Patient ID: ☐☐☐☐☐

The HOPEFUL Study

Hysterectomy Or Percutaneous Embolisation For Uterine Leiomyomata?

Please note that the index treatment referred to in this questionnaire is your first uterine artery embolisation (UAE) or your hysterectomy (if this was without a prior UAE).

SECTION 1: GENERAL INFORMATION

1. Today's date: ☐☐☐☐☐☐ *(dd/mm/yy)*

2. Please confirm your date of birth. ☐☐☐☐☐☐ *(dd/mm/yy)*

3. Please give us your initials. (This helps us to cross reference for our database without breaching your confidentiality) 1 First name initial ☐ 2 Surname initial ☐

4. What best describes your highest level of education? *(Please tick one box)*
   1 No formal exams taken ☐ 2 O Level/CSE/GCSE ☐ 3 A level/AS/A2 ☐
   4 First degree ☐ 5 Postgraduate Degree ☐ 6 Professional Qualifications ☐

5. What best describes your ethnic origin: *(please tick **one** box only)*
   (These categories are based on those used in the 2001 census of the UK population)

White		**Black or Black British**		**Chinese**	
1 British	☐	4 Caribbean	☐	7 Chinese	☐
2 Irish	☐	5 African	☐		
3 Other white?	☐	6 Other black?	☐		
3b(specify)		6b(specify)			
Mixed		**Asian or Asian British**		**Other ethnic group**	
8 White and Black Caribbean	☐	12 Indian	☐	16 Any other	☐
9 White and Black African	☐	13 Pakistani	☐	16b(specify).....	
10 White and Asian	☐	14 Bangladeshi	☐		
11 Other mixed?	☐	15 Other Asian?	☐		
11b(specify)		15b(specify)			

6. What is your height? a ☐/b ☐☐ (Feet/inches) ***or***c ☐☐☐ (cm)

7. What is your weight now? a ☐☐ /b ☐☐ (Stones/lbs) ***or***c ☐☐.☐ (kg)

8. Please tick the box that you feel best describes your cigarette smoking:

$_1$ never smoked ☐ *If you have never smoked please go straight on to question 10.*

$_2$ current smoker ☐

$_3$ ex-smoker ☐ $_{3b}$ smoked regularly in the past but stopped ☐☐ years ago

9. **a)** Have you smoked any cigarettes at all **during the last 12 months**? $_1$ yes ☐ $_2$ no ☐

b) If yes, approximately how many cigarettes per day? ☐☐

10. What was your age at menarche (first menstrual period)? ☐☐ years

11. a) How many children have you had? ☐

b) If you have had children, how many were born by caesarean section? ☐

12. a) Have you been through the menopause?

$_1$ yes-naturally ☐ $_2$ yes-surgically ☐ $_3$ no ☐ $_4$ not sure ☐

b) If yes, year of menopause: $_{b1}$☐☐☐☐ *(yyyy)*, ***or*** your age at menopause: $_{b2}$☐☐ years old

c) If no or not sure, please tell us **approximately** when was your last period?

Date: $_{c1}$☐☐/$_{c2}$☐☐ *(mm/yy)* **or** age: $_{c3}$☐☐ years.

13. a) Have any of your family members been diagnosed with uterine fibroids?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐

b) If yes, please complete the following:

	$_1$*Relationship to you*	$_2$*Age at diagnosis*	$_3$*Side of family (m=mother, f=father)*
i)			
ii)			
iii)			

14. a) Have any of your family members been diagnosed with breast cancer?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐

b) If yes, please complete the following:

	$_1$*Relationship to you*	$_2$*Age at diagnosis*	$_3$*Side of family (m=mother, f=father)*
i)			
ii)			
iii)			

SECTION 2: PRE TREATMENT

This section is about both your general health and about your health related to your fibroids, before your index treatment (either your first UAE or your hysterectomy).

Part A – General health before index treatment

15. a) Before your index treatment were you ever diagnosed with any of the following gynaecological conditions? *(please tick if yes and give relevant dates and details)*

	Gynaecological conditions	***Yes$_a$***	***Date$_b$***	***Details$_c$***
i)	Pelvic inflammatory disease			
ii)	Urinary tract infection/s			
iii)	Endometriosis			
iv)	Adenomyosis			
v)	Other *(Specify$_{vd}$ .....)*			

b) Before your index treatment were you ever diagnosed with any of the following other medical conditions? *(please tick if yes and give relevant dates and details)*

	Medical conditions	*Yes$_a$*	*Date$_b$*	*Details$_c$*
i)	Diabetes			
ii)	Stroke			
iii)	Pulmonary embolism (blood clot in the lung)			
iv)	Deep vein thrombosis (blood clot elsewhere)			
v)	A benign (non-cancerous) breast lump			
vi)	Osteoporosis (brittle bone disease)			
vii)	Ovarian cancer			
viii)	Other *(Specify$_d$ .....)*			

16. a) Before your index treatment did you have major surgery?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐ *If no or not sure, please go to question 17.*

b) If yes, please fill in the table below *(please tick if yes and give dates and details)*

	Prior surgery	***Yes$_a$***	***Date$_b$***	***Details$_c$***
i)	Were you sterilised (tubes tied/clipped/removed)?			
ii)	Did you have surgery for bowel problems?			
iii)	Did you have surgery for bladder problems?			
iv)	Did you have surgery for endometriosis?			
v)	Did you have a myomectomy?			
vi)	Other surgery? *(Specify.....)*			

17. a) Before your index treatment, were you on hormone replacement therapy (HRT)?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐ *If no or not sure, please go to question 18.*

b) If yes,

i) Approximately how long **in total** did you have HRT prior to your index treatment?

☐☐ yrs ☐☐ months

ii) Please tell us which type of HRT you had prior to your index treatment *(tick 1 or more boxes)*

$_1$ implant ☐ (approximate date of **last** implant: $_{ii1a}$☐☐ / $_{ii1b}$☐☐ *(mm/yy)*)

$_2$ tablets ☐ $_3$ patches ☐ $_4$ other ☐ (Please specify: $_{ii4a}$.....)

$_5$ not sure ☐

Part B – Fibroid specific health before your index treatment

18. a) Before your index treatment did you receive any other treatment for fibroids?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐ *If no or not sure, please go to question 19.*

b) If yes, please fill in the table below *(tick and give dates and details where relevant)*:

	Treatment	***Yes$_a$***	***Date$_b$***	***Details$_c$***
i)	Medical therapy – Gonadotropin-releasing hormone (Gn-RH) agonists			
ii)	Medical therapy – Androgens			
iii)	Medical therapy – Other medication			
iv)	Myomectomy			
v)	Endometrial ablation			
vi)	Myolysis (electrical current treatment)			
vii)	Cryomyolysis (Freezing treatment)			
viii)	Other			

19. We would like to know what the principal symptoms of your fibroids were like prior to your index treatment and whether your treatment changed these symptoms.

a) (i) Before your treatment were you troubled by heavy menstrual bleeding (with or without anaemia)?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐

(ii) If yes, since your treatment has this; $_1$ improved ☐ $_2$ stayed the same ☐ $_3$ worsened ☐

b) (i) Before your treatment were you troubled by painful periods? $_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐

(ii) If yes, since your treatment has this; $_1$ improved ☐ $_2$ stayed the same ☐ $_3$ worsened ☐

c) (i) Before your treatment were you troubled by bulk-related symptoms, for example abdominal mass causing pain, pressure on the bladder or bowel, or other?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐

(ii) If yes, since your treatment has this; $_1$ improved ☐ $_2$ stayed the same ☐ $_3$ worsened ☐

20. At the time of your index treatment for your fibroids which of the following best describes your feelings about your family size? (please tick **one** box)

1 I definitely did not want any/any more children ☐

2 I had hoped I might be able to have children/more children in the future ☐

3 Not sure ☐

4 Other ☐ 4b (*Specify* .....)

We would like to know more about the decisions that led to your index treatment for fibroids.

21. a) Were you offered a choice of treatment for your fibroids at your hospital consultation?

1 yes ☐ 2 no ☐ 3 not sure ☐ *If no or not sure, please go to question 22.*

If yes, please complete the following.

b) What treatments were you offered?

1 hysterectomy ☐ 2 myomectomy ☐ 3 uterine artery embolisation UAE ☐

4 Other ☐ (4b specify.....)

c) Which treatment did you choose?

1 hysterectomy ☐ 2 myomectomy ☐ 3 uterine artery embolisation UAE ☐

4 Other ☐ (4b specify.....)

d) Please could you tell us about what major factors influenced your choice of treatment?

1) .....

2) .....

3) .....

4) .....

5) .....

6) .....

7) .....

8) .....

SECTION 3: POST TREATMENT

This section asks you about your health since your index treatment.

Part A

22. In general, would you say your health is:

$_1$ excellent ☐ $_2$ very good ☐ $_3$ good ☐ $_4$ fair ☐ $_5$ poor ☐

23. How would you rate your health since receiving your fibroid treatment compared with before?

$_1$ much better ☐ $_2$ better ☐ $_3$ about the same ☐ $_4$ worse ☐ $_5$ much worse ☐

24. It is a few years since your treatment for fibroids, and we would like to know what your feelings are now about your treatment. *(Please tick)*

a) My expectations about my treatment have now been fulfilled $_1$ yes ☐ $_2$ no ☐

If no, please tell us why:$_{a2}$.....

.....

b) The treatment has relieved my symptoms $_1$ yes ☐ $_2$ no ☐

c) I feel much better since I had the treatment $_1$ yes ☐ $_2$ no ☐

d) If I needed to have treatment for fibroids I would undergo the same treatment

$_1$ yes ☐ $_2$ no ☐

e) I would recommend this treatment to a friend $_1$ yes ☐ $_2$ no ☐

f) I have suffered from problems caused by the treatment $_1$ yes ☐ $_2$ no ☐
If yes, please give details about the problems:

$_{f2}$.....

.....

.....

25. We would like to know what your bladder function is like now compared with **before** your **index** treatment.

a) (i) Before your treatment were you troubled by a frequent need to urinate during the day?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐

(ii) Since your treatment has this; $_1$ improved ☐ $_2$ stayed the same ☐ $_3$ worsened ☐

b) (i) Before your treatment were you troubled by a frequent need to urinate during the night?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐

(ii) Since your treatment has this; $_1$ improved ☐ $_2$ stayed the same ☐ $_3$ worsened ☐

c) (i) Before your treatment did you lose urine unexpectedly (e.g. when sneezing)?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐

(ii) Since your treatment has this; $_1$ improved ☐ $_2$ stayed the same ☐ $_3$ worsened ☐

26. a) Since your index treatment have you been diagnosed with any of the following gynaecological conditions? *(please tick if yes and give relevant dates and details)*

	Gynaecological conditions	***Yes$_a$***	***Date$_b$***	***Details$_c$***
i)	Pelvic inflammatory disease			
ii)	Urinary tract infection/s			
iii)	Endometriosis			
iv)	Adenomyosis			
v)	Other *(Specify$_{vd}$……)*			

b) Since your index treatment have you been diagnosed with any of the following other medical conditions? *(please tick if yes and give relevant dates and details)*

	Medical conditions	*Yes$_a$*	*Date$_b$*	*Details$_c$*
i)	Diabetes			
ii)	Stroke			
iii)	Pulmonary embolism (blood clot in the lung)			
iv)	Deep vein thrombosis (blood clot elsewhere)			
v)	A benign (non-cancerous) breast lump			
vi)	Osteoporosis (brittle bone disease)			
vii)	Ovarian cancer			
viii)	Other *(Specify$_d$……)*			

27. a) Since your index treatment, have you been admitted to hospital for any reason? This includes day case **or** overnight stays. $_1$ yes ☐ $_0$ no ☐ *If no, please go straight on to question 28.*

b) If yes, for each admission please tell us the approximate date, the reason for your admission and the investigation/treatment you received (if relevant). In addition please indicate number of **nights** you spent in hospital **or** tick the box if you were a day case.

	Date$_a$ *mm/yy*	***Reason/investigation/treatment$_b$***	***No. of nights in hospital$_c$***	***Day case?$_d$ ✓ if yes***
i)	☐☐/☐☐			
ii)	☐☐/☐☐			
iii)	☐☐/☐☐			
iv)	☐☐/☐☐			
v)	☐☐/☐☐			

28. a) Since your index treatment, have you had hormone replacement therapy (HRT) at any time?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐ *If no or not sure, please go to question 29.*

b) *If yes,please complete the following:*

i) Approximately how long **in total** have you had HRT since your index treatment?

☐☐ yrs ☐☐ months

ii) Which type of HRT you have had since your index treatment *(tick 1 or more boxes)*

$_1$ implant ☐ (approximate date of **last** implant:$_{ii1a}$ ☐☐ / $_{ii1b}$ ☐☐ *(mm/yy)*)

$_2$ tablets ☐ $_3$ patches ☐ $_4$ other ☐ (Please specify:$_{ii4a}$.....)

$_5$ not sure ☐

iii) Are you still having HRT? $_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐

$_{iiib}$If yes, please tell us the name of the HRT you are taking now:.....

29. a) We would like to know whether you still have your ovaries or whether they have been removed. Please tick **one** of the boxes below that best describes your case.

$_1$ both ovaries remain ☐ $_2$ one ovary remains ☐ $_3$ both ovaries removed ☐ $_4$ not sure ☐

b) If you now have **no** ovaries, when was the last one removed? ☐☐☐☐☐☐ *(dd/mm/yy)*

Part B – Treatment specific health post index treatment

If you had a hysterectomy but NO previous UAE treatment, please go straight on to Section 4. Answer questions 30 to 34 only if you have ever had UAE treatment for your fibroids.

30. a) Some women may be able to become pregnant after having undergone UAE treatment. Have you been pregnant since your UAE treatment? *(Please tick **one** box)*

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐

b) Please tell us the outcome of your pregnancy: $_{b1}$.....

.....

.....

.....

.....

31. a) Since your first UAE treatment, have you had further UAE treatment?

$_1$ yes ☐ $_2$ no ☐ $_3$ not sure ☐ *If no or not sure, please go to question 32.*

b) If yes, please tell us when you had these further treatments (month/year);

i) first subsequent treatment ☐☐/☐☐

ii) second subsequent treatment ☐☐/☐☐

iii) third subsequent treatment ☐☐/☐☐

32. a) After your UAE treatment(s) did you also have a hysterectomy?

1 yes ☐ 2 no ☐ 3 not sure ☐ *If no or not sure, please go to question 33.*

b) If yes, please could you answer the following if you are able to do so.

i) What was the date of your hysterectomy? ☐☐☐☐☐☐ *(ddmmyy)*

ii) What do you think were the reasons for your hysterectomy? *(you may tick more than one box)*

1 excessive bleeding ☐ 2 pelvic pain ☐ 3 pelvic pressure ☐ 4 urinary problems ☐

5 abnormal cells/CIN2/CIN3 ☐ 6 not sure ☐ 7 other ☐ 7a *Please specify* .....

33. a) After your UAE treatment(s) did you also have a myomectomy (surgical removal of fibroids only, keeping your uterus (womb))?

1 yes ☐ 2 no ☐ 3 not sure ☐ *If no or not sure, please go to question 34.*

b) If yes, please could you answer the following if you are able to do so.

i) What was the date of your myomectomy? ☐☐☐☐☐☐ *(ddmmyy)*

ii) What do you think were the reasons for your myomectomy? *(you may tick more than one box)*

1 excessive bleeding ☐ 2 pelvic pain ☐ 3 pelvic pressure ☐ 4 urinary problems ☐

5 abnormal cells/CIN2/CIN3 ☐ 6 not sure ☐ 7 other ☐ 7a *Please specify* .....

34. We would like to know what your periods were like **after treatment**, compared with **before** your **first** UAE treatment.

a) Compared with before your first UAE treatment, how often did your periods come after your first UAE treatment?

1 have no periods ☐ 2 less often ☐ 3 about the same as before ☐ 4 more often ☐

If you have no periods go straight on to Section 4, question 35

b) Compared with before your first UAE treatment, for how long did your menstrual bleeding last after your first UAE treatment?

1 far fewer days ☐ 2 fewer days ☐ 3 about the same ☐ 4 more days ☐ 5 many more days ☐

c) Compared with before your first UAE treatment, how heavy were your periods after your first UAE treatment?

1 very much lighter ☐ 2 lighter ☐ 3 unchanged ☐ 4 heavier ☐ 5 very much heavier ☐

d) Before your first UAE treatment did you suffer from period pains?

1 no pains ☐ 2 mild pains ☐ 3 moderate pains ☐ 4 severe pains ☐

e) Compared with before your UAE treatment what was your experience of period pains after your first UAE treatment? 1 better ☐ 2 about the same ☐ 3 worse ☐

SECTION 4: OTHER INFORMATION

Everyone, please fill in the following section

35. If there is anything else about your treatment/s for fibroids and your health which is important to you, please tell us in the space below: (for example this might include your feelings about your fertility, your uterus or ovaries)

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Thank you very much for your help.