: Rarely
3: Sometimes
4: Often
5: Always

**Any pelvic pain version questionnaire – ANY PAIN ADAPTATION OF THE ENDOMETRIOSIS HEALTH PROFILE (EHP)-30**

Definition: A health related quality-of-life (HRQoL) questionnaire specifically addressing the impact of endometriosis on the physical, psychologic, and social aspects of patients' lives.

During the **last 4 weeks**, how often, because of your PELVIC PAIN, have you

1: Been unable to go to social events because of the pain?
2: Been unable to do jobs around the home because of the pain?
3: Found it difficult to stand because of the pain?
4: Found it difficult to sit because of the pain?
5: Found it difficult to walk because of the pain?
6: Found it difficult to exercise or do the leisure activities you would like to do because of the pain?
7: Lost your appetite and/or been unable to eat because of the pain?
8: Been unable to sleep properly because of the pain?
9: Had to go to bed/lie down because of the pain?
10: Been unable to do the things you want to do because of the pain?
11: Felt unable to cope with the pain?
12: Generally felt unwell?
13: Felt frustrated because your symptoms are not getting better?
14: Felt frustrated because you are not able to control your symptoms?
15: Felt unable to forget your symptoms?
16: Felt as though your symptoms are ruling your life?
17: Felt your symptoms are taking away your life?
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19: Felt weepy/tearful?
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22: Felt bad tempered or short tempered?
23: Felt violent or aggressive?
24: Felt unable to tell people how you feel?
25: Felt others do not understand what you are going through?
26: Felt as though others think you are moaning?
27: Felt alone?
28: Felt frustrated as you cannot always wear the clothes you would choose?
29: Felt your appearance has been affected?
30: Lacked confidence?

Coding: All 30 questions are to be answered by selecting one of the options (Tick boxes)

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2: Rarely
3: Sometimes
4: Often
5: Always

PART 2: MODULAR QUESTIONS

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These questions concern the effect PELVIC PAIN has had on your work during the last 4 weeks. If you have not been in paid or voluntary employment during the last 4 weeks, please tick here  and move onto Section B.

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1. Had to take time off work because of the pain?
2. Been unable to complete tasks at work because of the pain?
3. Felt embarrassed about symptoms at work?
4. Felt guilty about taking time off work?
5. Felt worried about not being able to do your job?

Section B:

These questions concern the effect PELVIC PAIN has had on your relationship with your child/ children during the last 4 weeks. If you do not have any children, please tick here  and move onto Section C.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR PELVIC PAIN, HAVE YOU...

1. Found it difficult to look after your child/children?
2. Been unable to play with your child/children?

Section C:

These questions concern the effect PELVIC PAIN has had on your sexual relationships during the last 4 weeks.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR PELVIC PAIN, HAVE YOU...

1. Experienced pain during or after intercourse?
   If not relevant, please tick here
2. Felt worried about having intercourse because of the pain?
   If not relevant, please tick here
3. Avoided intercourse because of the pain?
   If not relevant, please tick here
4. Felt guilty about not wanting to have intercourse?
   If not relevant, please tick here
5. Felt frustrated because you cannot enjoy intercourse?
   If not relevant, please tick here

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These questions concern your feelings during the last 4 weeks about your treatment for PELVIC PAIN. Treatment means any surgery or prescribed medication for your endometriosis.

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2. Found it difficult coping with the side effects of treatment?
3. Felt annoyed at the amount of treatment you have had to have?

Section F:

These questions concern your problems conceiving during the last 4 weeks.

If this section is not relevant to you, please tick here .

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR PELVIC PAIN, HAVE YOU...

1. Felt worried about the possibility of not having children/more children?
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