

YouUr First Choice

Patient Information and Choice – UFE Patient Survey

YouUr First ChoiceE: An On-Line Survey of Women with Fibroids, the Information, Choice and Access They Had to Uterine Artery/Fibroid Embolisation and Alternatives to Hysterectomy for the Treatment of Fibroids

Title of Report: YouUr First ChoiceE: Patient Information and Choice A UFE Patient Survey - An On-Line Survey of Women with Fibroids, the Information, Choice and Access They Had to Uterine Artery/Fibroid Embolisation and Alternatives to Hysterectomy for the Treatment of Fibroids

Key words: UFE, UAE, embolisation, uterine artery embolisation, uterine fibroid embolisation, embolization, uterine fibroids, patients, choice, information; NICE Guidance.

1. BACKGROUND

Fibroids are a major public health issue affecting up to 80% of women, with 20% requiring treatment for symptoms such as heavy and painful periods, bulk symptoms and infertility. Sixty percent of all hysterectomies (approximately 39,000 p.a. in total) carried out in the NHS in England are for fibroids. More are carried out in the private sector.

Uterine Fibroid/Artery Embolisation [UFE or UAE] is a newer medical technology, started in the 1980s in France. It is an interventional radiology treatment for symptomatic fibroids, which is much less invasive than the standard treatment - abdominal hysterectomy, allows women to maintain their fertility (and to become pregnant) and return to work/normal life much quicker. It has been shown to be safe and effective by two NICE Interventional Procedures Reviews and it is recommended in NICE Clinical Guidelines on Heavy Menstrual Bleeding '07 as a first line treatment for women with symptomatic fibroids over 3cm, wishing to retain their uterus. NICE Guidelines also state that women should be offered this treatment, as well as hysterectomy and myomectomy. UFE is also much less expensive to both women and the NHS.

Despite NICE Guidelines many women are still contacting FEMISA asking how to access UFE and/or alternatives to hysterectomy and are still not being told about or offered UFE or other alternatives to hysterectomy.

FEMISA and the Medical Technology Group (FEMISA is a member) has therefore asked women to complete this on-line survey on what treatments they were offered and told about for their symptomatic fibroids. The survey ran from March to September 2011 and FEMISA is grateful to Woman's Hour for highlighting these issues and all the women for taking the time to complete the survey.

The questionnaire can be found in Appendix 1.

2. RESULTS

The full results and comments can be found in Appendix 2. The results reported here are those which are particularly important issues concerning access and choice for women.

2.1 About the Respondents

Ages ranged from 20 to over 60, with the largest number being in the age range 41-50 - 60% and 23% 31-40. Numbers of fibroids ranged from 1 to more than 5 with over 82% being over 3cm. The majority (59%) did not want a future pregnancy, although 26% did and 14% were undecided.

2.2 Information from GPs

The GP is the first port of call for women with symptomatic fibroids and although fibroids are perhaps one of the commonest health issues affecting women the vast majority of GPs do not give women complete or up to date advice about treatment options. 43% did not discuss treatment options with their GP, and while 42% of GPs mentioned hysterectomy only 14% mentioned fibroid embolisation and 19% myomectomy (which is not a new treatment). The advice they do give appears to be out of date and they do appear to be aware of NICE Guidelines or to follow them.

Which treatment options did your GP tell you about when your fibroids were diagnosed?

Answer Options	%
Drug Treatment (hormones/GnRH analogues/fibrinolytics)	32%
Endometrial Ablation	13%
Fibroid Embolisation	14%
Hysterectomy	42%
MR-guided Focused Ultrasound	3%
Myomectomy	19%
I did not discuss treatment options with my GP	43%
Other (please specify)	

Some illustrative comments from women who responded –

“I discussed this with my consultant, GP didn't know very much”

“Was told options were surgery or live with it - and that until I was prepared to have surgery she would not refer me and I shouldn't come back about it. (Have had myomectomy 5 years ago)”

“Referred to Gynaecology to discuss treatment options”

Conclusions

Fibroids are a very common public health issue and women might reasonably expect their GPs to advise them on treatment and keep themselves up to date with advances in treatment. UFE is the first line treatment for women with symptomatic fibroids [>3cm] wishing to maintain their uterus and yet only 14% of women were told about this by their GP.

2.2. Information and Choices from Gynaecologists

The differences in the treatments women are informed about and those offered is very disturbing. 73% are told about hysterectomy and 52% offered it. This contrasts with only 45% being told about fibroid embolisation and only 37% offered it and myomectomy 43% told about and only 21% offered. Drug treatment is normally only a temporary solution and 38% were told about this and only 28% offered it.

Answer Options	% Told About	% Offered
Drugs Treatment (hormones/GnRH analogues)	38%	28%
Endometrial Ablation	17%	11%
Fibroid Embolisation	45%	37%
Hysterectomy	73%	52%
MR-guided Focused Ultrasound	4%	2%
Myomectomy	43%	21%

Women's comments -

"I suggested to Gynaecologist about embolisation & he said it was an option but they didn't do it. I'd have to go elsewhere. This is perhaps why he didn't mention it to me???"

"I was instructed because of my age and marital status that I should have a hysterectomy and it was me who asked about embolisation"

Conclusion

The women were not fully informed about all the treatment options available to them or the possible complications and side effects of each. This is contrary to NICE Clinical Guidelines, GMC Guidelines and Government policy of fully informed patients and 'no decision about me without me'.

UFE

The number offered UFE, is possibly higher than might be expected, but it is apparent from some of the individual comments that some offers of UFE were initiated by the women themselves.

NICE Guidelines state that UFE should be considered as a first line treatment for women with symptomatic fibroids >3cm, wishing to retain their uterus.

Approximately 70% of women who were informed about UFE were in the main given adequate information about possible side effects and risks, although in 30% women were given little or incomplete information and in a few cases the information given was incorrect. One woman was told she was unsuitable for UFE, but in fact very few women are unsuitable.

Hysterectomy

NICE guidelines state that *"Taking into account the need for individual assessment, the route of hysterectomy should be considered in the following order: first-line vaginal; second-line abdominal"*. However, in our survey the type of hysterectomy was not discussed with 44% of women; vaginal and laparoscopic, less invasive options with only 7% [for each type], abdominal the most invasive type with 33% and with 10% total hysterectomy with removal of ovaries. NICE specifically bans the removal of healthy ovaries.

Women's comments -

"They didn't specify I HAD TO ASK THE DOCTOR!!!!"

"It was not clear which type but this is the one that I assume I was having as I was not aware there are so many different ones"

"I refused a hysterectomy therefore no information was given to me."

80% of the women offered hysterectomy were not fully informed about the risks and possible side effects. Of particular concern is that fact that only 15% were told about the risk of death.

Myomectomy

Although women with fibroids larger than 3cm are supposed to be offered myomectomy only 30% were and 70% of those were offered the most invasive type – abdominal myomectomy rather than laparoscopic/hysteroscopic. Only 10% were fully informed about the possible risks and side effects. Many gynaecologists only offer myomectomy to younger women wishing to become pregnant. This may be why some women were deemed unsuitable for this treatment.

Women's comments –

"I had a myomectomy in 2004 and embolisation this year"

"I was not a suitable candidate for this procedure"

"Due to the negativity of my gynaecologist I never discussed this - his attitude as 'of course if this doesn't work we'll just give you a hysterectomy' I was left feeling that if I went forward for surgery, I would end up with a hysterectomy which I really didn't want"

Information and Choice

59% of women felt they had not been given sufficient information about treatment options and their advantages and disadvantages. Asked what additional information they would have liked 73% responded – "about treatment choices". The lowest percentage was about hysterectomy, presumably because they had been better informed about this originally.

Answer Options	Response Percent
About treatment choices	73.0%
About drug treatments	45.9%
About endometrial ablation	50.0%
About fibroid embolisation	75.7%
About hysterectomy	47.3%
About MR-guided focused ultrasound	54.1%
About myomectomy	51.4%

Women's comments –

"what choices are available for me since I have no children and would like some one day"

"written info would have been helpful"

"I would have liked to have been offered a full choice of appropriate treatment"

About Fibroid Embolisation -

“what it is and would it be an option for me”

“I would like to have had this sooner”

About Myomectomy –

“I don't know what this is”

“what it is and would it be an option for me”

About Hysterectomy -

“gynaecologist mentioned this in the 10 minutes I was laying on the bed during and after the hysteroscopy”

“how it affects sex, plus urinary problems”

“there wasn't time the clinic was running 1/12 hrs behind”

81% of women supplemented the information they were given by their gynaecologist mainly from internet searches (97%), friends, colleagues or relatives (38%), NHS Choices (24%) and press articles (21%).

Women's comments -

“BBC - website and Women's Hour broadcast”

“Research on the internet”

“PubMed and Medline search for systematic reviews and scholarly articles”

“I really would have preferred UAE but I was told that it would be up to 6 months to get funding decision, referral to another trust and the final decision as to whether I was suitable. If UAE is not available everywhere it should be made easier to access treatment via another trust, I was told I would have to have another MRI done by the trust who offers UAE, couldn't understand why that trust couldn't use the one I'd already had done. I researched my options as all gynae could do was give me a leaflet on UAE, he was unable to discuss it with me as clinically he didn't have the experience. The internet was my support in making the decision to go for UAE, but unfortunately the NHS made it too complicated to access it. My uterus weighed 2.2 kg post hysterectomy”.

“My GP & Gynaecologist both want me to have a hysterectomy. I want to make an informed decision so have booked a private MRI scan & consultation with a fibroid specialist to enable me to do this. I feel I had no other option”

3. BARRIERS TO ACCESS TO PATIENT CHOICE AND NEWER LESS INVASIVE MEDICAL TECHNOLOGIES

Suggestions from One Woman -

“Some doctors should listen to their patients look at their records and investigate not just write a prescription.

Some Consultants need to be aware of the full range of treatments, the effects on the individual and their right to choose.

The GPs and hospital X need to drastically improve their care and administration. Something that could have been identified and treated quickly, efficiently and at fraction of the cost - physical, financial resources

3.1. GPs

The lack of knowledge by GPs and apparent failure to keep themselves up to date about treatment options and new medical technologies is very concerning. GPs are the first port of call for women [indeed all patients] and should support them. How can GPs support and advise their patients about the best treatment for them, if they do not know what treatments are available? Fibroids are extremely common, not a rare disease. They appear to be unaware of NICE guidelines or GMC Guidelines concerning patient information and informed choice.

This is a barrier for patients to access less invasive treatments and newer medical technologies. Soon GPs will lead the commissioning of healthcare for their patients. Do they need mandatory updates on treatments to do this?

In a recent Parliamentary answer to a question from Chris Heaton Harris MP for MTG –

(2) what plans he has to improve GP training on uterine fibroid embolisation to enable women with fibroids to choose such therapy as an alternative to hysterectomy; [49229]

(3) what information he plans to make available to patients with fibroids to enable them to make an informed decision about their treatment and care based on the different options available; [49230]

(4) whether he plans to encourage GPs to offer uterine fibroid embolisation to women with fibroids as an alternative to hysterectomy in line with the National Institute of Health and Clinical Excellence's clinical guideline 44 on heavy menstrual bleeding. [49231]

The answer from Ann Milton was -

“The content of curriculum and quality and standard of training for medical professions is the responsibility of the appropriate professional regulatory body. The content and standard of medical training is the responsibility of the General Medical Council (GMC), which is the competent authority for medical training in the United Kingdom. GMC is an independent professional body.”

In view of this response we would ask what is the Royal College of GPs and the GMC going to do to improve the training of GPs to ensure they are up to date with treatment options for common diseases? How will they monitor and management this to ensure patients have the information they need to make a properly informed choice about treatment and be fully informed, unlike the experience of some of the women who responded to our survey?

3.2. Gynaecologists

In order to make informed decisions about their treatment patients/women need full information about all treatment options and their advantages, disadvantages and risks. Women are not receiving this from many gynaecologists.

Historically there has been some professional rivalry between gynaecologist and interventional radiologists, who perform UFE (and focused ultrasound) about referring women for UFE and shared care. FEmISA has been pleased to see to see this relationship improve for the benefit of patients.

However, it would appear from the results of this survey, that women are still not being properly or fully informed about all their treatment options and are not being given sufficient information to make an informed decision. Many gynaecologists are not compliance with NICE Clinical Guidelines on Heavy Menstrual Bleeding, GMC Guidelines on informing patients or Government policy on 'no decision about me without me'. Some must use the excuse that NICE Guidelines say that UFE should be "considered" as a first line treatment for women who wish to retain their uterus as their prerogative to not inform the women about this option at all. This is totally unacceptable.

NICE Guidelines go on to say that *"Taking into account the need for individual assessment, the route of hysterectomy should be considered in the following order: first-line vaginal; second-line abdominal hysterectomy"*.

Hospital episode statistics show the overall numbers of hysterectomies in the NHS in England 09-10 were 39,396 Finished Consultant Episodes. Of these ~79% were abdominal, the most invasive type with the longest recovery time for women, while only 21% were vaginal or hystero/laparoscopic which NICE advocates.

Myomectomy is supposed to be offered to women as an alternative to hysterectomy and UFE, but only 30% of women were offered this. Some gynaecologists consider this is only a treatment for younger women wishing to become pregnant and it is not available at many hospitals. As seen with hysterectomy although laparo/hysteroscopic treatments are available, which are less invasive with quicker recovery times most myomectomies are abdominal. Myomectomy represents only 6% of combined hysterectomy and myomectomy treatments.

A Woman's Comment –

"I'm appalled by how little is known about fibroids by the gynaecologists that I have encountered. I am always told there is so little research into it as it's not life threatening and also not many women suffer from fibroids. I can't believe the amount of research I have had to do myself and also that I have had to pass onto my gynaecologist. Surely they have to continue to keep their knowledge up to date with advancements in health care and procedures. How can embolisation still be referred to as 'cutting edge' when it has been performed in my hospital for 9-10 years? The entire process has left me constantly questioning medical professionals who I previously thought were highly intelligent and caring individuals. I have been disgusted with the advice that has been provided to me throughout my late 20's and now that I am entering the ripe old age of 36 it does not bode well for future consultations. Staying positive has been very difficult!"

FEmISA and MTG would be pleased to work with the Royal College of Obstetricians and Gynaecologist to help gynaecologists appreciate a women's perspective on treatment and on the information they require. Gynaecologists treat a very large number of women each day, but for the women it is life changing experience and they have to live with the results of their treatment.

“My horror is the way gynaecologists want a quick fix and view your womb only as a tool for child-bearing”

3.3. Information

Women/all patients need comprehensive unbiased information about all the treatment options. One woman advocated information leaflets and in fact NICE suggests this before their outpatient appointment.

The best way to ensure full unbiased information are patient information leaflets on all the treatment options and their pros and cons. Most people are not used to hospital appointments and find this very stressful. Anxiety about their condition and treatment can mean that not all the information is taken in. Comprehensive, objective leaflets that they can take home, read, discuss and ask questions about is the best way of informing patients.

Despite the fact that Hospital Trusts have web sites, few are used as they could be to provide patient information. There are some excellent examples of how Trust web sites can be used.

The University of Southampton NHS FT has a page on each of the medical specialities and the page on gynaecology includes a link to a page on UFE and a patient story from who a women who had this treatment. The web site also contains information about each consultant and their particular areas of interest, expertise and research. As patients will be able to choose their consultant team as well as hospital other Hospital Trusts should follow this excellent example.

The Oxford Radcliffe Hospital contains information on the web site about the treatments they offer for fibroids, including UFE and laparoscopic and vaginal hysterectomy. It also gives some information about the gynaecologists.

Most hospital web sites do not mention the treatments they offer, the consultants who perform them or have patient information leaflets on treatment procedures.

3.4. NHS Processes and Referrals

It was particularly sad to see the comment from the respondent who had to have a hysterectomy she did not want as the referral to another hospital for UFE would have taken far too long. Others complained of funding arguments between the local PCT and the hospital providing UFE.

FEmISA has found it necessary to research and provide information on all the hospitals providing UFE as where possible myomectomy, as this information is not available on NHS Choices or NHS Direct web sites.

With national ‘Payment by Results’ tariffs for fibroid treatments and a ‘Best Practice’ tariff for UFE there should be no excuse or delay in referring patients. PCTs should provide funding for treatments such as UFE recommended in NICE Guidelines. FEmISA sometimes has to assist women in gaining access to UFE and this should not be necessary.

A woman’s Experience

“I am requesting that those who are patients of the NHS receive a tailored letter to their symptoms/level of discomfort and most importantly, that the word 'elective' is spelled out, i.e. that although a date may be scheduled and someone such as me has family flying over to provide after care and a coil to stem the bleeding, the procedure may not happen at all. This was the case with

me and my bleeding because so out of control that I could either get signed off work until such time as I could be treated or be taken off the Trust's books and go private. The latter I did by obtaining a bank loan!"

APPENDICES

APPENDIX 1 – QUESTIONNAIRE

Patient Information and Choice

THE NHS white paper 'Equity and Excellence: Liberating the NHS' states that patients can choose their treatments, their consultant and their hospital. We need information to enable us to make these choices.

NICE Guidelines for 'Heavy Menstrual Bleeding' (including treatment for fibroids) states that women seeking treatment with fibroids of over 3cm must be offered fibroid embolisation, myomectomy and hysterectomy.

We know from the enquiries we receive that this does not always happen, so we would be grateful if you could fill in this quick questionnaire, which is anonymous, about your experience. We will feed what is actually happening back to the NHS to improve the situation and help other women. The survey will only take a few minutes. Please tick the choices or put comments in the boxes. You can skip questions or leave the survey if you want to.

Thank you for your help.

1. Which treatment options did your GP tell you about when your fibroids were diagnosed?

Please tick appropriate box(es)

Drug Treatment (hormones/GnRH analogues/fibrinolytics)	<input type="radio"/>
Endometrial Ablation	<input type="radio"/>
Fibroid Embolisation	<input type="radio"/>
Hysterectomy	<input type="radio"/>
MR-guided Focused Ultrasound	<input type="radio"/>
Myomectomy	<input type="radio"/>
I did not discuss treatment options with my GP	<input type="radio"/>

Other (please specify)

2. Which diagnostic tests did you have?

- Blood test for hormone levels
- Ultrasound scan
- MRI scan
- Hysteroscopy [a scope through your abdomen]

Other (please specify)

Patient Information and Choice

3. How many fibroids were you told you had?

- 1
 2
 3
 4
 5
 More than 5
 Wasn't told

4. Did you wish to have a future pregnancy?

- Yes
 No
 Undecided

5. Please could you indicate what age group you are in.

6. Which treatment options did your gynaecologist tell you about and which were offered to you?

	Told About	Offered
Drugs Treatment (hormones/GnRH analogues)	<input type="checkbox"/>	<input type="checkbox"/>
Endometrial Ablation	<input type="checkbox"/>	<input type="checkbox"/>
Fibroid Embolisation	<input type="checkbox"/>	<input type="checkbox"/>
Hysterectomy	<input type="checkbox"/>	<input type="checkbox"/>
MR-guided Focused Ultrasound	<input type="checkbox"/>	<input type="checkbox"/>
Myomectomy	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify)

Patient Information and Choice

7. What information were you given about the treatments you were offered?

	Length of hospital stay	Possible short-term complications	Home assistance needed	Restrictions on activity while recovering	Medium and longterm complications/side effects	Time back to work	Time to feeling completely well	Death risk/rate	Not told
Drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Endometrial Ablation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fibroid Embolisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Myomectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hysterectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MR-guided Focused Ultrasound	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Were any of your fibroids larger than 3cm?

(Fibroids larger than 3cm MUST be offered fibroid embolisation, myomectomy and hysterectomy?)

- Yes
 No
 Wasn't told/don't know

9. Were you offered endometrial ablation?

- Yes
 No

10. Please tell us what information you were given about endometrial ablation?

Length of hospital stay

Possible short-term complications

Home assistance needed

Restrictions on activity while recovering

Medium and longterm complications/side effects

Time back to work

Time to feeling completely well

Death risk/rate

11. Were you offered drug treatments - GNHR/hormones or fibrinolytics?

- Yes
 No

Patient Information and Choice

12. Please tell us what information you were given about the drug treatments?

Length of time they can be used

Possible short-term complications

Medium and longterm complications/side effects

Time to feeling completely well

Death risk/rate

13. Were you offered fibroid embolisation?

Yes

No

14. Please tell us what information you were given about fibroid embolisation?

Length of hospital stay

Possible short-term complications

Home assistance needed

Restrictions on activity while recovering

Medium and longterm complications/side effects

Time back to work

Time to feeling completely well

Death risk/rate

15. Were you offered a hysterectomy?

Yes

No

Patient Information and Choice

16. What options for the type of hysterectomy were you given?

- None
- Abdominal
- Vaginal
- Laparoscopic
- Total hysterectomy - womb and cervix (neck of the womb) are removed.
- Subtotal hysterectomy - womb is removed leaving the cervix (neck of the womb) in place
- Total hysterectomy with bilateral salpingo-oophorectomy: the womb, cervix, fallopian tubes (salpingectomy) and the ovaries (oophorectomy) are removed
- Radical hysterectomy - the womb and surrounding tissues are removed, including the fallopian tubes, part of the vagina, ovaries, lymph glands and fatty tissue.

Other (please specify)

17. Please tell us what information you were given about hysterectomy?

Length of hospital stay	<input type="text"/>
Possible short-term complications	<input type="text"/>
Home assistance needed	<input type="text"/>
Restrictions on activity while recovering	<input type="text"/>
Medium and longterm complications/side effects	<input type="text"/>
Time back to work	<input type="text"/>
Time to feeling completely well	<input type="text"/>
Death risk/rate	<input type="text"/>

18. Were you offered MR-Guided focused ultrasound?

- Yes No

Patient Information and Choice

19. Please tell us what information you were given about MR-guided focused ultrasound?

Length of hospital stay

Possible short-term complications

Home assistance needed

Restrictions on activity while recovering

Medium and longterm complications/side effects

Time back to work

Time to feeling completely well

Death risk/rate

20. Were you offered a myomectomy?

Yes

No

21. If you were offered myomectomy what options were you given?

Abdominal

Laparoscopic

Hysteroscopic

Other (please specify)

Patient Information and Choice

22. Please tell us what information you were given about myomectomy??

Length of hospital stay	<input type="text"/>
Possible short-term complications	<input type="text"/>
Home assistance needed	<input type="text"/>
Restrictions on activity while recovering	<input type="text"/>
Medium and longterm complications/side effects	<input type="text"/>
Time back to work	<input type="text"/>
Time to feeling completely well	<input type="text"/>
Death risk/rate	<input type="text"/>

23. Did you feel you were given sufficient information about the treatment options available and their advantages and disadvantages/complications?

- Yes
 No

24. What additional information would you liked to have been given?

About treatment choices	<input type="text"/>
About drug treatments	<input type="text"/>
About endometrial ablation	<input type="text"/>
About fibroid embolisation	<input type="text"/>
About hysterectomy	<input type="text"/>
About MR-guided focused ultrasound	<input type="text"/>
About myomectomy	<input type="text"/>

25. Did you supplement the information given by your gynaecologists from elsewhere?

- Yes No

Patient Information and Choice

26. If yes where did you find the information?

- Web site
- Women's magazines
- Press articles
- Patient Groups
- NHS Choices
- NHS Direct
- Your GP
- Friend, colleague or relative
- Local Hospital web site

Other (please specify)

27. If you have had or chosen a treatment for your fibroids which treatment did you choose and why?

Drugs - (short-term up to 6 months)

Endometrial Ablation

Fibroid Embolisation

Hysterectomy

MRI focused ultrasound

Myomectomy

Other please specify

28. Please could you tell us

Where you live - Town and Country

The name of the hospital you attended

The name of your gynaecologist if known

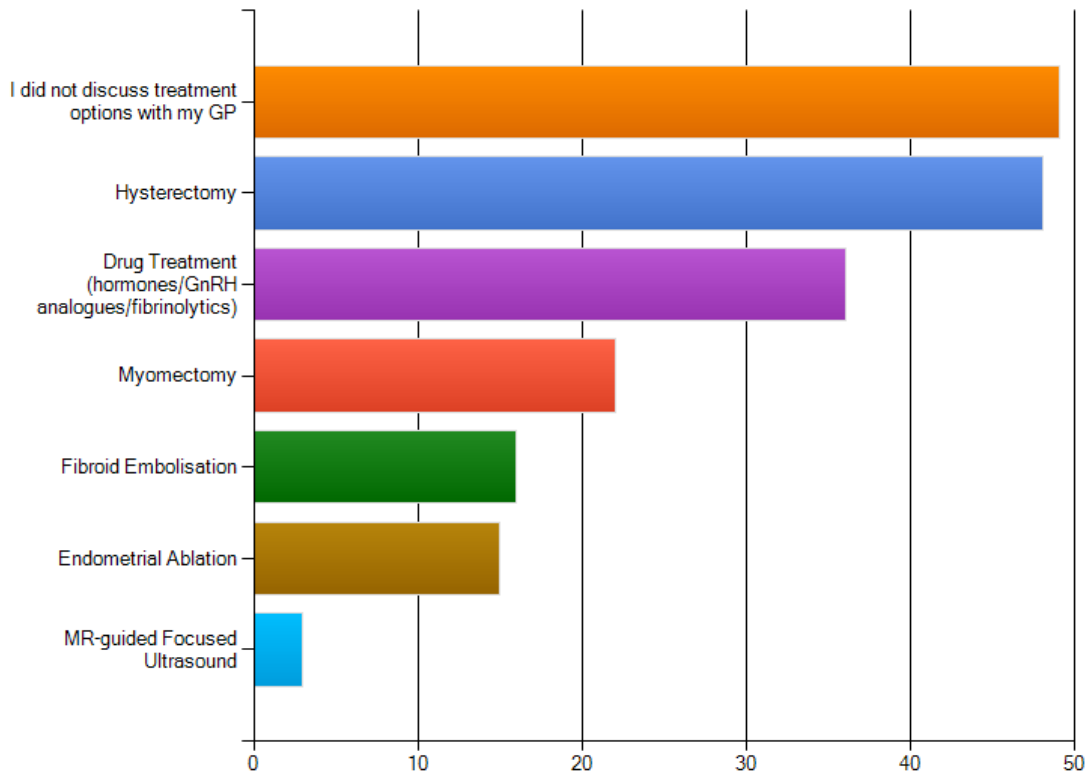
29. Please tell us about your experience and add any other suggestions or comments you may have which would improve the diagnosis, information and choices you were given to help others

APPENDIX 2 – SURVEY RESULTS

Question 1.

Which treatment options did your GP tell you about when your fibroids were diagnosed?		
Answer Options	%	Response Count
Drug Treatment (hormones/GnRH analogues/fibrinolytics)	32%	36
Endometrial Ablation	13%	15
Fibroid Embolisation	14%	16
Hysterectomy	42%	48
MR-guided Focused Ultrasound	3%	3
Myomectomy	19%	22
I did not discuss treatment options with my GP	43%	49
Other (please specify)		22
<i>answered question</i>		113
<i>skipped question</i>		7

Which treatment options did your GP tell you about when your fibroids were diagnosed?



Individual Comments

Number	Other (please specify) Categories
1	I was told by Gynaecologist that I had to have them surgically removed. I've been given the date of the op but no other information. I plan to telephone her secretary tomorrow

	and request more details e.g. what is op etc. I was made to sign a consent form and Gynae explained that in the event of heavy bleeding during the op they may have to do a hysterectomy.
2	hysteroscopy and resection of fibroids and Mirena
3	discussed with consultant
4	I discussed this with my consultant, GP didn't know very much.
5	The Gynaecologist offered me Hysterectomy after trying HRT treatment for 3 months
6	wasn't really given the opportunity to discuss
7	I was given tranexemic acid and told to get on with it
8	mirena? coil Was told options were surgery or live with it - and that until I was prepared to have surgery she would not refer me and I shouldn't come back about it. (Have had myomectomy 5 years ago)
9	It was the consultant who advised me on treatment and I went on to have two myomectomies.
10	myomectomies.
11	mirena coil (for progesterone)
12	Referred to Gynaecology to discuss treatment options
13	GP found lump referred me to gynaecologist.
14	Just wait for the menopause during which time fibroid will shrink naturally
15	A consultant gave me options - not GP
16	The mirena coil and a combination of tranexamic and mefenamic acid
17	Mirena coil
18	my GP referred me to a gynaecologist after seeing a suspicious growth of some sort
19	uterine coil I did not discuss treatment options as my dr wanted to refer me for confirmation that it was fibroids.
20	was fibroids.
21	I was referred to gynae dept by a hospital consultant
22	watch and wait

Question 2.

Which diagnostic tests did you have?		
Answer Options	Response Percent	Response Count
Blood test for hormone levels	27.0%	31
Ultrasound scan	94.8%	109
MRI scan	22.6%	26
Hysteroscopy [a scope through your abdomen]	20.0%	23
Other (please specify)		9
<i>answered question</i>		115
<i>skipped question</i>		5

Individual Comments

Number	Response Date	Other (please specify)	Categories
1		CT Scan and womb biopsy	
2		Hysteroscopy via vagina; CT scan	
3		None	
4		MRI done abroad	
5		Polpectomy/TCHF	
6		Internal examination	
7		Biopsy of the fibroids	

8
9

vaginal
scan
CT Scan

Conclusion

Most women had ultrasound scans, which is the normal diagnostic test for fibroids, although the number and position of fibroids can usually only be shown with an MRI scan. Few blood tests were performed. MRI is preferred before fibroid embolisation as it shows the size, number and position of fibroids.

Question 3.

How many fibroids were you told you had?		
Answer Options	Response Percent	Response Count
1	22.7%	27
2	11.8%	14
3	8.4%	10
4	3.4%	4
5	4.2%	5
More than 5	28.6%	34
Wasn't told	21.0%	25
<i>answered question</i>		119
<i>skipped question</i>		1

Conclusion

Interestingly the largest proportion had more than 5 fibroids, which is particularly suitable for embolisation treatment. Nearly 19% were not told, probably because they only had ultrasound which would not have been detailed enough to tell.

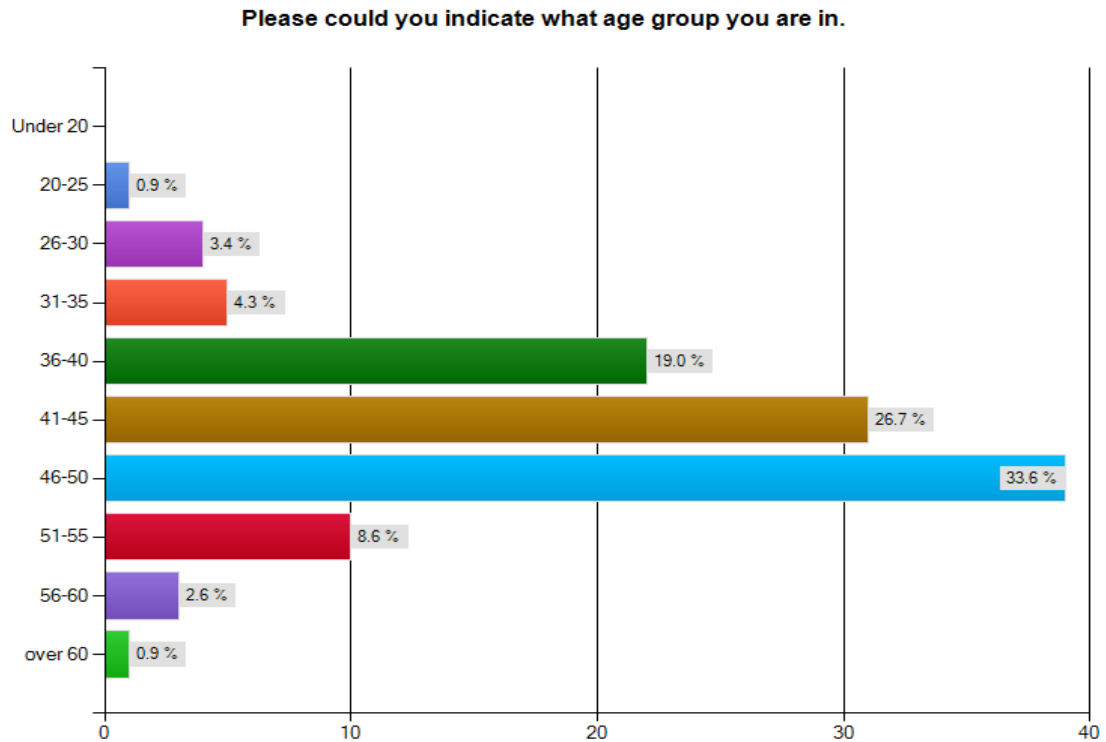
Question 4.

Did you wish to have a future pregnancy?		
Answer Options	Response Percent	Response Count
Yes	26.3%	31
No	59.3%	70
Undecided	14.4%	17
<i>answered question</i>		118
<i>skipped question</i>		2

Conclusion

Most, nearly 60% did not want a future pregnancy, but this is unsurprising as fibroids are of most nuisance to women in their 40s.

Question 5.



Conclusion

It could be assumed that women under 40 would potentially be of child bearing age. This represents 31% of respondents.

Question 6.

Which treatment options did your gynaecologist tell you about and which were offered to you?					
Answer Options	% Told About	Told About	% Offered	Offered	Response Count
Drugs Treatment (hormones/GnRH analogues)	38%	39	28%	29	45
Endometrial Ablation	17%	18	11%	11	21
Fibroid Embolisation	45%	47	37%	38	57
Hysterectomy	73%	76	52%	54	87
MR-guided Focused Ultrasound	4%	4	2%	2	6
Myomectomy	43%	45	21%	22	47
Other (please specify)					23
<i>answered question</i>					104
<i>skipped question</i>					16

Individual Comments

Number	Response Date	Categories
1		treatment option is this operation, was not told the name of it
2		come off HRT or face major surgery
3		None
4		None just told by 2 GPs at the practice that one I'm menopausal the problem will be resolved had the Mirena coil fitted, after having polyps removed- this (coil) worked well for a while, but then very heavy bleeding reoccurred(I called it a reverse period- 20 odd days bleeding, then 5/6 days no bleed!) eventually the coil came out and this was found out at a check at the hospital for a scan. this all happened before I had y two sons, but have very bad pains and have been told my fibroids are in the wall of the uterus, also have polycystic ovaries. I
5		Not been referred - see note above
6		Resection
8		tranexamic acid/mefenemic acid referred from Lewisham to Guys nearly a year ago. Dispute over who pays for the MRI. After many phone calls and letters from my GP Guys will now see me in Aug
9		Tran cervical resection (TCRF)
10		none
11		Didn't see gynaecologist
12		none
13		Didn't see a gynaecologist
14		I suggested to Gynaecologist about embolisation & he said it was an option but they didn't do it. I'd have to go elsewhere. This is perhaps why he didn't mention it to me???
15		was only told about embolisation when I asked myself and was told it was an unproven procedure, was only referred to a radiologist after I needed an iron infusion because hb levels had dropped (3 months later needed a 5 unit blood transfusion)s
16		I was instructed because of my age and marital status that I should have a hysterectomy and it was me who asked about embolisation
17		Mirena coil
18		tranexamic acid
19		uterine coil
20		Mirena IUS devise
21		coil
22		watch and wait
23		

Conclusion

The women were not fully informed about all the treatment options available to them. This is contrary to NICE Clinical Guidelines, GMC Guidelines and Government policy of fully informed patients and 'no decision about me without me'.

The number offered UFE, is possibly higher than might be expected, but it is apparent from some of the individual comments that some offers of UFE were initiated by the women themselves.

NICE Guidelines state that UFE should be considered as a first line treatment for women with symptomatic fibroids >3cm, wishing to retain their uterus. All guidelines seem to be widely ignored and women are not being properly informed or given a full choice of treatments.

Question 7.

What information were you given about the treatments you were offered?											
Answer Options	Length of hospital stay	Possible short-term complications	Home assistance needed	Restrictions on activity while recovering	Medium and long term complications/side effects	Time back to work	Time to feeling completely well	Death risk/rate	% Not Told	Not told	Response Count
Drugs	4	14	2	2	13	4	7	4	64%	36	56
Endometrial Ablation	4	2	2	2	4	2	2	2	83%	34	41
Fibroid Embolisation	30	23	4	9	17	23	16	13	43%	27	63
Myomectomy	23	19	9	11	13	17	8	8	49%	28	57
Hysterectomy	36	29	17	29	26	32	23	15	46%	39	84
MR-guided Focused Ultrasound	1	1	1	1	1	1	1	1	97%	34	35
									59%	198	336
										<i>answered question</i>	106
										<i>skipped question</i>	14

Conclusion

Patients should be fully informed about the risks and benefits of all the treatments available to make a fully informed decision. It is extremely concerning that approximately 60% were not. They cannot possibly make an informed decision. Although the death risk from hysterectomy is much higher than other treatments the number of patients informed was the same as those for embolisation. Most patients could not make an informed decision about treatment based on this.

Question 8.

Were any of your fibroids larger than 3cm? (Fibroids larger than 3cm MUST be offered fibroid embolisation, myomectomy and hysterectomy?)		
Answer Options	Response Percent	Response Count
Yes	82.2%	97
No	4.2%	5
Wasn't told/don't know	13.6%	16
<i>answered question</i>		118
<i>skipped question</i>		2

The vast majority had fibroids over 3cm, which means that endometrial ablation would not be appropriate, but they should be offered UFE, hysterectomy and myomectomy.

Question 9.

Were you offered endometrial ablation?		
Answer Options	Response Percent	Response Count
Yes	14.3%	3
No	85.7%	18
<i>answered question</i>		21
<i>skipped question</i>		99

Only 3 women were offered endometrial ablation, but as most had fibroids that were too large for this procedure, that is not surprising.

Question 10.

The only women who answered the question about what she was told about endometrial ablation was fully informed.

Question 11.

Were you offered drug treatments - GNHR/hormones or fibrinolytics?		
Answer Options	Response Percent	Response Count
Yes	31.3%	35
No	68.8%	77
<i>answered question</i>		112
<i>skipped question</i>		8

Question 12.

Please tell us what information you were given about the drug treatments?

Answer Options	Response Percent	Response Count
Length of time they can be used	92.3%	24
Possible short-term complications	76.9%	20
Medium and long term complications/side effects	65.4%	17
Time to feeling completely well	57.7%	15
Death risk/rate	53.8%	14
	<i>answered question</i>	26
	<i>skipped question</i>	94

Number	Length of time they can be used	Possible short-term complications	Medium and long term complications/side effects	Time to feeling completely well	Death risk/rate
1	using up until I have the hysterectomy	yes	yes		
2	up to 12 months	chemical menopause	bone density affected if used long term	several months post cessation of use	n/a
3	6 months	menopause			
4	6 months but only having 3 months worth	none	none	Unknown	none
5	yes	yes			
6	3 to 6 month depend on hysto or not	menopause symptoms	menopause symptoms	varies from person to person	nothing said
7	None	None	None	None	None
8		induces the menopause but is reversible			
9	can't remember	early onset menopause - hot flushes	osteoporosis, embolism	can't remember	can't remember
10	Mirena coil - effective up to five years	cramps / bleeding	no information	no information	no information
11	6 months				
12	I was told it was a treatment that was short term only	possible pain	getting hairy	immediate	none
13	6 months	Menopausal symptoms	Menopausal	No	No
14	I wasn't keen on taking any drugs so declined any further information.				

15			Only mentioned menopause symptoms such as hot flushes and dry skin and mood swings		
16	none given	none given	none given	none given	none given
17	2 years	break through bleeding	depression/heavy bleeding	until symptoms go or until decide on surgery???	N/A
18	3 months	flushes, sleep problems, increased bleeding		3 months prior to hysterectomy	
19	Drugs offered pre Myomectomy to shrink fibroids if that was the option I was to take. referred to radiologist also to review possibility of embolisation. No Info on MrGFUS				
20	6 months	osteoporosis	menopause		
21	6 months	menopausal type side effects	none mentioned	none mentioned	none mentioned

22	Any information was taken from drug information leaflets not given by gynaecologist or GP				
23	2 rounds (but not how long that would be)	Hot flushes	Potential for triggering full menopause	? - don't recall being told	Not told - is there a risk?
24	only got given one lot then an MRI				
25	n information given	NO information given	no information given	no information given	no information given
26	used for 2 months prior to op	no information given	no information given	no information given	no information given

Question 13.

Were you offered fibroid embolisation?		
Answer Options	Response Percent	Response Count
Yes	37.0%	40
No	63.0%	68
<i>answered question</i>		108
<i>skipped question</i>		12

Question 14.

Please tell us what information you were given about fibroid embolisation?		
Answer Options	Response Percent	Response Count
Length of hospital stay	100.0%	30
Possible short-term complications	86.7%	26
Home assistance needed	83.3%	25
Restrictions on activity while recovering	80.0%	24
Medium and long term complications/side effects	76.7%	23
Time back to work	93.3%	28
Time to feeling completely well	83.3%	25
Death risk/rate	86.7%	26
<i>answered question</i>		30
<i>skipped question</i>		90

Number	Length of hospital stay	Possible short-term complications	Home assistance needed	Restrictions on activity while recovering	Medium and long term complications/side effects	Time back to work	Time to feeling completely well	Death risk/rate
1	1-2 days					short time off work		all procedures have risks
2	1-2 nights	Pain, discharge	Some	Take it easy	Possible early menopause	1 week	6 months to know full result	Was told %, very low
3	one night couple of visits to hospital 60 miles away	pain sickness	yes	yes		yes	yes	yes
4			none	none	none	no	no	1%
5	2 days	Infection	None	None	Early menopause	after 2-3 days	after 2-3 days	nil
6	no	no	no	no	no	no	no	no potential for this as in all operations but less so as only local anaesthetic
7	at least one night	severe pain and the chance of developing infection which could be very dangerous if not treated quickly	none	minor restrictions	none	within a week but dependant on my needs	2 week	
8	None	None	None	None	None	None	None	None

9	over night	pain, bleeding/expulsion of fibroids, fever	no	no; short recovery time	possibly around pregnancy; not much else	couple of weeks rest	couple of days/weeks - depended on individual	low
10	few days	if things go wrong then would have to have Hysterectomy	yes	2-3weeks	early menopause but would leave ovaries may eventually have to have an hysterectomy	N/A	months+ no information really	I was unsuitable patient for this procedure
11	overnight	very painful	no	no, pain lead		about 2 weeks when I felt better 1wk		no
12	over night	high temp, cramps infection, flushes	Didn't need	infection, high temp,	as above	-2wks	2-4 wks	yes
13	1-2 nights	painful.2-3 weeks at home	None needed	None needed	Infections, could lead to hysterectomy possible pain, temperature and increase in bleeding	2-3 weeks, possibly sooner.	2 weeks	None told
14	1 night	possible severe pain discharge, persistent bleeding or amenorrhea	no	none after first few days		3-4 weeks	3-6 weeks	very low
15	overnight				Potential to still require further intervention e.g. Hysterectomy. Also potential of menopause starting,	2 weeks	few months	
16	1-2 Days	Cramping	No	No		1-2 weeks	Can't recall	No

17	2 days	infection				2weeks		
18	1 night	unsure	not mentioned	not mentioned	poss. need for hysterectomy	2 weeks	not mentioned	virtually nil
19	2-3 days overnight or two nights if no home assistance	pain like period pain	none offered	no driving, no lifting first few days	nothing stated	2-3 weeks	not told variable, pain can come and go, usually not long	not told
20	Up to two days, from patient information leaflet	pain, infection	first few days only		loss of uterus, loss of functioning ovaries	2 weeks		not discussed
21								
22	2 Days	Infection	Some help needed	Light Duties	Need of hysterectomy	3 Weeks	3 Months	0
23	1 nights stay	Infection, bleeding from puncture sites	For the first 24 hours	No driving for 48 hours	Discharge/post embolisation	10/15 days	No information given	No information given
24	1 day	pain similar to contractions	mother taking care of me	just to take it easy for first week or so	loss of some fibroids	3 weeks	6 weeks	rare but has been a case of death due to blood clots
25	up to 1 night	pain	not told	not told	not told	up to 2 weeks	?	?
26	no info given on this	no info given on this	no info given on this	no info given on this	no info given on this	no info given on this	no info given on this	no info given on this

27	no information, being referred to specialist								n/a
28	2 days	infection	yes			when I am ready	weeks		only 1 recorded death
29	one night	heavy bleed, pain,	none	yes	hysterectomy, infection	2 weeks			
30	1-2 days in hospital	pain, bleeding, possible infection.	none	none	possible early menopause.	at least 2 weeks off work	none		1 death

Approximately 70% of women who were informed about UFE in the main were in the main given adequate information about possible side effects and risks, although in 30% women were given little or incomplete information and in a few cases the information given was incorrect. One woman was told she was unsuitable for UFE, but in fact very few women are unsuitable.

Question 15.

Were you offered a hysterectomy?		
Answer Options	Response Percent	Response Count
Yes	68.3%	71
No	31.7%	33
<i>answered question</i>		104
<i>skipped question</i>		16

Question 16.

What options for the type of hysterectomy were you given?

Answer Options	Response Percent	Response Count
None	43.9%	25
Abdominal	33.3%	19
Vaginal	7.0%	4
Laparoscopic	7.0%	4
Total hysterectomy - womb and cervix (neck of the womb) are removed.	28.1%	16
Subtotal hysterectomy - womb is removed leaving the cervix (neck of the womb) in place	15.8%	9
Total hysterectomy with bilateral salpingo-oophorectomy: the womb, cervix, fallopian tubes (salpingectomy) and the ovaries (oophorectomy) are removed	10.5%	6
Radical hysterectomy - the womb and surrounding tissues are removed, including the fallopian tubes, part of the vagina, ovaries, lymph glands and fatty tissue.	0.0%	0
Other (please specify)		18
<i>answered question</i>		57
<i>skipped question</i>		63

Number Other (please specify)

- 1 offered it if I bleed during op and it can't be controlled
- 2 Will discuss with me after scan
- 3 total but not sure which
- 4 not discussed
- 5 I refused a hysterectomy therefore no information was given to me.
- 6 I do not know
- 7 I didn't want a hysterectomy so N/A
- 8 was told to have all the family I might like, and only then to consider a complete hysterectomy, have never heard of any other kind.
- 9 I can't remember details as I had the surgery in 1993. I think the above is correct but as soon as I heard about e.g. as an alternative to hysterectomy I focused on that.
- 10 Was told it would depend on size and location of fibroid
- 11 Didn't go into details as I told him under no circumstances did I want one.
- 12 They didn't specify I HAD TO ASK THE DOCTOR!!!!
- 13 I did want this, so the information was minimal
- 14 Hysterectomy of uterus (ovaries remaining) mentioned but not pushed until other options investigated.
- 15 I refused the concept of hysterectomy
- 16 hysterectomy and ovaries
- 17 I needed to have a biopsy to eliminate the possibility of cancer causing the growths and bleeding

18 and therefore, I might need a radical hysterectomy or subtotal
 It was not clear which type but this is the one that I assume I was having as I was not aware there
 are so many different ones.

Question 17.

Please tell us what information you were given about hysterectomy?		
Answer Options	Response Percent	Response Count
Length of hospital stay	90.2%	37
Possible short-term complications	73.2%	30
Home assistance needed	70.7%	29
Restrictions on activity while recovering	73.2%	30
Medium and long term complications/side effects	68.3%	28
Time back to work	82.9%	34
Time to feeling completely well	68.3%	28
Death risk/rate	65.9%	27
	<i>answered question</i>	41
	<i>skipped question</i>	79

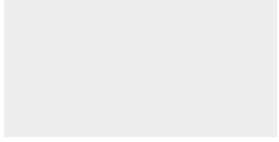
Number	Response Date	Length of hospital stay	Possible short-term complications	Home assistance needed	Restrictions on activity while recovering	Medium and long term complications/side effects	Time back to work	Time to feeling completely well	Death risk/rate
1		5-7 days	all given	YES -6 weeks minimum	YES - 6 weeks	yes	3-6 months	3-6 months	yes
2		2-3 weeks		not told	not told	not told	3months	3 months	not told
3		non	non	non	non	non	non	non	non
4					3 month recovery		3 to 4 months	6 months	
5		4-5 days		yes			6 weeks		all procedures have risks
6		couple of days	infection	some		menopause	6 weeks		
7		2 nights					3 weeks		
8		no	no	no	can't drive	no	already knew		1%
9		I don't know	I don't remember	I don't remember	No idea	Possibly long term, I do not remember	Since I do not work I did not ask	No idea	Nothing
10		Maybe 7 days	Bleeding, pain in abdomen	Home help	No driving, no lifting.	None	None	None	None

11	not discussed in detail as I was not keen												
12	none	none	none	none	none	none	none	none	none	none	none	none	none
13	no info given about any of this												
14	5-6 days		DVT and embolism, possible complications with surgery, infection risk	would need assistance at home for a few days	driving, vacuuming and lifting restrictions for 6 weeks minimum	hormone imbalance	12 weeks	12-14 weeks	can't remember				
15	0	0	0	0	0	0	0	0	0	0	0	0	0
16	3 days	no	no	no	no	no	6 weeks	no	no	no	no	no	no
17	Can't remember exactly but at least a week I think	Can't remember	Yes especially as I had two young children.	Lifting and driving	Can't remember even wanting to know!								
18	3 - 10 days, probably around 4 or 5	infection	yes	not able to drive 4 wks after, need help w housework etc	prolapse, incontinence, loss of sexual feeling, m'opause	n/a	3 months	possibility of death as with any surgery					

19	I refused this option	menopause		3months	I had to do my own research on the internet for info			Menopause and complications I went on INTERNET!!!
20	None given	None given	None given	None given	None given	None given	None given	None given
21	1-2 days	not mentioned	not mentioned	not mentioned	not mentioned	not mentioned	not mentioned	not mentioned
22	length of hospital stay					3 months before back to work		
23	A short stay in hospital	None as this would resolve all my problems						
24	y	y	y	y	y	y	y	
25	03/05/2011	none	help required	none	none	6-8 weeks	6-8 weeks	not discussed
26	5 days	DVT.	yes, help generally, by family.	no driving, hoovering, lifting.	bladder weakness	2-3 months	3-6 months	Yes, possible
27	5-7 days	pain, infection, constipation	yes	yes 6-8 weeks	pain, menopause	6-8 weeks	up to 12 weeks	very low

28	1 week	No detailed discussion as this option was not the primary one under consideration.					up to 2 months	3-6 months	
29	none	none	none	none	none	none	a couple of months	none	not mentioned!
30				a leaflet about activity I could/couldn't do after the operation					
31	5 days	bleeding	not mentioned	not to pick up anything heavy	not sure		6 months	not mentioned	not sure
32		no information as I didn't want a hysterectomy							
33		not discussed as chose UAE before details of hysterectomy	infection, pain,	for some weeks	numerous, for some weeks	non-functioning ovaries	8 weeks	once post-op wound healed, no symptoms if no complications	not discussed

34	No information given	No information given	No information given	No information given	No information given	No information given	No information given	No information given
35	Not told	Not told	Not told	Not told	Was told that I would be entirely satisfied and no complications	Not told	Not told	Not told
36	none	none	none	none	none	none	none	none
37	no info given on this	no info given on this	no info given on this	no info given on this	no info given on this	no info given on this	no info given on this	no info given on this
38	info. leaflet given - 3 - 5 days in hospital	no info given	info. leaflet given	info. leaflet given	no info. given	6 weeks	6 weeks	no information given
39	5 to 7 days	Infection	Someone to stay but I don't know how long for.	No driving or work for at least 12 weeks		less than 24 hours before the op I was told it was likely to be 16 weeks recovery	no time given	not given
40						sick note for 4 months	told it would take up to 4 - 6months before feeling well	
41						told I would need a long period		



off work.

Question 18.

Were you offered MR-Guided focused ultrasound?		
Answer Options	Response Percent	Response Count
Yes	6.9%	7
No	93.1%	94
<i>answered question</i>		101
<i>skipped question</i>		19

This is a newer treatment available at fewer centres.

Question 19.

Please tell us what information you were given about MR-guided focused ultrasound?		
Answer Options	Response Percent	Response Count
Length of hospital stay	100.0%	2
Possible short-term complications	50.0%	1
Home assistance needed	50.0%	1
Restrictions on activity while recovering	50.0%	1
Medium and long-term complications/side effects	50.0%	1
Time back to work	50.0%	1
Time to feeling completely well	50.0%	1
Death risk/rate	50.0%	1
<i>answered question</i>		2
<i>skipped question</i>		118

Question 20.

Were you offered a myomectomy?		
Answer Options	Response Percent	Response Count
Yes	29.6%	29
No	70.4%	69
<i>answered question</i>		98
<i>skipped question</i>		22

Women with fibroids >3cm are supposed to be offered myomectomy but only 30% were.

If you were offered myomectomy what options were you given?		
Answer Options	Response Percent	Response Count
Abdominal	70.8%	17
Laparoscopic	16.7%	4
Hysteroscopic	25.0%	6
Other (please specify)		6
<i>answered question</i>		24
<i>skipped question</i>		96

Number	Categories
1	I had a myomectomy in 2004 and embolisation this year.
2	not sure
3	I was not a suitable candidate for this procedure due to the negativity of my gynaecologist I never discussed this - his attitude as 'of course if this doesn't work we'll just give you a hysterectomy' I was left feeling that if I went forward for surgery, I
4	would end up with a hysterectomy which I really didn't want
5	Not stated - the consultant said that this was only a potential but she did not believe I was a suitable candidate
6	I understand that this means I would have had a vertical or horizontal cut.

Question 22.

Please tell us what information you were given about myomectomy		
Answer Options	Response Percent	Response Count
Length of hospital stay	90.5%	19
Possible short-term complications	85.7%	18
Home assistance needed	76.2%	16
Restrictions on activity while recovering	85.7%	18
Medium and long-term complications/side effects	85.7%	18
Time back to work	81.0%	17
Time to feeling completely well	81.0%	17
Death risk/rate	81.0%	17
<i>answered question</i>		21
<i>skipped question</i>		99

Number	Response Date	Length of hospital stay	Possible short-term complications	Home assistance needed	Restrictions on activity while recovering	Medium and long term complications/side effects	Time back to work	Time to feeling completely well	Death risk/rate
1		done as day case	yes	yes	YES	yes	yes	yes	yes
2		actual stay was 8 days	Major operation	Yes	Yes	Yes	2 months	6 months	Low
3		not discussed in detail							
4		the first time I was collected a few hours after the op, next time I had to stay in 1 night			take it easy for 2-3 days at home on the sofa	told that the fibroids can grow back		not really told	small chance of haemorrhage
5		one week	N/A	Yes	Yes	No	Yes - 2 months	3 months	No
6		several days	blood loss; need for hysterectomy	nothing mentioned	nothing mentioned	can't remember	several weeks; depending	not mentioned	not mentioned

7	4-5 days	complications with surgery, DVT, embolism, infection risk	one or two days assistance	driving and vacuuming, no lifting anything heavier than a kettle for 6 weeks. Gentle exercise only.	hormone imbalance, fibroids could grow again	12 weeks	12-14 weeks	can't recall
8	3-10 days	bleeding, pain, disinterest in sex	I needed a helper	not lifting, no exercise	possible loss of uterus, fertility, blood loss/transfusion	6-8 weeks	6-8 weeks	small but not insignificant
9	A week	No	No	Yes; could not drive	No exercise - its major surgery...	6 weeks	a lot longer - I had the operation twice in about 3/4 years	
10		Too much blood loss			Too much blood loss			Too much blood loss and poss. Hysterectomy if complications

11	yes			yes		yes		
12	3 days	Very sore and difficulty in getting around for a few weeks	Yes	Yes	Yes the fibroids may grow back	Yes 4- 6 weeks	No	No
13	3-5 days	none	help required	some	regrowth of fibroids	8-10 weeks	8-10 weeks	not discussed
14	1 week	Very Painful - more severe than hysterectomy	Convalescence period required after surgery perhaps in convalescent home,	No heavy exercise/work	May still require hysterectomy if not work or if complications were to arise during the surgery.	Can't recall	Can't recall	As with any surgery there is always risk.
15	none	none	none	none	may have to have hysterectomy if it doesn't work	none	none	none
16	Not told	Not told	Not told	Not told	Not told	Not told	Not told	Not told
17	24 hours	None	None	None	None	2 weeks	?	?

18	day surgery	no info	told needed someone with me for 48 hours following op	no driving for at least 24 hours	no info	was told by consultant that I could be back after 4days following surgery - nurse said may need longer as everyone different	no info	given info leaflet about general anaesthetic risk
19		possibility of cutting uterus perhaps necessitating removal - I decided not to have the myomectomy after this						
20	Told to read up via internet- no information in Gynae Dept	N/a	n/a	n/a	n/a	2months	n/a	n/a
21	as for hysterectomy on in previous question	as for hysterectomy on in previous question	as for hysterectomy on in previous question	as for hysterectomy on in previous question	as for hysterectomy on in previous question	as for hysterectomy on in previous question	as for hysterectomy on in previous question	as for hysterectomy on in previous question

Question 23.

Did you feel you were given sufficient information about the treatment options available and their advantages and disadvantages/complications?		
Answer Options	Response Percent	Response Count
Yes	41.9%	13
No	58.1%	18
<i>answered question</i>		31
<i>skipped question</i>		89

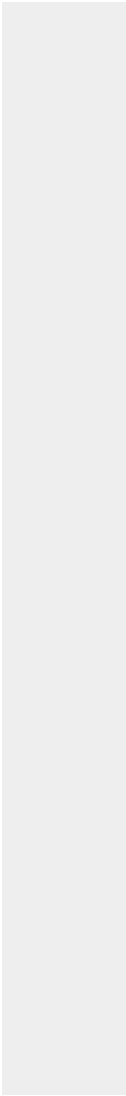
Question 24.

What additional information would you liked to have been given?		
Answer Options	Response Percent	Response Count
About treatment choices	73.0%	54
About drug treatments	45.9%	34
About endometrial ablation	50.0%	37
About fibroid embolisation	75.7%	56
About hysterectomy	47.3%	35
About MR-guided focused ultrasound	54.1%	40
About myomectomy	51.4%	38
<i>answered question</i>		74
<i>skipped question</i>		46

Number	About treatment choices	About drug treatments	About endometrial ablation	About fibroid embolisation	About hysterectomy	About MR-guided focused ultrasound	About myomectomy
1						had never heard of this	
2	alternative treatments			more about fibroid			
3	what choices are available for me since I have no children and would like some one day	what drugs are out there as an alternative to surgery	I have never heard about it till my friend from Africa mentioned it today	same as above, never heard about it	gynaecologist mentioned this in the 10 minutes I was laying on the bed during and after the hysteroscopy	what it is, I don't know what it is	I don't know what this is
4	all the possible options		what it is and would it be an option for me	what it is and would it be an option for me		what it is and would it be an option for me	what it is and would it be an option for me
5	more information about HRT and embolisation			more information - I had to mention to consultant		don't know what type of scan I will be getting	

6 More info re-
sub rather
than total
hysterectomy

Was offered
embolisation
but told I
would have to
apply for
funding from
PCT, be
referred to
another
hospital to see
Gynae and
Radiologist
and it would
be their
decision as to
whether I was
suitable.
Gynae said as
his trust didn't
do it he
couldn't say
whether I was
suitable, even
though he'd
seen my MRI
scan. Basically
all would
depend on
doc's at other
hospital and
whether I got
funding, I
would have
liked him to
say I was
suitable or not
and that I had
a good or bad
chance of



getting funding

7				V unclear about long term effects on reducing heavy periods		No idea about this
8				I would like to have had this sooner		
9	yes!	more detail about the side effects			how it affects sex, plus urinary problems	
10	yes	yes		yes		any
11	wish to get rid of it but non surgery needed					
12	Any kind of choice would have been helpful!					
13	something closer to home , asked about ablation told not available	not mentioned, were mentioned by GP, not gynae	why it's not available or an option		there wasn't time the clinic was running 1/12 hrs behind.	written info would have been helpful

14	I wonder if it's possible for me to have embolisation done	Is HRT treatment for fibroids	What is it?	It would be good to know more about whether it's possible for me to have it done because I have a very large fibroid	Does it kill?	Please tell me more.	What's the risks?
15	would have liked to discuss alternatives			would like to know if this would be suitable for me			
16	definitely, none given	All available, none given	Not offered	Not offered	Rectocele, pelvic weakness, Bladder weakness, Back pain.	Not offered	Everything, Would have been far better. I am a wreck.
17	I would have liked to have been offered a full choice of appropriate treatments	When the drugs were not effective I would have liked other options	I would have liked to have known about how effective this treatment is	I would have liked to have been offered this as an option. Instead I found out myself.	Rates and types of morbidity	Any information	Any information
18	None	None	None	None	None	None	None
19	All seemed to involve major surgery, so left it for now			This is the option I want to pursue with my GP			
20	None	None	None	None	None	None	None

21	information for all was given very quickly although encouraged to take my time to think about it.						any information would have been useful
22				this sounds interesting, but am not sure if my fibroids 'fit the bill'			
23	Yes	Yes	Yes	Yes	No	Yes	No
24	Have had 3 ultrasounds - only given info & letter for GP once - no options discussed other than "well you'll have to have surgery or live with it"	None	None	None	That we would talk further when I was prepared to consider it	none	previously had one - no info needed
25				would like to have heard about it!			
26	That there are choices	That there are some available	That it is an option and why	That it is an option and why	What options, pros and cons	That it is an option and why	That it could be available even if I didn't want more kids

27	information on all possible treatments	alternatives to Mirena coil	any information	any information	more about the pros and cons	any information	any information
28	yes	yes	yes	yes	yes	yes	yes
29	General guidance was very poor						
30	live rurally so was only offered local t'ment options			earlier intervention might have made this a possibility	info was good but I asked a lot of questions!	the info about this was completely privately sought	
31			know what this is	know what this is			
32							It was less about the fibroids it was about getting pregnant
33	any and all available	any and all available	any and all available	any and all available	any and all available	any and all available	any and all available
34	I would want to have access to least invasive First	side effects and short/med/long term effects	recovery time other treatments if this unsuccessful	complications and other patients stories who had it done	all different types of hysterectomy not to be offered first	how it works and fertility	fertility and why do the grow back, why so much blood loss!!

35	I seemed to be given very few choices- they said because it's so huge my options are limited	This was mentioned but nothing about the long term side-effects	I wasn't told about this at all	The first gynaecologist I saw told me this wasn't possible as it was too new. I then went private as I was disgusted by his ignorance and attitude and know for a fact it's a possibility.	Yes- the first consultant seemed very keen - too keen to send me down this route. My fibroid is 24 cm -it's one of biggest ever seen and therefore this would be major surgery - but he didn't mention the dangers.	I wasn't even given this option	This seemed to be discounted though I'm not sure why
36	My GP said I had to have a hysterectomy, gynaecologist didn't offer any treatment						
37				success rate			
38	Anything would have been useful.	"	"	"	"	"	"
39	other treatments available	about drugs	what this is	what this is	recovery, dangers, side effects	more info	more info
40	yes	yes	yes	yes	last resort	yes	was given info about this

41	I would have liked to have known about embolisation much sooner	I was given no advice	No advice given	No advice given. I had to find out for myself and made all enquires and had to plead with my consultant	Alternative to this procedure rather than this being the only answer!	No advice given	Alternatives risks / rewards
42	mri					yes	
43	Much more		anything would have been good	anything would have been good	I was told I couldn't have one - no good reason given	not mentioned at all.	not mentioned
44	none	none	none	none	none	any info would have been good	any info would have been good
45						No mention of MrGFUS possibly as not available in Ireland. I found out about it myself and corresponded with St Mary's in London on it.	

46	info about all other treatments whether that hospital offered them or not	some mention of this would have been nice	told this would not be suitable and resecting womb lining would do the same job	would have liked to be made aware of this option even though that hospital didn't do the procedure	risks, recovery time, Gynaecologist suggested that effects on sex life would not be 'physical' by which I assumed he meant any effects would be psychological and therefore my fault	I had no idea this was even an option	I assume this was what the Gynaecologist referred to as 'resecting the fibroid' and also 'chipping away at it'
47				What is this? Can I have more kids?			
48			had this and it didn't work	never heard about this before internet search.	basically no detail given except leaflet about post operation activity		

49	not much. Initial gynaecologist was pushing for hysterectomy only. Subsequent gynaecologist offered more options.				would have liked to be told more but really don't want to go down this route		
50	All treatment choices regardless of availability at my local hospital			I found out about this myself and had to ask for it.		I asked about this and my consultant did not seem to be aware of it.	My local hospital said it would not do this procedure because of the risks attached.
51		Not offered	Not offered	Had to ask - wasn't offered	the only option I was given to start with	didn't know this existed	Told I wasn't suitable but not why

52				when I asked about this I was given the impression that this wasn't an option, was a new procedure without proven results, in fact I am the first referral from the western isles to the intervention radiologist at Raigmore Hospital.			
53	Yes	Yes		Yes		Yes	Yes
54	Available alternatives	length of time and side effects	What it was and what it did	Safety and success rates, possible risks	Safety, success rates, possible risks	What is this?	Availability and limitations on applicability of treatment
55	only hysterectomy offered with removal of ovaries mentioned as						
56	afterthought		yes	yes			

57	What is available on the NHS	What is available on the NHS	No information given	I have had two embolisations, therefore knew how the procedure worked	No information given
58	I actually researched everything myself as I am a health service researcher. My whole consultation was badly handled and it was me who pushed for embolisation				
59	discuss diet, exercise and choices - no none interested	told too expensive	Yes	full information rather than just told this was the best option	Yes
60			Yes		told couldn't have

61	leaflets would be useful, it's hard to remember details verbally when you've just been told you have a large growth -even if it is benign!	leaflets would be useful, it's hard to remember details verbally when you've just been told you have a large growth -even if it is benign	leaflets would be useful, it's hard to remember details verbally when you've just been told you have a large growth -even if it is benign	leaflets would be useful, it's hard to remember details verbally when you've just been told you have a large growth - even if it is benign	leaflets would be useful, it's hard to remember details verbally when you've just been told you have a large growth -even if it is benign	leaflets would be useful, it's hard to remember details verbally when you've just been told you have a large growth -even if it is benign	leaflets would be useful, it's hard to remember details verbally when you've just been told you have a large growth -even if it is benign
62			not known about at time of visit				
63	The doctor did not give me any help.						
64	more choices in treatments especially less invasive ones	yes	yes	yes	no	yes	no

65	was not told about all options open to me. not UAE. did research myself on internet and reading books	I suffered severe side-effects on gnarl injection they gave me but nobody told me about these	would like to have been told what this is?	Would like to have been offered this option at my very first hospital appt. over a year ago now. was never offered this option by any of the gynaecologists I have seen	the different types of hysterectomy. long-term health issues	would like to have been told what this is?	would like this to have been offered as a serious alternative to hysterectomy
66	Full D&C Scrap given first time round which lasted 3-4yrs	Not keen on taking drugs of any kind long term	Would have liked any information on my choices	If this was available to me		More info on what this is!!	More info regarding difference between Hysterectomy & this
67	More choice and help			The option to have this procedure			
68	Drugs and Embolisation information was only given when I asked specific questions	If they are suitable and their effectiveness	what it is and if it would be suitable	what it is and if I was suitable	the risks	what it is and if I was suitable for it	the risks
69				as above			
70					why they want to take my ovaries out		

71				doctor, didn't even know what fibroids were!!	it wasn't my only option.		
72				recovery time, how long pain lasts after procedure			
73	none	none, didn't want drug treatments	none	I was given plenty of information and had this done.	none, didn't want to have one.	none	none
74				I would have liked more info on this.			

Question 25.

Did you supplement the information given by your gynaecologists from elsewhere?		
Answer Options	Response Percent	Response Count
Yes	81.0%	81
No	19.0%	19
<i>answered question</i>		100
<i>skipped question</i>		20

Question 26.

If yes where did you find the information?		
Answer Options	Response Percent	Response Count
Web site	97.1%	66
Women's magazines	11.8%	8
Press articles	20.6%	14
Patient Groups	14.7%	10
NHS Choices	23.5%	16
NHS Direct	14.7%	10
Your GP	14.7%	10
Friend, colleague or relative	38.2%	26
Local Hospital web site	4.4%	3
Other (please specify)		21
<i>answered question</i>		68
<i>skipped question</i>		52

Number	Other (please specify)
1	readers digest
2	British Fibroid Trust, Hysterectomy Association
3	Sought a 2nd opinion, now using a private specialist instead of via NHS
4	I work in a medical library & have access to medical books, journals & electronic resources.
5	Dr K at RD&E
6	I am an ex nurse
7	went to the library to find out more information
8	Bought Fibroids by Johanna Skilling
9	BBC - website and Women's Hour broadcast
10	my mum in Australia
11	BBC radio 4 programme in the late 1990s
12	I had to do my own extensive research on the internet!!
13	Various websites
14	I went to a herbalist specialising in women's reproductive issues
15	Research on the internet.
16	books. the essential guide to hysterectomy by Dr Steicher
17	scientific journal papers
18	private appointment with another gynaecologist at another hospital
19	PubMed and Medline search for systematic reviews and scholarly articles

- 20 read women's bodies, women's wisdom by Dr Christiane Northrup
- 21 leaflet printed by the hospital that did my procedure.

Question 27.

If you have had or chosen a treatment for your fibroids which treatment did you choose and why?		
Answer Options	Response Percent	Response Count
Drugs - (short-term up to 6 months)	15.3%	9
Endometrial Ablation	6.8%	4
Fibroid Embolisation	62.7%	37
Hysterectomy	10.2%	6
MRI focused ultrasound	6.8%	4
Myomectomy	16.9%	10
Other please specify	20.3%	12
<i>answered question</i>		59
<i>skipped question</i>		61

Question 28.

Number	Response Date	The name of the hospital you attended
1		YSBYTY GWYNEDD, BANGOR
2		Surrey & Sussex Healthcare NHS Trust
3		Huddersfield infirmary
4		Blackheath hospital
5		Ninewells
6		Dewsbury
7		RD&E Wonford
8		Southampton general
9		KPJ Hospital
10		Royal Bolton hosp.
11		Hereford
12		Derby Royal
13		Cumberland Infirmary
14		RD&E
15		Queen Elizabeth Queen Mother Hospital, Margate
16		Birmingham Women's Hospital.
17		Nevil Hall Abergavenny
18		St Mary's Paddington
19		Pembury Hospital
20		N/A
21		UCH
22		Kent and Canterbury
23		Chelsea & Westminster, also
24		
25		London Bridge Hospital
26		Guy's & St Thomas'
27		Queen Elizabeth, Woolwich
28		GP's surgery and family planning clinic
29		Leicester Royal Infirmary
30		Stoke Mandeville

31	Guys and St Thomas'
32	Whipps Cross
33	Hereford
34	Whipps Cross
35	Royal Devon & Exeter
36	Private Hospital in Ipswich for 1st Myc/London Independent for second.
37	Homerton, North Middx, Royal London Hosp
38	Friarage, Northallerton
39	Stoke Mandeville
40	Queens Medical Centre
41	Calderdale
42	Addenbrookes
43	Chase Farm
44	St Peter's Hospital
45	Raigmore
46	Ninewells
47	Singleton Hospital Swansea
48	Royal Devon & Exeter
49	Raigmore Hospital
50	RVI ,Newcastle
51	Mater Private Hospital and also Mater Public Hospital
52	Royal Infirmary
53	Leighton
54	Kettering General Hospital
55	Sussex County
56	Corbett Hospital - Mr Fitzgibbon and Women's Hospital, Birmingham - Mrs Blunt
57	Royal Lancaster Infirmary, but Wythenshawe for the procedure
58	Royal Hallamshire then referred to Northern General
59	Royal Infirmary of Edinburgh

60	Western Isles Hospital
61	Peterborough City Hospital
62	
63	Saffron Walden Community Hospital
64	Royal London Middlesex, Newham, Queen Elizabeth
65	
66	Birmingham Heartland Hospital
	Initially, the Jessop Wing of the Royal Hallamshire Hospital and was eventually referred to the Northern General Hospital and due to postponement of the embolisation, sourced and booked with a private clinic
67	
68	Staffordshire Mid Hospital
69	Tetbury then St Michaels Bristol
70	St Michael's
71	Raigmore
72	the surgery GP
73	Queens Medical Centre
74	John Radcliffe and Churchill
75	Hillingdon hospital
76	JR Oxford
77	Wrexham Maelor Hospital Great Western Hospital, Swindon
78	then referred to RUH Bath
79	Halifax
80	
81	can't remember.
82	
83	Lewisham
84	Royal Devon and Exeter
85	St Peters for ultra sound

APPENDIX 3. PARLIAMENTARY QUESTION AND ANSWER ON UFE

Chris Heaton-Harris: To ask the Secretary of State for Health (1) what assessment has been made of the (a) economic effects and (b) effects on patients of uterine fibroid embolisation as an alternative to hysterectomy; [49228]

(2) what plans he has to improve GP training on uterine fibroid embolisation to enable women with fibroids to choose such therapy as an alternative to hysterectomy; [49229]

(3) what information he plans to make available to patients with fibroids to enable them to make an informed decision about their treatment and care based on the different options available; [49230]

(4) whether he plans to encourage GPs to offer uterine fibroid embolisation to women with fibroids as an alternative to hysterectomy in line with the National Institute of Health and Clinical Excellence's clinical guideline 44 on heavy menstrual bleeding. [49231]

Anne Milton: The National Institute for Health and Clinical Excellence published guidelines in November 2010. *[the second Interventional Procedures Review of UFE]* It is for the national health services to take account of the National Institute for Health and Clinical Excellence guideline on uterine fibroid embolisation. We have no plans for further action.

The content of curriculum and quality and standard of training for medical professions is the responsibility of the appropriate professional regulatory body. The content and standard of medical training is the responsibility of the General Medical Council (GMC), which is the competent authority for medical training in the United Kingdom. GMC is an independent professional body.

The NHS Choices website:

www.nhs.uk

includes detailed information for patients on fibroids, treatment options and where treatment is available.

Information for patients with fibroids can be found at:

www.nhs.uk/conditions/fibroids/Pages/Introduction.aspx

However, while it is not practicable or desirable for the Government to prescribe the exact training that any individual doctor will receive we are, of course, aware of the need to ensure perceived areas of weakness in training curricula are addressed. For that reason, we are liaising with the Regulators and the Academy of Medical Royal Colleges about how best to ensure curricula do meet requirements.