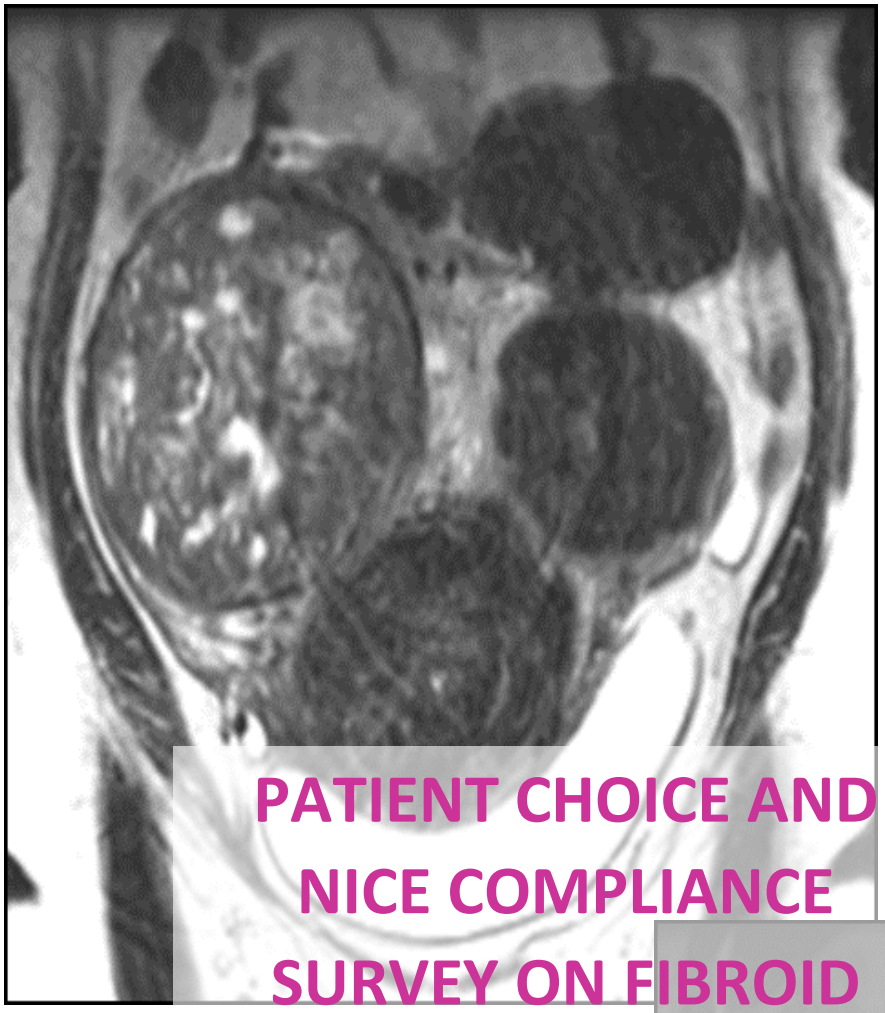

PATIENT CHOICE AND NICE COMPLIANCE SURVEY ON FIBROID TREATMENT

ACUTE NHS TRUSTS IN ENGLAND

CONDUCTED IN 2016

FEmISA
Fibroid Embolisation: Information, Support & Advice

Front cover MRI scans 4 fibroids - 34-week uterus before and after UAE

ACKNOWLEDGEMENTS

FEmISA would like to thank PB Consulting – particularly Melissa Barnet and Dan Jones for their help

Medical Marketing Consultants Ltd

Medical Marketing Consultants who sponsor FEmISA, conducted the FOI surveys and analysed and assisted in writing this report www.medicalmarketingconsultants.co.uk

Some of the data from this report has been included in the report from the All Party Parliamentary Group on Women's Health '***Informed Choice? Giving women control of their healthcare*** – https://static1.squarespace.com/static/5757c9a92eeb8124fc5b9077/t/58d8ca34f7e0ab027a19247c/1490602579808/APPG+Womens+Health+March+2017+web+title.pdf

FEmISA supports the recommendations of their report –

Recommendations

1. **Information resources** – women need to be offered written information on gynaecological issues with a full range of information about the condition and what their options are. These leaflets should be endorsed by the relevant clinical bodies and patient groups and the same generic, pre-approved leaflets should be made available at all centres, Trusts and gynaecology clinics. GPs, secondary care clinicians and nurses should provide or signpost women to high quality information and resources about endometriosis and fibroids, their impact and treatment options.
2. **Endorsed best practice pathway** – this would mean that women would be streamlined more quickly into the right care, saving costs from unplanned admissions and ensuring women get access to all treatments. This should be agreed by the relevant Royal Colleges and patient groups.
3. **Education to include menstrual health at secondary schools along with wider awareness** – far too often women put up with symptoms and incredible pain because they are not aware of what is 'normal' and they feel stigmatised by talking about 'women's problems'. Education modules should be included for the RCGP and RCOG for recognising and treating fibroids and endometriosis.
4. **Multi-disciplinary teams and clinicians working together** – to ensure access to all treatments for women. Best practice pathway should be followed in this regard.
5. **NICE Guidance** where it exists should be followed. These should not be implemented variably across the country as is currently the situation.

(Please see FEmISA's patient survey on the information and choices they are given,[1] and the Medical Technology Group's report - **YoUr First ChoicE** Patient Information and Choice – UFE Patient Survey on patient access to UFE/UAE[2]. (FEmISA is a member of the Medical Technology Group)

[1] http://www.femisa.org.uk/images/stories/downloads/patient_information__%20choice_survey_report.pdf

[2] http://www.mtg.org.uk/wp-content/uploads/2016/07/UFEResearchReport.pdf

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EXECUTIVE SUMMARY

FEmISA, carried out a Freedom of Information request to all acute NHS Trusts in England during 2016 to find out about NICE compliance, and how it was ensured that all patients received full objective information on their treatment options.

- Although 74% of acute NHS hospital Trusts had a policy to inform patients of their treatment options only 45% monitor this by asking patients. This has consequences for informed patient consent and later litigation, but more importantly many patients do not even know what their treatment options are.
- Only 28% of hospitals send out patient information leaflets on all treatment options to patients before their outpatient appointments. Approximately 50% of Trusts do not record patient information or choice as a category on their complaints system and therefore do not monitor it effectively. Only 44% of Trusts monitor patient information and choice by asking patients in surveys.
- NICE Guidelines represent the best evidence-based clinically and cost-effective healthcare and are the minimum standards that the public and the NHS should expect. While 88% of hospital trusts had a policy about compliance with NICE guidelines only 45% of Trusts require an update of all care pathways to include latest NICE Guidelines and review this at Director level.
- The recommendations from NICE Heavy Menstrual Bleeding Clinical Guidelines [2007] state that women with symptomatic fibroids >3cm must be informed about and offered hysterectomy, UAE and myomectomy. Many women complain to FEmISA and other fibroid patient support groups that they are not given any choice or told of any alternative treatment options other than hysterectomy by their gynaecologist. 67% of Trusts take no measures to ensure women are aware of their treatment options and offered choice.
- These NICE Guidelines also recommend that women should be sent information before her out-patient appointment. Only 2 Trusts do this.
- NICE Interventional Procedures Guidance on UAE states that patient selection should be carried out by a multi-disciplinary team (gynaecologists and interventional radiologists working together). FEmISA advocates a multi-disciplinary outpatient clinic, so women are fully informed. Only 7 Trusts offer this and women report that otherwise it is very difficult to access UAE or to see an Interventional Radiologist who performs UAE.
- Women are referred by their GP to a gynaecologist for hospital treatment of their fibroids. Only 3 hospitals stated that their gynaecologist received any training on UAE and that was informal training given by the local interventional radiologists. Gynaecologists therefore lack the knowledge to inform women about UAE or give them any advice as to whether they are suitable. This strengthens the case for multi-disciplinary fibroid clinics.
- It is notable that where women have informed choice as at a hospital with a multi-disciplinary fibroid outpatient clinic e.g. Heartlands Hospital, that UAE rates are significantly higher than the average. Here they performed 241 UAE procedures over 2 years, significantly more than other hospitals.
- At Heartlands Hospital over 2 years, of the 1077 women diagnosed with fibroids 392 (36%) had hysterectomy, 44 (4%) open myomectomy and 241 (22%) UAE. (This echoes findings in a previous MTG survey where at the same hospital, 61% of women had UAE compared with an average nationally of 10% UAE, 61% abdominal hysterectomy 6% laparoscopic, 6% vaginal and 16% myomectomy.[3]) This must be a benchmark nationally for UAE.

[3] http://www.mtg.org.uk/wp-content/uploads/2016/07/UFEResearchReport.pdf

- From this survey, the national average is hysterectomy 73%, and UAE 6%. This confirms that most women are not able to make informed choices about their fibroid treatment.
- Across the nation women with fibroids are being denied informed choice about their treatment options. They are being denied access to the safest, least invasive treatment, which preserves their fertility and unlike the gynaecological surgical treatments for fibroids has been formally and independently reviewed for safety and efficacy. Hospitals do not monitor the information given to women about their treatment options. Gynaecologists lack knowledge about UAE to give any advice to women about it and do not comply with NICE Guidelines on Heavy Menstrual Bleeding. There is also a significant element of professional rivalry from gynaecologist towards interventional radiologists and UAE, which is against the interests of women patients. This is at great cost to the women, their families, their employers, the NHS and society.

RECOMMENDATIONS

1. All NHS Trusts and CCGs must have a policy to ensure that all patients are fully, properly and objectively informed about all their treatment options and their risks and told about the complications and morbidity and mortality rates. This must be audited at least annually in a detailed patient questionnaire where patients are asked about the treatment options and information they were given. It is not sufficient to ask 'did you receive all the information you needed?' since this does not determine if they were fully and properly informed.

2. National patient information leaflets need to be developed by the relevant Royal Colleges and Medical Societies and importantly the patient support groups. In this instance for fibroid diagnosis and treatment they would be - RCOG, BSIR, RCR, The Hysterectomy Association, FEmISA, The Fibroid Network, the British Fibroid Trust, TOHETI etc. These need to be available nationally – on hospital web sites, in GP surgeries, NHS Choices and hospital outpatients.

3. Multidisciplinary fibroid clinics with gynaecologists and interventional radiologists should be set up in all hospitals where in-patient fibroid treatment is offered to ensure that women are fully, objectively and properly informed about all their treatment options. Where hospitals do not offer UAE and refer patients to another hospital it should be ensured that all patients have the opportunity to be referred to the interventional radiologist to discuss UAE in detail before making any decision about the treatment they want.

4. RCOG needs to work with BSIR to set up training for gynaecologists on UAE, so they are better informed. They also need to work together for the benefit of patients, which all too rarely happens at the moment, to the detriment of women. Gynaecologists, as well is lacking knowledge on interventional radiology treatments including UAE and MRgFUS (magnetic resonance-guided focused ultrasound) appear to see them as competing treatments provided by a different speciality that must be avoided at all costs. Women patients must be the first priority and are not at the moment.

5. All hospitals offering interventional radiology treatments including UAE, should ensure that consultant interventional radiologists have admitting rights, named consultant status and are allocated beds on a regular basis to ensure women with fibroids and other patients have access to interventional radiology treatments.

1. ABOUT FEmISA

FEmISA (Fibroid Embolisation: Information, Support and Advice) is an independent, voluntary patient support group and was set up by women whose fibroids were successfully treated by embolisation (sometimes referred to as UAE or UFE – uterine artery/fibroid embolisation – an interventional radiology treatment). Many of us were keen to avoid hysterectomy and we want to ensure that other women have access to embolisation for the treatment of uterine fibroids by: -

- informing potential patients/women and GPs and gynaecologists about embolisation and its benefits
- promoting embolisation as the treatment for uterine fibroids
- supporting women with fibroids
- helping and lobbying to ensure that all women have access to this treatment

FEmISA is a UK based not-for-profit organisation. It is run by volunteers and funded by group members. FEmISA does not receive any financial support through advertising, nor benefit from free website hosting or similar sponsorship.

FEmISA was set up over 15 years ago to help other women avoid hysterectomy and have informed choice of the treatment they want. Members felt that women needed support as UFE was then relatively new. We did not envisage that 15 years later we would still be in the same situation of women suffering with fibroids only being offered hysterectomy (unless they were young), and having great difficulty making informed choice or accessing this treatment.

2. INTRODUCTION

FEmISA carried out a Freedom of Information request to all acute NHS Trusts in England during 2016 to find out about NICE compliance, and how it was ensured that all patients received full, objective information on their treatment options. The questions concerned treatments for fibroids (benign tumours of the womb), heavy menstrual bleeding and insulin pumps. (Insulin pumps will be considered in another report) An additional report on how CCGs (Clinical Commissioning Groups who commission and purchase healthcare in their local area) ensure the providers are compliant with NICE will be published shortly.

The motivation for this survey was because of the overwhelming feedback from a large number of women contacting FEmISA and other fibroid patient support groups that they were not informed about the treatment options and just told by their gynaecologists that they had fibroids and 'their only option was hysterectomy' which many women did not want.

NICE Clinical Guidelines on Heavy Menstrual Bleeding 2007 (being reviewed) state that women with symptomatic fibroids >3cm should be offered hysterectomy (removal of the uterus or womb and sometimes other parts of the female reproductive tract), myomectomy (surgical removal of fibroids alone) and UAE (or UFE - uterine artery/fibroid embolisation a less invasive treatment performed by interventional radiologists) by their gynaecologist. Many women are not offered choice and depending on their age are told either 'their only option is hysterectomy' if they are older or myomectomy if younger with pregnancy wishes. Most women are referred to a gynaecologist and have little access to an interventional radiologist who performs UAE, a much safer less invasive treatment than hysterectomy or myomectomy, which retains a woman's fertility. Most gynaecologists have little if any training in UAE and insufficient knowledge to tell a woman if she is unsuitable for UAE, yet many women are told that they are 'unsuitable' and stopped from seeking advice from an interventional radiologist.

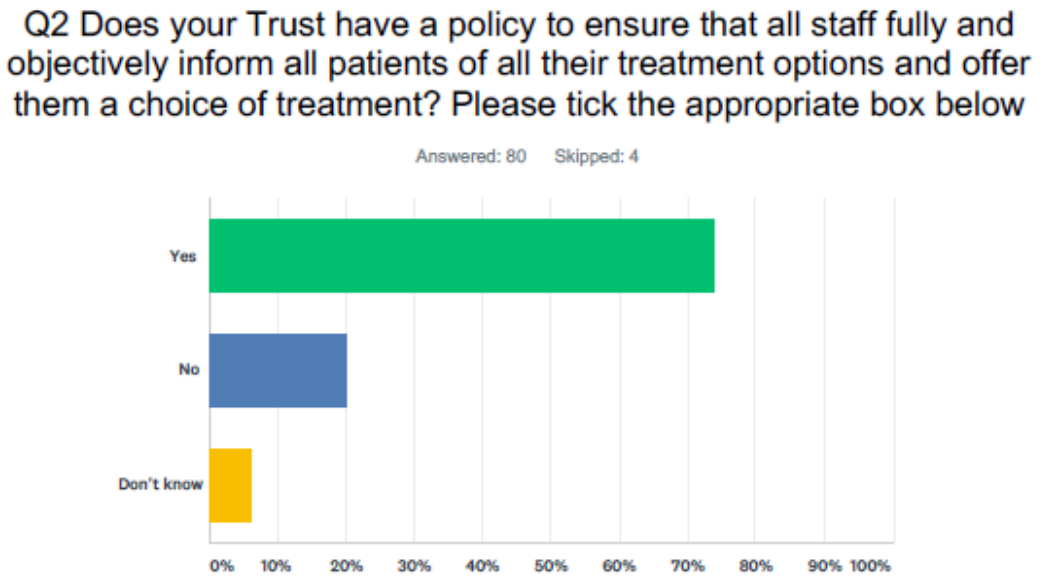
3. METHODOLOGY

Freedom of Information requests were sent to all NHS acute hospital Trusts in England during 2016. It is a legal requirement that public organisations respond to Freedom of Information requests within 20 working days. It is therefore very concerning that only 81 acute NHS hospital trusts responded, the rest either ignoring the request, although they were chased, or saying they could not provide the information in the time available. All the data requests were exactly the same information that the trusts need to provide to NHS Data – Hospital Episode Statistics.

The questionnaire can be found in Appendix 1. Answers to questions 8 to 11 inclusive will be considered in a separate report.

4. SURVEY RESULTS

Eighty-one acute NHS Trusts responded to the FOI survey and a list can be found in Appendix 2.

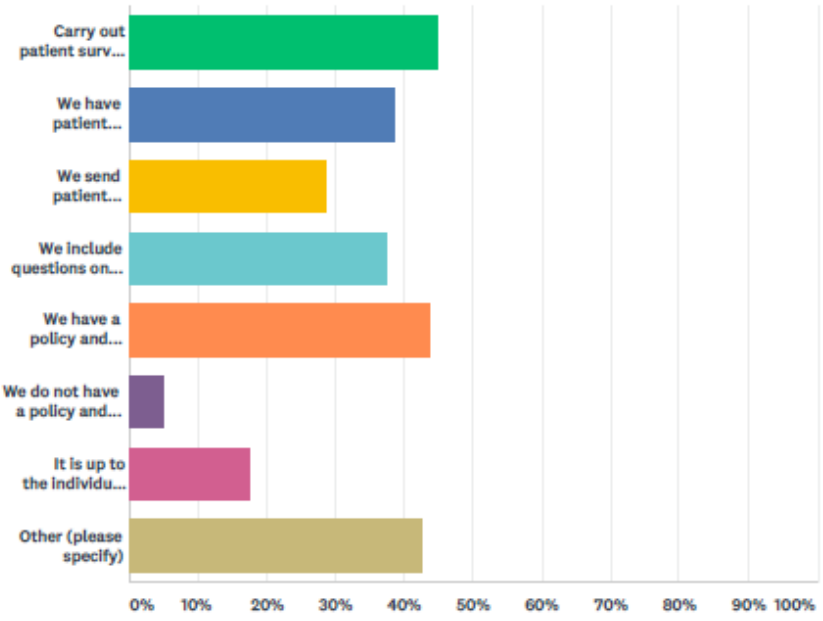


ANSWER CHOICES	RESPONSES	
Yes	73.75%	59
No	20.00%	16
Don't know	6.25%	5
TOTAL		80

The majority of hospitals [74%] had a policy to ensure that patients are fully and objectively informed of their treatment options, but 20% did not and others were developing or revising policies. Since patients cannot give informed consent without being properly informed it is very surprising that not all hospitals had this policy in place.

Q3 How do your monitor your staff to ensure that all patients are properly and objectively informed? [Please tick all answers that apply]

Answered: 80 Skipped: 4



ANSWER CHOICES	RESPONSES	
Carry out patient surveys to ensure they have been given all the information about all their treatment options?	45.00%	36
We have patient information leaflets available all treatments on our web site	38.75%	31
We send patient information leaflets about all treatments options before their outpatient clinic so they can discuss them with their doctor	28.75%	23
We include questions on patient information and treatment options in all patient surveys	37.50%	30
We have a policy and expect all staff to comply	43.75%	35
We do not have a policy and do not think this important	5.00%	4
It is up to the individual clinician	17.50%	14
Other (please specify)	42.50%	34
Total Respondents: 80		

Having a policy does not mean that all staff will comply and it must be monitored, audited and acted upon to ensure compliance. The most effective way of doing this would be to ask the patients themselves about what treatments and information they should have been told about and what they actually received. It is very concerning that only 45% of Trusts do this. Sending out information to patients on all their treatment options before they attend an outpatient's clinic, would also be a very good way of helping to ensure patients are properly informed, but only 27% of Trusts do this. It is very concerning that 18% leave it to the individual clinician and 40% expect staff to comply, without monitoring them. It is no wonder that many patients are not being properly, objectively or fully informed of their treatment options and so consequently they cannot make an informed decision about their treatment. The first concern must be for the patient, but there are also significant legal implications. The claims for consent issues reported by the NHS Litigation Authority in 2014/15 was over £15million.

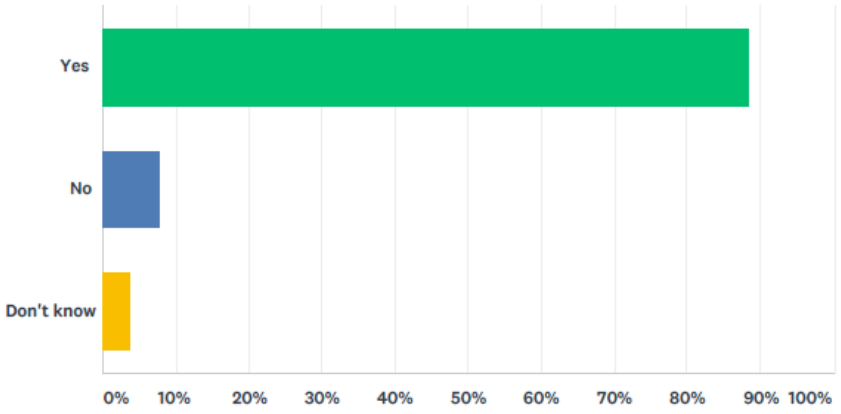
There were 34 'other' answers which can be found in Appendix 3.

Q4 How many complaints has your Trust received in the last 2 years about lack of patient information and choice of treatment? Answered: 78 Skipped: 6

Most Trusts did not record 'lack of patient information and choice' as a category in their complaints database, thus 28 [36%] of Trusts said the number was unknow, a further 12 [14%] said there were none, but this may have been because this category was not recorded. Several mentioned that this category is not recorded in the national patient survey database. 35 Trusts gave a number, which ranged from 1 to 649 in one Trust under the broad category of "communication/information to patients". There is certainly a considerable opportunity to improve monitoring of patient complaints to measure this properly and it is concerning that this is not already being carried out in over half the Trusts.

Q5 NICE Clinical and Diagnostic Guidelines set minimum standards that patients would expect for the quality of their healthcare. Does your Trust have a policy to ensure that all your staff comply with all NICE Clinical and Diagnostic Guidelines? Please tick appropriate box

Answered: 78 Skipped: 6

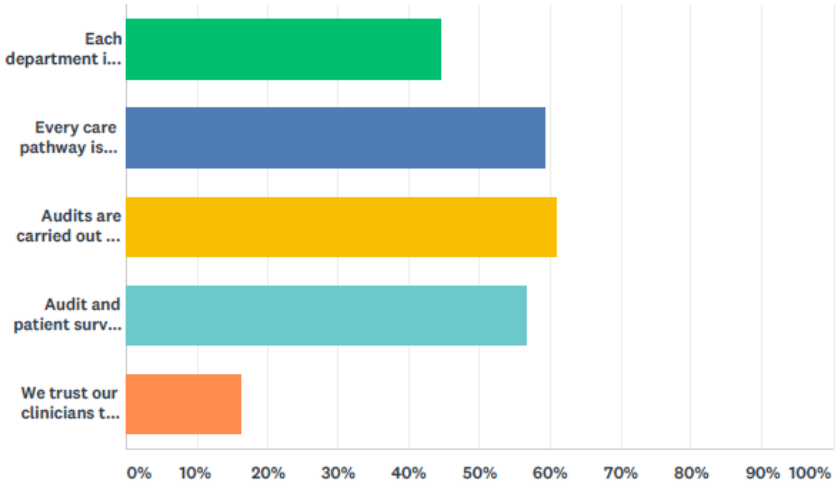


ANSWER CHOICES	RESPONSES	
Yes	88.46%	69
No	7.69%	6
Don't know	3.85%	3
TOTAL		78

NICE (The National Institute for Health and Care Excellence) produces evidence based recommendations for clinical and diagnostic guidelines, which must be regarded as the minimum standards that patients and the NHS would expect. 88% of Trusts had a policy on NICE guidelines compliance, 8% did not and 4% didn't know mainly as these were being developed.

Q6 How do you monitor each of your clinical departments and clinicians to ensure their compliance with all NICE Guidelines? [Please tick all that apply]

Answered: 74 Skipped: 10



ANSWER CHOICES	RESPONSES	
Each department is required to update all care pathways to include the latest NICE Guidelines and this is reviewed by a Director	44.59%	33
Every care pathway is reviewed by their clinical lead to ensure compliance with all NICE Guidelines	59.46%	44
Audits are carried out in each clinical department to ensure NICE Guideline compliance and reported to the Board	60.81%	45
Audit and patient surveys are carried out to ensure compliance	56.76%	42
We trust our clinicians to comply with NICE Guidelines but do not monitor this	16.22%	12
Total Respondents: 74		

Unlike NICE Technology Appraisals compliance with NICE Guidelines is not mandatory and it is apparent that few Trusts take all new NICE guidelines, embed them into care pathways and monitor and audit compliance. Most Trusts will review NICE guidelines and decide whether they will adopt them or not. Only 45% [33] of Trusts responding to this question are required to update all care pathways to include latest NICE Guidelines and review this at Director level. 61% of those responding to this question, 45 Trusts, do carry out a review by the clinical lead to ensure compliance and audit this. 16% trust their clinicians to comply without monitoring. This must lead to a concern about the evidence-based standards the Trusts are using and the quality of clinical and patient care.

Q7 How many complaints has your Trust received in the past 2 years about lack of compliance with NICE Guidelines?

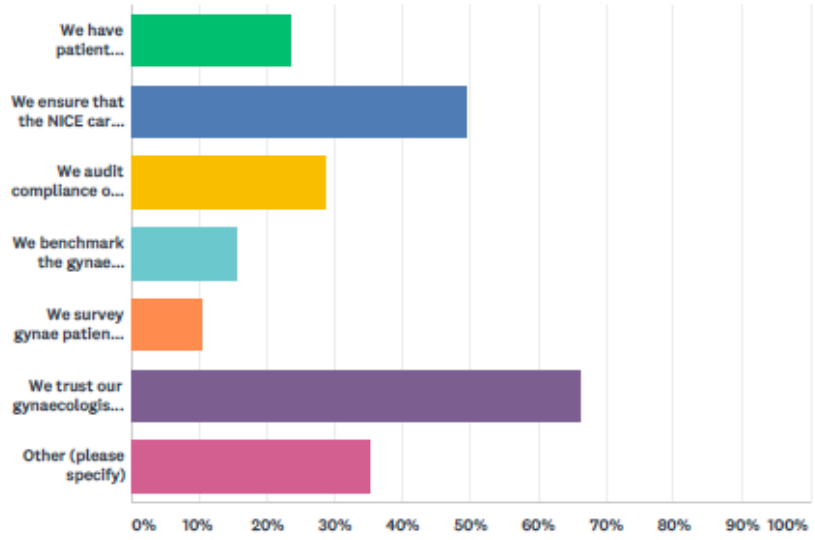
Answered: 77 Skipped: 7

The detailed responses can be found in Appendix 4, but of the 77 Trusts responding only 20 were able to give a numerical answer, most did not know or did not record NICE compliance as patient complain category. Most patients would not have knowledge of detailed NICE recommendations, so the number of complaints specifically related to NICE compliance would be low, but are seldom properly recorded.

Questions 8-11 are about insulin pumps and the subject of another report.

Q12 NICE Clinical Guidelines on Heavy Menstrual Bleeding (CG44 Jan '07), whichincludes uterine fibroids, states that all women with fibroids >3cm requiring hospitaltreatment must be offered hysterectomy, uterine artery embolisation and myomectomy.How does your Trust ensure that all women are given the choice of all 3 treatments and that there is no age discrimination in treatment choices given to women? [Please tick all that apply]

Answered: 77 Skipped: 7



ANSWER CHOICES	RESPONSES	
We have patient information leaflets available on all the fibroid treatments on our web site	23.38%	18
We ensure that the NICE care pathway for HMB is embedded in our gynae care pathway	49.35%	38
We audit compliance on a regular basis	28.57%	22
We benchmark the gynae treatments carried out in our Trust against others to ensure compliance	15.58%	12
We survey gynae patients regularly to ensure they are properly and fully informed and given all the treatment choices	10.39%	8
We trust our gynaecologists to inform women of all appropriate treatments	66.23%	51
Other (please specify)	35.06%	27
Total Respondents: 77		

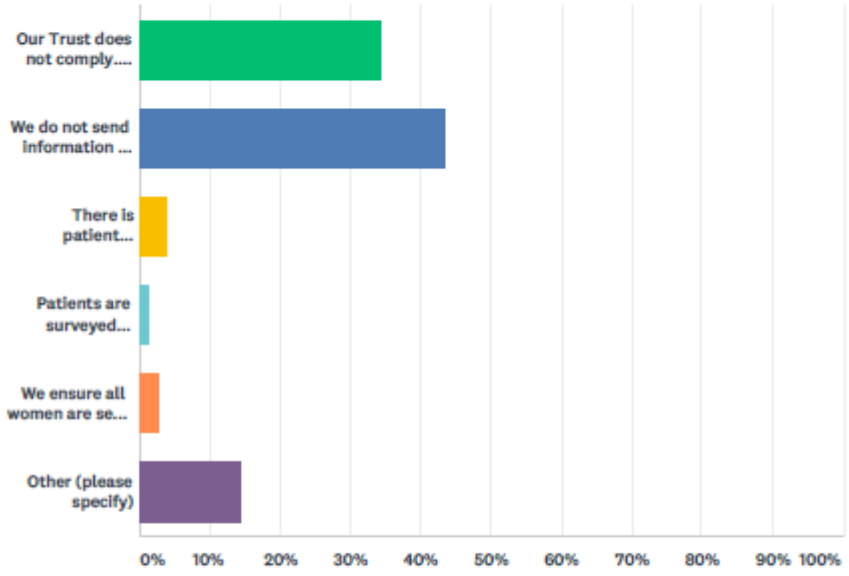
This question was posed as so many women complain to FEmISA and other fibroid patient support groups that they are not given any choice or told of any alternative treatment options other than hysterectomy, by their gynaecologist.

It is therefore very concerning that 67% [51] Trusts take no measures to ensure women are aware of their treatment options and offered choice. 'Other 'detailed responses can be found in Appendix 5. However, of the 27 detailed 'other responses only one stated that all women receive information about all the treatments. In most cases it is left to the gynaecologists of what is thought 'clinically appropriate', which, in practice means in many hospitals, if she is young and wants children offer myomectomy, if older offer hysterectomy.

Women who are referred for hospital treatment by their GP for fibroids or heavy menstrual bleeding will be referred to a gynaecologist. Gynaecologist perform and are trained and educated about hysterectomy and myomectomy, but not about uterine artery embolisation and do not perform this treatment and have little knowledge of it. It is an interventional radiology procedure.

Q13 NICE Guidelines on Heavy Menstrual Bleeding state that "1.3.1 A woman with HMB referred to specialist care should be given information before her outpatient appointment." How does the Trust ensure compliance? [Please tick all that apply]

Answered: 76 Skipped: 8



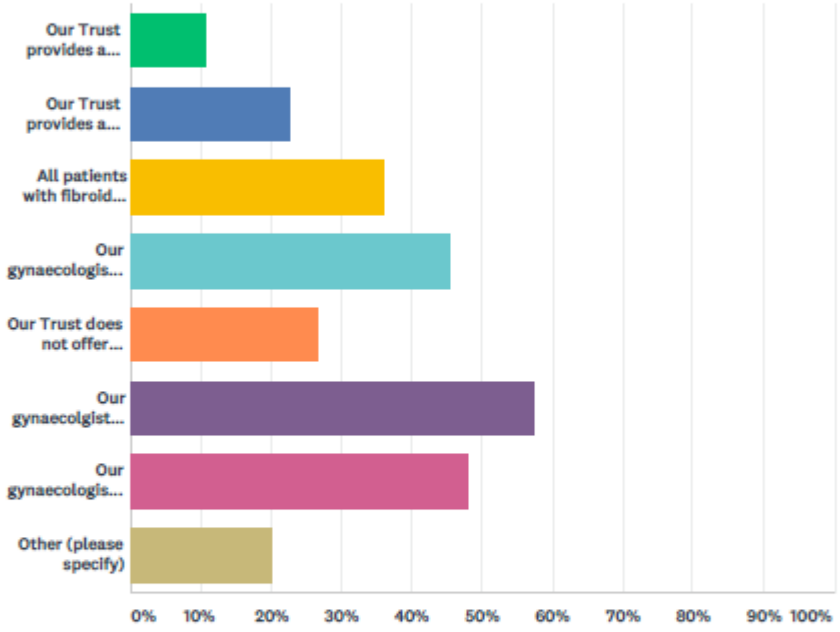
ANSWER CHOICES	RESPONSES	
Our Trust does not comply. Patients are given the information that the gynaecologist thinks appropriate at their outpatients appointment	34.21%	26
We do not send information out before the outpatient appointment. It is given to the patient at the outpatients appointment	43.42%	33
There is patient information on our web site and they can help themselves	3.95%	3
Patients are surveyed regularly to ensure they receive information before outpatients clinics and are given choice	1.32%	1
We ensure all women are sent information before outpatients clinics and we audit this with patients	2.63%	2
Other (please specify)	14.47%	11
TOTAL		76

The recommendations from NICE Heavy Menstrual Bleeding Clinical Guidelines are that women should be sent information before her out-patient appointment. If it included information on all treatment options this would ensure that women were not reliant on their gynaecologists for this. It is very concerning that only 2 Trusts send out information before the outpatient appointments. In most cases this is the only way they could be sure that women are fully informed about all their treatment options.

Detailed answers to Other can be found in Appendix 6.

Q14 NICE Interventional Procedures Guidance on Uterine Artery Embolisation (IPG 367Nov '10) states that - 1.3 Patient selection should be carried out by a multidisciplinary team, including a gynaecologist and an interventional radiologist.How does your Trust ensure multidisciplinary team working between gynaecologists and interventional radiologists to ensure women have access to all fibroid treatment recommended by NICE? [Please tick all that apply]

Answered: 75 Skipped: 9



ANSWER CHOICES	RESPONSES	
Our Trust provides a fibroid outpatient clinic where all patients have access to gynaecologists and interventional radiologists to discuss all treatment options	10.67%	8
Our Trust provides a menstrual clinic as advised in RCOG HMB audit (Nov '14)	22.67%	17
All patients with fibroids have access to the interventional radiologists who carry out fibroid embolisation (UAE) to discuss this option with them	36.00%	27
Our gynaecologists confer with the interventional radiologists when they feel it necessary	45.33%	34
Our Trust does not offer (UAE), but we inform all patients about it and refer them to another hospital	26.67%	20
Our gynaecolgists are well informed and knowledgeable about UAE and refer patients where appropraite	57.33%	43
Our gynaecologists will refer patients for UAE upon request	48.00%	36
Other (please specify)	20.00%	15
Total Respondents: 75		

FEmISA and the APPG (All Party Parliamentary Group) on Women's Health advocate a multi-disciplinary fibroid outpatient clinic where both gynaecologist and interventional radiologists work together to ensure that all women are fully informed about their treatment options, but only 7 (9%) Trusts offer this. These are –

- Heart of England NHS Foundation Trust
- Calderdale and Huddersfield NHS FT
- East Kent Hospitals University NHS FT
- University Hospitals Bristol NHS Foundation Trust

- Royal United Hospital Bath
- Hull and East Yorkshire Hospitals NHS Trust
- UCL
- (Luton and Dunstable University Hospital – this hospital does not offer UAE and therefore cannot run a multi-disciplinary fibroid clinic)

Only 22% 17 hospitals had menstrual clinics as recommended by RCOG.
57% 43 hospitals state that their gynaecologists were well informed and knowledgeable about UAE, but this contradicts the answers to Questions 15 and 16 below.

Although 36 Trusts state that their gynaecologist will refer patients for UAE on request and 34 state that their gynaecologist confer with interventional radiologists when necessary, women report to FEmISA that it is often very difficult to see an interventional radiologist or be referred for UAE.

Detailed answers to Other can be found in Appendix 7.

Q15 NICE Guidelines on Heavy Menstrual Bleeding (HMB) states that - 1.10.1 All those involved in undertaking surgical or radiological procedures to diagnose and treat HMB should demonstrate competence (including both technical and consultation skills) either during their training or in their subsequent practice. How does the Trust ensure all gynaecologists receive adequate training on UAE?

Answered: 76 Skipped: 7

Women who are referred for hospital treatment by their GP for fibroids or heavy menstrual bleeding will be referred to a gynaecologist. Gynaecologist perform and are trained and educated about hysterectomy and myomectomy, but not about uterine artery embolisation [UAE] and do not perform this treatment and have little knowledge of it. It is an interventional radiology procedure.

However, unless the hospital offers a multi-disciplinary fibroid outpatients clinic it will be the gynaecologist who will be responsible for informing the woman of her treatment options. Properly, fully and objectively informing patients requires considerable knowledge, education and training about UAE, which most gynaecologists do not have or undertake. As a consequence, many women are told that they are 'unsuitable' for UAE and their only option is hysterectomy when this is untrue (that is even if they are told about UAE at all). Most women are suitable for UAE and there are very few who are not and they would need to be properly assessed by an interventional radiologist, rather than a gynaecologist.

In asking this question an assessment was being made about whether the gynaecologists have sufficient, or any education, training or knowledge about UAE. All but 4 Trusts responded that UAE is carried out by interventional radiologists and therefore the question was not relevant, but it is. It is apparent that in all but a handful of Trusts gynaecologists receive no training in UAE and lack sufficient knowledge to make judgments about the suitability of women to have UAE. Only 3 Trusts responded that their gynaecologists receive training on UAE from the interventional radiologists and only one that gynaecologist are assessed on UAE. These are the exceptions -

"Gynaecologists attend educational sessions in UAE by the interventional radiologists, who actually perform these procedures"

"Our Gynaecologists do not have any formal training in UAE. It is undertaken by the Radiologists. However, our Gynaecologists are expected to be aware of the procedure, the indications for it (and contra-indications) and how it is carried out, plus any side-effects, risks and complications. It is up to individual Gynaecologists to familiarise themselves with the procedure, particularly if they are going to be offering it to patients as a treatment option. This is all part of Good Medical Practice. The process of enlightening Gynaecologists about the procedure should be part of each Gynaecologist's CPD - this is an area that is monitored through the appraisal process"

What is particularly concerning is that in hospitals were UAE is not carried out there will be an even greater deficit of knowledge about UAE by gynaecologists.

Detailed answers can be found in Appendix 8.

Q16 How is the training of gynaecologists about UAE monitored and recorded?

Answered: 76 Skipped: 7

As in the last question most respondents assumed that gynaecologist did not need to know about UAE. Although some mentioned RCOG training programmes and CPD, none were specifically for UAE. This confirms the need for multidisciplinary fibroid clinics.

Detailed answers can be found in Appendix 9.

Q17 How many patients referred to your Trust in the last 2 years had a primary main diagnosis of heavy menstrual bleeding - Diagnostic Code N92?

Answered: 71 Skipped: 12

The average number was 403 over 2 years i.e. 201 p.a. but the range was wide from 83-1,628 patients over 2 years.

Q18 How many patients referred to your Trust in the last 2 years in total (i.e. both primary and secondary main diagnosis) had a diagnosis of heavy menstrual bleeding Diagnostic Code N92

Answered: 71 Skipped: 12

The average number was 750 over 2 years i.e. 375 p.a. but the range was wide from 1-2,101 patients over 2 years.

Q19 How many patients had a primary main diagnosis of uterine leiomyoma/fibroids in the last two years Diagnostic Code D25.0 - 25.02 and D25.9

Answered: 77 Skipped: 6

The average number was 328 over 2 years i.e. 164 p.a. but the range was wide from 0-1,350 patients over 2 years.

Q20 How many patients in total (i.e both primary and secondary main diagnosis) hada diagnosis of uterine leiomyoma/fibroids in the last two years Diagnostic Code D25.0 - 25.02 and 25.9

Answered: 76 Skipped: 7

The difference between this and the last figures is that women are likely to have had additional hospital diagnostic tests and more have been diagnosed with fibroids. The average number was 364 over 2 years i.e. 182 p.a. but the range was wide from 9-2,023 patients over 2 years.

Q21 How many patients with a diagnosis of heavy menstrual bleeding or fibroids (N92 and D25.0- 25.02 and 25.9) had a hysterectomy in the last 2 years Code Q07.1- Q08.9?

Answered: 77 Skipped: 6

The average number was 278 over 2 years i.e. 139 p.a. but the range was wide from 0-1,056 patients over 2 years. On average, this shows a hysterectomy rate of women who have been diagnosed with heavy menstrual bleeding and fibroids 27% and 73% for women with fibroids.

Q22 What were the ages of these women who had hysterectomy in the last 2 years Code Q07.1- Q08.9? (Please indicate the numbers for each age range below)

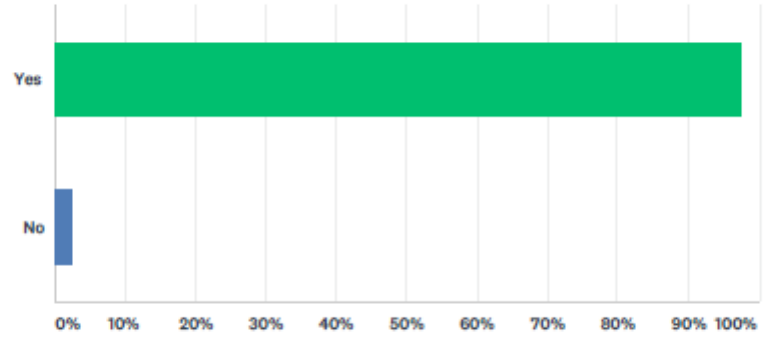
Answered: 76 Skipped: 7

< 29 years old	30-34	35-39	40-44	45-49	50-54	>54	total
231	647	1617	4521	6863	3843	4630	22352
1%	3%	7%	20%	31%	17%	21%	

It is concerning that women under 29 years of age are having hysterectomies, when we are not considering treatment of cancer. There is a correlation of hysterectomy rate and age.

Q23 Does your Trust provide myomectomy - surgical removal of the fibroid(s) alone?

Answered: 78 Skipped: 5



ANSWER CHOICES	RESPONSES	
Yes	97.44%	76
No	2.56%	2
TOTAL		78

Most hospitals provided myomectomy, surgical removal of the fibroid alone, rather than removal of the whole uterus, as with hysterectomy. The figures however are distorted, as under the codes used hysteroscopic investigation of the uterus is included, which does not include treatment of fibroids, so figures, particularly in older women do not reflect treatment of fibroids.

Q24 If 'Yes' how many myomectomies did your Trust perform in the last 2 years - open myomectomy code Q09.2, a endoscopic myomectomy in the last 2 years Code Q17.1?

Answered: 77 Skipped: 6

The average number was 399 over 2 years i.e. 200 p.a. but the range was wide from 5-1,493 patients over 2 years Myomectomy for fibroid removal tends to be offered to younger patients while many older women have hysteroscopic investigations. There was some confusion between all endoscopic procedures on the uterus and endoscopic myomectomy and in many cases these statistics have been confused.

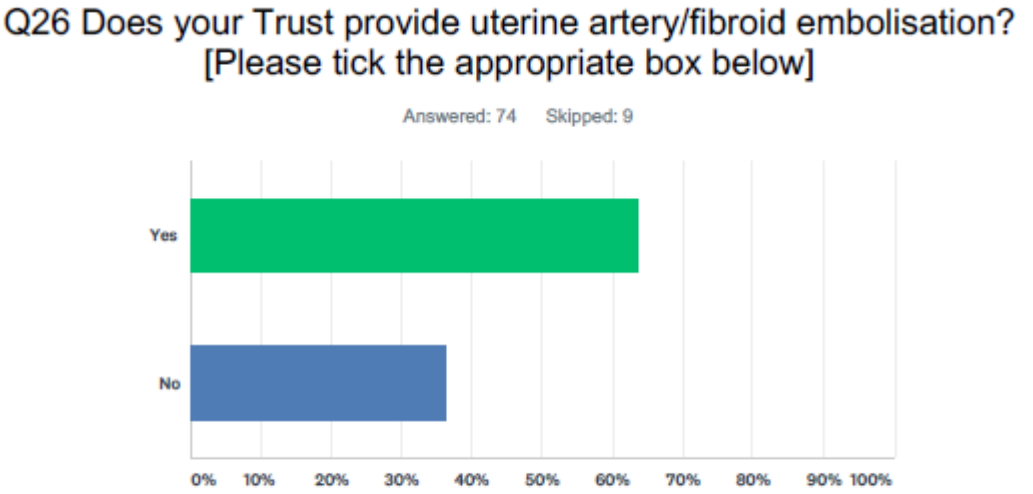
Q25 What were the ages of the women who underwent myomectomy in the last 2 years (codes Q09.2 -9.3 + Q16.1 + Q17.1 and 17.4)? [Please indicate the numbers in each age range below]

Answered: 73 Skipped: 10

< 29 years old	30-34	35-39	40-44	45-49	50-54	>54	total
957	2100	3287	4421	5144	4913	12006	32828
3%	6%	10%	13%	16%	15%	37%	

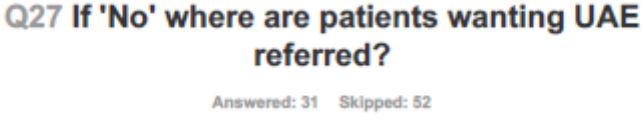
Younger women are offered myomectomy to preserve their uterus, whereas older women have hysteroscopic procedures mainly for diagnosis. This can be seen more clearly in the National HES data below. There is an issue about older women being offered myomectomy. It appears to be assumed that if a woman is presumed too old to have children she has no need of her uterus. The equivalent presumption is not applied to men and is discriminatory.

HES NATIONAL DATA FOR ENGLAND 14/15	< 29 years old	30-34	35-39	40-44	45-49	50-54	>54	total
Open myomectomy	172	484	634	655	332	82	57	2,416
%	7%	20%	26%	27%	14%	3%	2%	100%
Endoscopic resection of lesion of uterus	699	1,170	1,976	3,382	4,793	4,569	11,393	27,982
%	2%	4%	7%	12%	17%	16%	41%	100%



ANSWER CHOICES	RESPONSES	
Yes	63.51%	47
No	36.49%	27
TOTAL		74

64% of Trusts offered UAE.



In all but 4 hospitals, where the arrangements for women wanting UAE were unknow, there are referral arrangements in place to a number of more specialist local hospitals. The list can be found in Appendix 10.

Q28 If 'Yes' how many patients had uterine artery/fibroid embolisation in the last 2 years?

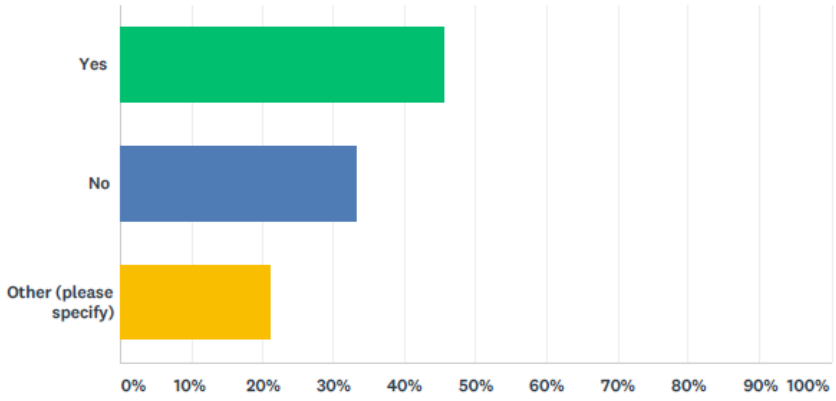
The average number was 40 over 2 years i.e. 20 p.a. but the range was wide from 0-241 patients over 2 years. This is significantly less than hysterectomy or myomectomy, certainly due to access barriers for women of lack of information and lack of knowledge from gynaecologists.

It is notable that where women have informed choice as at a hospital with a multi-disciplinary fibroid such as the one operated at Heartlands Hospital, that UAE rates are significantly higher than the average. Here they performed 241 UAE procedures over 2 years, significantly more than other hospitals. The UAE procedures in this have reduced considerably as this Trust no longer takes referrals from outside its own CCG area.

In this hospital over 2 years, of the 1077 women diagnosed with fibroids 392 (36%) had hysterectomy, 44 (4%) open myomectomy and 241 (22%) UAE.
The national average is hysterectomy 73%, (the myomectomy figure is unreliable as it contains hysteroscopic procedures) and UAE 6%.

Q29 Does your Trust provide beds for UAE patients on a regular basis - say once a week, as are provided for hysterectomy patients?

Answered: 57 Skipped: 26

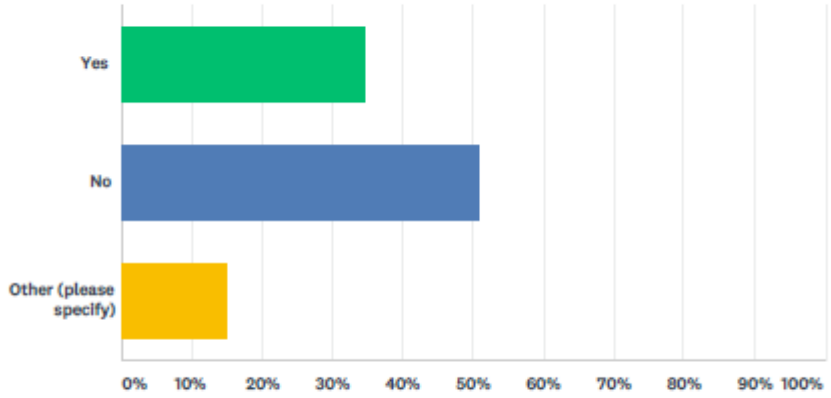


ANSWER CHOICES	RESPONSES	
Yes	45.61%	26
No	33.33%	19
Other (please specify)	21.05%	12
TOTAL		57

Another consideration is whether there are beds within the hospital for UAE. Many interventional radiologists have no allocated beds and take second place to hysterectomy or other gynae patients. An example of this is in Stoke Mandeville Hospital where UAE patients have treatment dates cancelled in preference to hysterectomy patients. Only 45% of hospitals had allocated beds for UAE, thus making access to UAE more difficult for patients. Responses to 'other' can be found in Appendix 11.

Q30 Do your interventional radiologists have admitting rights and named consultant status?

Answered: 61 Skipped: 22



ANSWER CHOICES	RESPONSES	
Yes	34.43%	21
No	50.82%	31
Other (please specify)	14.75%	9
TOTAL		61

It is quite appalling that Interventional Radiologists do not have admitting rights, as gynaecologists do in 51% of the hospitals responding. This represents another significant barrier to women seeking UAE and indeed all interventional radiology treatments, which are safer and less invasive, with shorter hospital stays and patients recover quicker.

Only 21 [34%] Trusts give interventional radiologists admitting rights and named consultant status. This mean that without this status their patients have to use gynae beds under gynaecologist, who are not in favour of UAE.

Trusts which do not give Interventional Radiologists admitting rights are listed in Appendix 14 and 'other' answers in Appendix 13.

Q31 What were the age ranges of the women who had uterine artery/fibroid embolisation in the last 2 years Code RC41Z?

Answered: 37 Skipped: 46

< 29 years old	30-34	35-39	40-44	45-49	50-54	>54	total
22	85	189	470	616	265	47	1672
1%	5%	11%	28%	37%	16%	3%	

Women receiving UAE tend to be in their forties and fifties. The figures for UAE are considerably lower than they should be, as women have significant barriers to overcome to gain access to this, the safest and least invasive treatment for fibroids.

5. CONCLUSION

5.1. Policies for Informing Patients

The NHS Constitution states –
"You have the right to be given information about the test and treatment options available to you, what they involve and their risks and benefits"[4]

NHS England states -
Shared Decision Making
"No decision about me, without me. This can only be realised by involving patients fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone.
Shared Decision Making is a process in which patients, when they reach a decision crossroads in their health care, can review ***all the treatment options available to them and participate actively with their healthcare professional in making that decision.***
With current, clinical information, relevant to their particular condition, about all the options available to them patients are helped to work through any questions they may have, explore the options available, and take a treatment route which best suits their needs and preferences."[5]

The NHS is failing to comply with the NHS constitution and is not taking informed patient choice seriously. Although 74% of acute NHS hospital trusts responding had a policy on informing patients 26% did not or did not know if they did. Only 45% carry out patient surveys to ensure the policy is being carried out. Responsibility does not end with formulating a policy, it must be ensured that the policy is carried out and all staff are compliant.

Most Trusts did not record complaints about lack of patient information and choice, many stated this was because it was not a category on the national patient complaint database. If true this is not acceptable and must be remedied.

5.2. Compliance with NICE Guidelines

NICE receives £69.8 million from taxpayers (via DH, Health Education England, NHS England etc) [NICE Annual Report 2016] and produces evidence based guidance for diagnosis and clinical management for a number of conditions, as well as Technology Appraisals, Interventional Procedures Reviews and many more evidence-based reviews to improve the quality and outcomes of healthcare and the NHS. Although compliance with NICE guidelines is not mandatory, apart from Technology Appraisals, they represent the minimum standards that patients and the public should expect from the NHS. One might question why taxpayers fund NICE at this level, if the guidance can be ignored and patient outcomes are compromised as a result. Many commissioners and providers of healthcare in the NHS fall far short of these standards. The Medical Technology Group, FEmISA is a member, has called for compulsory compliance with NICE Guidelines, but the Government does not wish implement this.

[4] The NHS Constitution https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england

[5] NHS England Shared Decision Making https://www.england.nhs.uk/ourwork/pe/sdm/

While 88% of responding hospital trusts said they have a policy to ensure that all staff are compliant with NICE guidelines, only 45% review care pathways for compliance at Director level and 60% carry out audits on NICE compliance, which are reported to the Board. 16% do nothing. Only 20 trusts were able to report the number of complaints they received about NICE compliance.

5.3. Compliance with NICE Clinical Guidelines on Heavy Menstrual Bleeding [current 2007]

> In the current NICE Guidelines, it states -
> *1.3.1 A woman with HMB referred to specialist care should be given information before her outpatient appointment*

This is very sensible advice as it is the only way to ensure that women are actually told objectively, or at all, about all their treatment options, particularly as we have seen from previous responses that this is not properly monitored. It also gives women the opportunity to read, understand and ask questions about possible treatments. It is well documented that many patients are not able to take in all the information they are given in an outpatient clinic and there is also limited time for patients to discuss treatment options properly, for what for them will be a life-changing event. Only 2.6% [2] Trusts send out information to patients before their outpatient clinics. This is absolutely unacceptable and this needs to be audited by NHS England and the Care Quality Commission.

Although not included in this survey, a previous FEmISA patient survey[6] showed that women found the information they were given inadequate. The findings of the more recent report *"Informed Choice? Giving women control of their healthcare"*[7] published by the All Party Parliamentary Group [APPG] on Women's Health, to which FEmISA contributed significantly, also echoed this. That report recommended that national patient information be developed with the relevant Royal Colleges and Medical Societies and patient groups. FEmISA strongly supports this as the information given on some hospital web sites is often inaccurate, incomplete and insufficient.

Current NICE Guidelines on HMB state that women with fibroids >3cm must be offered hysterectomy, UAE and myomectomy. However, only 29% of Trusts audit this on a regular basis and even fewer, 10% survey patients. 67% of hospitals trust their gynaecologists to inform women of all appropriate treatments. Clearly their trust is misplaced, as seen from the patient surveys above and some comments –

> *"We offer patient information packs, leaflets, booklets to complement the clinician's' recommendation for a treatment or intervention"*

[6] http://www.femisa.org.uk/images/stories/downloads/patient_information__%20choice_survey_report.pdf

[7] https://static1.squarespace.com/static/5757c9a92eeb8124fc5b9077/t/58d8ca34f7e0ab027a19247c/1490602579808/APPG+Womens+Health+March+2017+web+title.pdf

> *"We do not routinely offer all women with fibroids >3cm requiring hospital treatment hysterectomy, UAE and myomectomy. This is not age discrimination, but rather clinical judgement, requiring treatment to be tailored to the individual. It would not be appropriate to offer a 15 year old nulliparous girl with a 3cm fibroid hysterectomy, nor would it be appropriate to offer a post-menopausal patient with large symptomatic fibroids a myomectomy due to the high associated morbidity and lack of requirement to preserve fertility."*

This comment provoked several questions – *Where does 'clinical judgement' allow informed choice on the woman's part? Why does this gynaecologist think that myomectomy has a higher morbidity rate than hysterectomy? Why is it assumed that if a woman is post-menopausal it is acceptable to remove her uterus and have the least safe and most invasive in-patient treatment available with the longest recuperation time?*

The NICE Interventional Procedures Review on UAE recommended multidisciplinary team working between gynaecologists and interventional radiologists to ensure women have access to all fibroid treatments and may also go some way to overcoming the biases seen above. Only 9%, 7 hospitals have multidisciplinary fibroid outpatient clinics where women can see both gynaecologists and interventional radiologists to be fully, properly and objectively informed about all the treatment options. Although 57% said their gynaecologists are well informed and knowledgeable about UAE, this is completely untrue. Gynaecologists have no training or education at all on UAE and are in no position to inform or guide women on their treatment options. They lack the knowledge on UAE to advise women, particularly if they are suitable or not. The vast majority are. This does not stop them from advising women they are unsuitable, when they are not and they then pressurise women into hysterectomy.

FEmISA did write to the President of RCOG about the complete lack of training for gynaecologists on UAE, suggesting that a course be developed with BSIR, but received no response. Gynaecologist therefore lack the knowledge about UAE to run fibroid clinics and advise patients. This shows the absolute need for multidisciplinary fibroid clinics run by gynaecologists and interventional radiologists working together.

Recent complaints to FEmISA exemplify the lack of information and choice for women from gynaecologists. Gynaecologists try to push women towards hysterectomy and do not inform them of safer and less invasive alternatives – UAE or other treatments that would preserve their fertility – UAE and myomectomy -

> *"I have fibroids and am very concerned that I've had to be very proactive in avoiding hysterectomy. If I hadn't done my research and been assertive I doubt very much I would've been told of the alternatives by the specialists. I had to mention UAE of my own volition and then it was a case of "that's a different department" "you'd have to be the right candidate" "you'd need an MRI, you're not claustrophobic, are you?" The reason for hysterectomy has been given mainly because my age - the assumption is I've "completed my family" (and won't be suing the hospital)?!"*

"I had a myomectomy about 13 years ago and my fibroids grew back. I have one large one which is affecting my quality of life but the only option the consultant is offering me is a hysterectomy. Would I be able to have UFE at another trust away from my catchment area?"

"Due to symptomatic fibroids, I have been on drugs and IUD …… The IUD was pushed out and the drugs do not work. … I have been bleeding for three months. The doctor I was referred to at JR hospital told me the only surgical option is hysterectomy. I don't want to lose my womb, so I am trying to find other options…… last weekend, I was admitted to A&E as my blood test shows I had severe anaemia"

The diagnostic and treatment figures show that there is considerable age discrimination and this is shown in the quotes from patients above, who were in their 40s or 50s. It is assumed by many gynaecologists that if a woman no longer wants to be become pregnant she will no longer want her uterus and therefore only needs to be offered hysterectomy. Gynaecologists should know that the uterus also has other very important functions particularly in orgasm, where it plays an important role and removal of the uterus - hysterectomy itself is a cause of pelvic organ prolapse. There has been very little research in the effect of hysterectomy on sexual function and few women told about the risk of prolapse.

Women with fibroids have many considerations when making decisions about their preferred treatment – the risks – what is the likelihood of death, serious injury and complications? Will the treatment work? How painful is it? What are the longer term complications and side effects? How long will I be in hospital? What care will I need by a family member at home, who would have to take time off work also? How long will I be unable to drive? How long will I be off work, particularly those running their own businesses or in senior positions? How good is the hospital and doctor operating on me? Please see 4.3.1. for the comparative safety of treatments for fibroids

The assumption that a woman who does not want or who is too old to become pregnant has no further need of her uterus is somewhat Victorian, based on misogyny and is discriminatory, both in terms of age and sex. A very common condition that afflicts men of a certain age is benign prostatic hyperplasia (prostate enlargement). Men also have a chance approaching 100% of getting prostatic cancer, but most die of something else. When seeking treatment for the symptoms of benign prostatic hyperplasia men are not asked if they still want to father children, as many women are, or if they still want to enjoy sex, which most women aren't asked. They are not normally offered a prostatectomy unless they have cancer. Men and women are treated very differently and women are discriminated against.

The survey shows that there is age discrimination about the treatments women receive. If a woman is in her 20s or 30s she is most likely to receive myomectomy, if in her 40s or 50s she is most likely to have a hysterectomy or if assertive and knowledgeable enough, UAE.

5.3.1. Comparative Safety of In-patient Treatments for Uterine Fibroids

Hysterectomy and myomectomy have never been formally or independently reviewed for safety efficacy.

Hysterectomy

The VALUE Study [8] funded by the Department of Health in 2004 was the first serious audit of the outcomes of hysterectomy over 12 months with only a 6-week follow-up showing the morbidity and mortality of hysterectomy. The complications were found to be severe, operative complications occurred in 3% and mortality and morbidity was far higher than advertised previously. One of the authors Prof Klim McPherson went on to study more aspects of the complications arising from hysterectomy, which previous went unmentioned including sexual dysfunction.[9] There has never been a formal review of the safety of hysterectomy. The mortality for abdominal hysterectomy is 176 p.a. (0.6%) within 90 days of the procedure [HES]. Other statistics can be found on the FEmISA web site [10]

Hospital stay is normally 5 days and return to work 10 weeks[11] Driving is restricted after hysterectomy.

Myomectomy

This has never been reviewed for safety or efficacy. The mortality is unknown. In a study - *Minimally invasive surgical techniques versus open myomectomy for uterine fibroids SO: Cochrane Database of Systematic Reviews: Bhave Chittawar et al - The conclusion was …. "More studies are needed to assess rates of uterine rupture, occurrence of thromboembolism, need for repeat myomectomy and hysterectomy at a later stage."*[12]

Gupta JK, Sinha A, Lumsden MA, Hickey M. Uterine artery embolization for symptomatic uterine fibroids Cochrane Database Syst Rev. 2012 May 16;5:CD005073.
In this meta-analysis the conclusion was …… There was very low quality evidence to suggest that myomectomy may be associated with better fertility outcomes than UAE, but this information was only available from a selected subgroup in one small trial. ……
It was also mentioned that the major complication rate for myomectomy***" is less well defined"*** **i.e. unknown**[13]
Hospital stay is normally a few days for abdominal myomectomy and driving is restricted.

[8] http://onlinelibrary.wiley.com/doi/10.1111/j.1471-0528.2004.00174.x/full

[9] https://www.ncbi.nlm.nih.gov/pubmed/16098153

[10] http://www.femisa.org.uk/index.php/treatment-comparison-tables

[11] Cardiovasc Intervent Radiol. 2006 Mar-Apr;29(2):179-87. Pain and return to daily activities after uterine artery embolization and hysterectomy in the treatment of symptomatic uterine fibroids: results from the randomized EMMY trial. Hehenkamp WJ1, Volkers NA, Birnie E, Reekers JA, Ankum WM.

[12] *http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD004638.pub3/abstract*

[13] *http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD005073.pub4/full*

UAE

UAE has been reviewed for safety and efficacy by NICE –

"Current evidence on uterine artery embolisation (UAE) for fibroids shows that the procedure is efficacious for symptom relief in the short and medium term for a substantial proportion of patients. There are no major safety concerns. Therefore this procedure may be used provided that normal arrangements are in place for clinical governance and audit."[14]

There have been no reported deaths from UAE for many years. There is further information on the FEmISA web site[10]

Hospital stay is normally overnight. Return to work is a few days to 3 weeks and there is no restriction on driving.

5.4. Interventional Radiology

Although a relatively new clinical speciality, especially compared with gynaecology, interventional radiology offers considerable advantages to patients and the NHS. For those unfamiliar with interventional radiology The British Society of Interventional Radiology [BSIR] define it as –

> "Interventional Radiology" (IR) refers to a range of techniques which rely on the use radiological image guidance (X-ray fluoroscopy, ultrasound, computed tomography [CT] or magnetic resonance imaging [MRI]) to precisely target therapy. Most IR treatments are minimally invasive alternatives to open and laparoscopic (keyhole) surgery. As many IR procedures start with passing a needle through the skin to the target it is sometimes called pinhole surgery!
>
> The essential skills of an interventional radiologist are in diagnostic image interpretation and the manipulation of needles and the use of fine catheter tubes and wires to navigate around the body under imaging control. Interventional radiologists are doctors who are trained in radiology and interventional therapy. No other specialty possesses this unique combination of skills![15]

Strategically the NHS should be moving to invest in interventional radiology since it is much safer, more cost effective, less invasive and has a much quicker hospital throughput than old very invasive surgical techniques. As treatment access is often via a blood vessel there is almost no surgical trauma or any possibility of surgical injury to internal organs and no scar. Consequently, patients have a shorter hospital stay and recovery and return to work or normal life is much quicker. As it is safer it can also be used for patients who would be at risk from general anaesthetic and invasive surgery – the obese, the frail elderly and those with co-morbidities.

It is therefore not only surprising, but reflects very poorly on the management of many hospitals that consultant interventional radiologists do not have admitting rights, as all consultant gynaecologist do, in 51% of hospital trusts that have interventional radiology. Interventional Radiologists carry out many other very beneficial minimally invasive procedures in neurology, cancer treatment, men's health, vascular disease, haemorrhage, drainage of ducts and infections and biopsies to name but a few.

[14] https://www.nice.org.uk/guidance/ipg367/chapter/1-Guidance

[15] http://www.bsir.org/patients/what-is-interventional-radiology/

This is further exacerbated in the case of UAE, by the fact that only 46% of hospitals offering UAE provide beds for it on a regular basis, so having often fought hard to avoid hysterectomy a woman wishing to have UAE will have a further hurdle to get a treatment date and bed.

6. RECOMMENDATIONS

1. All NHS Trusts and CCGs must have a policy to ensure that all patients are fully, properly and objectively informed about all their treatment options and their risks and told about the complications and morbidity and mortality rates. This must be audited at least annually in a detailed patient questionnaire where patients are asked about the treatment options and information they were given. It is not sufficient to ask 'did you receive all the information you needed?' since this does not determine if they were fully and properly informed.

2. National patient information leaflets need to be developed by the relevant Royal Colleges and Medical Societies and importantly the patient support groups. In this instance for fibroid diagnosis and treatment they would be - RCOG, BSIR, RCR, The Hysterectomy Association, FEmISA, The Fibroid Network, the British Fibroid Trust, TOHETI etc. These need to be available nationally – on hospital web sites, in GP surgeries, NHS Choices and hospital outpatients.

3. Multidisciplinary fibroid clinics with gynaecologists and interventional radiologists should be set up in all hospitals where in-patient fibroid treatment is offered to ensure that women are fully, objectively and properly informed about all their treatment options. Where hospitals do not offer UAE and refer patients to another hospital it should be ensured that all patients have the opportunity to be referred to the interventional radiologist to discuss UAE in detail before making any decision about the treatment they want.

4. RCOG needs to work with BSIR to set up training for gynaecologists on UAE, so they are better informed. They also need to work together for the benefit of patients, which all too rarely happens at the moment, to the detriment of women. Gynaecologists, as well is lacking knowledge on interventional radiology treatments including UAE and MRgFUS (magnetic resonance-guided focused ultrasound) appear to see them as competing treatments provided by a different speciality that must be avoided at all costs. Women patients must be the first concern and are not at the moment.

5. All hospitals offering interventional radiology treatments including UAE, should ensure that consultant interventional radiologists have admitting rights, named consultant status and are allocated beds on a regular basis to ensure women with fibroids and other patients have access to interventional radiology treatments.

APPENDIX 1

FOI QUESTIONNAIRE

Patient Choice & NICE Compliance Survey - FOI Acute NHS Trusts

'No decision about me without me'.

FEmISA and INPUT are conducting a Freedom of Information Survey as we have found that many patients do not have access to newer, less invasive, NICE approved treatments, as they are not informed about them.
It is Government policy that patients should be fully and objectively informed about their treatment options to make an informed choice. NHS Providers are also expected to be compliance with NICE Guidelines, Appraisals and Reviews as these represent the minimum quality of care that patients and the NHS should expect.
Thank you for participating in our survey. Your feedback is important.

1. Please enter the name of your Trust.

2. Does your Trust have a policy to ensure that all staff fully and objectively inform all patients of all their treatment options and offer them a choice of treatment? *Please tick the appropriate box below*

- ◯ Yes
- ◯ No
- ◯ Don't know

If yes, please could you send us a copy of your policy.

3. How do your monitor your staff to ensure that all patients are properly and objectively informed? [*Please tick all answers that apply*]

- ☐ Carry out patient surveys to ensure they have been given all the information about all their treatment options?
- ☐ We have patient information leaflets available all treatments on our web site
- ☐ We send patient information leaflets about all treatments options before their outpatient clinic so they can discuss them with their doctor
- ☐ We include questions on patient information and treatment options in all patient surveys
- ☐ We have a policy and expect all staff to comply
- ☐ We do not have a policy and do not think this important
- ☐ It is up to the individual clinician
- ☐ Other (please specify)

1

4. How many complaints has your Trust received in the last 2 years about lack of patient information and choice of treatment?

5. NICE Clinical and Diagnostic Guidelines set minimum standards that patients would expect for the quality of their healthcare. Does your Trust have a policy to ensure that all your staff comply with all NICE Clinical and Diagnostic Guidelines? *Please tick appropriate box*

- ○ Yes
- ○ No
- ○ Don't know

Please provide us with a copy of your Trust's policy on NICE Guideline compliance.

6. How do you monitor each of your clinical departments and clinicians to ensure their compliance with all NICE Guidelines? [*Please tick all that apply*]

- ☐ Each department is required to update all care pathways to include the latest NICE Guidelines and this is reviewed by a Director
- ☐ Every care pathway is reviewed by their clinical lead to ensure compliance with all NICE Guidelines
- ☐ Audits are carried out in each clinical department to ensure NICE Guideline compliance and reported to the Board
- ☐ Audit and patient surveys are carried out to ensure compliance
- ☐ We trust our clinicians to comply with NICE Guidelines but do not monitor this

7. How many complaints has your Trust received in the past 2 years about lack of compliance with NICE Guidelines?

8. NICE Technology Appraisal Guidance 151 (TAG 151 Jul 08) states that continuous subcutaneous insulin infusion (CSII or insulin pump) therapy is a treatment option for adults and children with type 1 diabetes who meet certain criteria. How does your Trust ensure that all patients who meet the criteria are given the option of insulin pump therapy? [*Please tick all that apply*]

- ☐ Patients are given the information that the diabetologist thinks appropriate at their outpatients appointment
- ☐ We audit to ensure clinicians are using the criteria set by NICE without added restrictions
- ☐ There is patient information on our web site and they can help themselves
- ☐ Other (please specify)

9. Which brands of insulin pump are offered at your Trust? [*Please tick the appropriate box below]*

- ◯ Animas
- ◯ Medtronic
- ◯ OmniPod
- ◯ Roche (Accu-Chek).

Other (please specify)

10. What is the number of people with Type 1 diabetes registered with this Trust?

11. What is the number of patients using insulin pumps attending clinic at this Trust?

12. NICE Clinical Guidelines on Heavy Menstrual Bleeding (CG44 Jan '07), which includes uterine fibroids, states that all women with fibroids >3cm requiring hospital treatment must be offered hysterectomy, uterine artery embolisation and myomectomy. How does your Trust ensure that all women are given the choice of all 3 treatments and that there is no age discrimination in treatment choices given to women? [*Please tick all that apply]*

- ☐ We have patient information leaflets available on all the fibroid treatments on our web site
- ☐ We ensure that the NICE care pathway for HMB is embedded in our gynae care pathway
- ☐ We audit compliance on a regular basis
- ☐ We benchmark the gynae treatments carried out in our Trust against others to ensure compliance
- ☐ We survey gynae patients regularly to ensure they are properly and fully informed and given all the treatment choices
- ☐ We trust our gynaecologists to inform women of all appropriate treatments
- ☐ Other (please specify)

13. NICE Guidelines on Heavy Menstrual Bleeding state that "1.3.1 A woman with HMB referred to specialist care should be given information before her outpatient appointment." How does the Trust ensure compliance? [Please tick all that apply]

- ○ Our Trust does not comply. Patients are given the information that the gynaecologist thinks appropriate at their outpatients appointment
- ○ We do not send information out before the outpatient appointment. It is given to the patient at the outpatients appointment
- ○ There is patient information on our web site and they can help themselves
- ○ Patients are surveyed regularly to ensure they receive information before outpatients clinics and are given choice
- ○ We ensure all women are sent information before outpatients clinics and we audit this with patients
- ○ Other (please specify)

14. NICE Interventional Procedures Guidance on Uterine Artery Embolisation (IPG 367 Nov '10) states that -

1.3 Patient selection should be carried out by a multidisciplinary team, including a gynaecologist and an interventional radiologist.

How does your Trust ensure multidisciplinary team working between gynaecologists and interventional radiologists to ensure women have access to all fibroid treatment recommended by NICE? [Please tick all that apply]

- ☐ Our Trust provides a fibroid outpatient clinic where all patients have access to gynaecologists and interventional radiologists to discuss all treatment options
- ☐ Our Trust provides a menstrual clinic as advised in RCOG HMB audit (Nov '14)
- ☐ All patients with fibroids have access to the interventional radiologists who carry out fibroid embolisation (UAE) to discuss this option with them
- ☐ Our gynaecologists confer with the interventional radiologists when they feel it necessary
- ☐ Our Trust does not offer (UAE), but we inform all patients about it and refer them to another hospital
- ☐ Our gynaecolgists are well informed and knowledgeable about UAE and refer patients where appropraite
- ☐ Our gynaecologists will refer patients for UAE upon request
- ☐ Other (please specify)

15. NICE Guidelines on Heavy Menstrual Bleeding (HMB) states that -

1.10.1 All those involved in undertaking surgical or radiological procedures to diagnose and treat HMB should demonstrate competence (including both technical and consultation skills) either during their training or in their subsequent practice.

How does the Trust ensure all gynaecologists receive adequate training on UAE?

16. How is the training of gynaecologists about UAE monitored and recorded?

17. How many patients referred to your Trust in the last 2 years had a primary main diagnosis of heavy menstrual bleeding - Diagnostic Code N92?

18. How many patients referred to your Trust in the last 2 years in total (i.e. both primary and secondary main diagnosis) had a diagnosis of heavy menstrual bleeding Diagnostic Code N92

19. How many patients had a primary main diagnosis of uterine leiomyoma/fibroids in the last two years Diagnostic Code D25.0 - 25.02 and D25.9

20. How many patients in total (i.e both primary and secondary main diagnosis) had a diagnosis of uterine leiomyoma/fibroids in the last two years Diagnostic Code D25.0 - 25.02 and 25.9

21. How many patients with a diagnosis of heavy menstrual bleeding or fibroids (N92 and D25.0- 25.02 and 25.9) had a hysterectomy in the last 2 years Code Q07.1- Q08.9?

22. What were the ages of these women who had hysterectomy in the last 2 years Code Q07.1- Q08.9? (*Please indicate the numbers for each age range below)*

< 29 years old	
30-34	
35-39	
40-44	
45-49	
50-54	
>54	

23. Does your Trust provide myomectomy - surgical removal of the fibroid(s) alone?

- ◯ Yes
- ◯ No

24. If 'Yes' how many myomectomies did your Trust perform in the last 2 years - open myomectomy code Q09.2, a endoscopic myomectomy in the last 2 years Code Q17.1?

25. What were the ages of the women who underwent myomectomy in the last 2 years (codes Q09.2 - 9.3 + Q16.1 + Q17.1 and 17.4)? [*Please indicate the numbers in each age range below]*

< 29 years old	
30-34	
35-39	
40-44	
45-49	
50-54	
>54	

26. Does your Trust provide uterine artery/fibroid embolisation? [Please tick the appropriate box below]

- ○ Yes
- ○ No

27. If 'No' where are patients wanting UAE referred?

28. If 'Yes' had uterine artery/fibroid embolisation in the last 2 years Code RC41Z?

29. Does your Trust provide beds for UAE patients on a regular basis - say once a week, as are provided for hysterectomy patients?

- ○ Yes
- ○ No
- ○ Other (please specify)

30. Do your interventional radiologists have admitting rights and named consultant status?

- ◯ Yes
- ◯ No
- ◯ Other (please specify)

31. What were the age ranges of the women who had uterine artery/fibroid embolisation in the last 2 years Code RC41Z?

< 29 years old	
30-34	
35-39	
40-44	
45-49	
50-54	
>54	

7

APPENDIX 2

RESPONDENTS

Q1 Please enter the name of your Trust.

Answered: 81 Skipped: 3

#	RESPONSES
1	University Hospital Southampton NHS Foundation Trust
2	University Hospital Lewisham
3	The Royal Wolverhampton NHS Trust
4	Whittington Hospital NHS Trust
5	West Hertfordshire Hospitals NHS Trust
6	Heart of England NHS Foundation Trust
7	Derby Teaching Hospitals NHS Foundation Trust
8	Northampton General Hospital Trust
9	Calderdale and Huddersfield NHS FT
10	Cambridge University Hospitals NHS Foundation Trust.
11	Kettering General
12	County Durham & Darlington NHS Foundation Trust
13	East Kent Hospitals University NHS FT
14	The Royal Free London NHS Foundation Trust
15	Barnsley Hospital NHS Foundation Trust
16	East Cheshire NHS Trust
17	Lancashire Teaching Hopsitals NHS Trust
18	Epsom and St Helier University Hospitals NHS Trust
19	Torbay & South Devon NHS Foundation Trust
20	North Middlesex
21	Great Western Hospitals NHS Foundation Trust
22	University Hospitals Bristol NHS Foundation Trust
23	George Eliot Hospital NHS Trust
24	Poole Hospital NHS Foundation Trust
25	Mid Cheshire Hospitals NHS Foundation Trust
26	Peterborough and Stamford Hospitals NHS Foundation Trust
27	University Hospitals Coventry and Warwickshire NHS Trust
28	Wrightington, Wigan and Leigh NHS Foundation Trust
29	Northern Devon Healthcare NHS Trust
30	University Hospital of leicester NHS Trust
31	King's College NHS Foundation Trust
32	East Sussex Healthcare NHS Trust
33	South Tees Hospitals NHS Foundation Trust
34	Southend University Hospital NHS Foundation Trust
35	Countess of Chester Hospital NHS Foundation Trust
36	The Princess Alexandra Hospital NHS Trust
37	The Dudley Group NHS Foundation Trust
38	Quenn Elizabeth Hospital Kings Lynn NHS FT

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39	Kingston Hospital NHS Foundation Trust
40	Frimley Health NHS Foundation Trust
41	Ipswich Hospital Trust
42	London North West Healthcare NHS Trust
43	Medway NHS Foundation Trust
44	Royal Devon & Exeter NHS Foundation Trust
45	Hillingdon Hospitals NHS FT
46	South Tyneside NHS Foundation Trust
47	east and North Herts NHS Trust
48	Milton Keynes
49	Mid Yorkshire Hospitals NHS Trust
50	Surrey And Sussex Healthcare NHS Trust
51	Walsall Healthcare NHS Trus
52	Oxford University Hospital NHS Foundation Trust
53	Royal United Hospital Bath
54	Hinchingbrooke Health Care Trust
55	Dartford and Gravesend
56	The Rotherham NHS Foundation Trust
57	Royal Berkshire NHS FT
58	Nottingham University Hospitals NHS Trust
59	Hull and East Yorkshire Hospitals NHS Trust
60	West Hertfordshire Hospitals
61	Northumbria Healthcare NHS Foundation Trust
62	Luton and Dunstable University Hospital
63	Airedale NHS Foundation Trust
64	University Hospitals of Morecambe Bay NHS Foundation Trust 2
65	Salford Royal NHSFT
66	Sheffield Teaching Hospitals NHS Foundation Trust.
67	ASHFORD & ST PETER's HOSPITALS NHS FOUNDATION TRUST
68	North Tees and Harlepool NHS FT
69	UCL
70	Yeovil District Hospital NHS Foundation Trust
71	North Cumbria University Hospitals NHS Trus
72	Wirral University Teaching Hospital NHS Foundation Trust (WUTH
73	Guy's and St Thomas' NHS Foundation Trust
74	Doncatser and basetlaw
75	Buckinghamshire Healthcare NHS Trust
76	Weston Area Health MHS Trust
77	Aintree NHS Trust
78	East Lancashire Hospitals NHS Trust
79	Gateshead Health NHS Foundation Trust
80	The Pennine Acute Hospitals NHS Trust
81	Southport & Ormskirk NHS Trust

APPENDIX 3

Q3 How do your monitor your staff to ensure that all patients are properly and objectively informed? [Please tick all answers that apply]

#	OTHER (PLEASE SPECIFY)
1	Other (please specify): some treatment options will also be covered by the patient's own GP and the choice has already been made by the patient at their GP practice prior to being referred to the hospital
2	Many specialities use patient information packs, leaflets, booklets to complement the clinician's recommendation for a treatment or intervention. This is particularly the case in those specialities with nurse specialists e.g. diabetes, haematology, respiratory, obstetrics
3	The Trust's Patient Experience Team ensure that questionnaires providing feedback regarding our services particularly the quality of discharge are acted upon
4	some cancer services have standard national information leaflets online. Other patient information leaflets are available to staff to distribute to patients via the Trust's intranet.
5	No, UAE patients are admitted under a named Gynaecology consultant at Barnet, if these patients experience any problems, then the consultant gynaecologist will liaise with interventional radiology consultant, in terms of how best to manage
6	We have patient information leaflets available for a large number of treatments on our web site We include questions on patient information and treatment options in appropriate patient surveys We have recently ratified a patient information policy that is being implemented Individual clinicians are expected to provide patients with information in a format that is easily understood and helps the patient make treatment choices. We are establishing a patient information committee and will be monitoring uptake of patient information All leaflets and information are available to be translated into languages required by the patient
7	There is a clinical audit of the Consent policy, it looks at whether patients have been given information regarding the treatment they are receiving but not specifically that they have received information regarding all treatment options.
8	Please note that the trust carries out a wide range of surveys national and local and upload a wide variety of leaflets on our website. We cannot state absolutely that we cover every topic area.
9	Good Clinical Practice, AND part of the Consent Policy
10	Not all treatment have patient leaflets
11	UH Bristol participates in the national patient survey programme. These surveys ask patients a number of questions about information provision in respect of their care and treatment decisions
12	We are currently in discussions with the CCG regarding set up of a task and finish group in relation to the auditing of consent
13	The Trust display posters called 'You Said we Did' which highlights examples of improvements which can include patient information – example attached. Please refer to Attachment 3 - You said we did - Ref 2955
14	Annual consent audit and weekly documentation audit
15	We carry out quarterly clinical audits on the consent process which includes the provision of patient information
16	The annual Trust Mandatory Consent Audit includes questions regarding evidence that 'benefits, risks and alternatives (including no treatment)' are explained to the patient
17	Please see monitoring section of policy - none sent
18	Other (please specify)- the Clinical Governance Department conduct an annual Consent audit, which involves reviewing the consent documentation and interviewing patients to determine if they have been informed about all treatment options
19	An annual consent audit is carried out. This consent audit is included on the Trust audit plan
20	Currently the Trust is undertaking an audit of whether it is compliant with NICE guidelines for Heavy menstrual bleeding. The hospital took part in the RCOG Heavy Menstrual Bleeding Audit – published July 2014. The gynaecology department was consistently above the national mean in all areas of provision. 87.5% satisfied with information (mean 81.4%), 69.9% definitely involved with decision making (mean 61.1%).
21	Leaflets are available for procedures and provided to patients for discussion within the consultation
22	we involve all our patients in the decisons about the options they have in regard to their treatment
23	We have a comprehensive programme of measuring patient satisfaction through the Friends and Family Test and other continuing surveys, whether national or local.
24	We carry out multiple audits that include treatment option discussion with patients such as an annual Consent Policy audit. We monitor complaints and incidents, and patient feedback. Patients on some pathways e.g. the potential cancer fast track pathways and interventional procedure pathways such as endoscopy, are sent information prior to their appointments. We use EIDO patient information leaflets as well as some locally produced and approved ones, which are given out once a diagnosis is confirmed. We also have a patient information service office and patients are often directed there if they want further information
25	for most treatments

26	- regular clinical audits of the consent process and send some patients information
27	Infomation provision is considered as part of the annual audit of consent processes performed in each directorate
28	May be included in letters to patients
29	Some information leaflets available, some surveys contain questions about information
30	some patient surveys not all
31	We have patient information leaflets available on our website, however we cannot guarantee that these are available for all treatments. Leaflets are also given to patients at appointments and links to support sites are available on the service pages of our website. Informing patients of treatment options and choice is covered by our consent policy.
32	Also appraisal system and Directorate Governance meetings
33	one to ones, PDR's clinical supervision, Pump MDT Meeting
34	The third statement above is relevant to some specialty areas but not all. We would not necessarily have full knowledge of treatment needs until patients are seen in our clinic. Patients will be given leaflets in or after clinic once treatment options have been identified. | Other: competency frameworks, work based learning, peer review, patient experience/feedback.

APPENDIX 4

Question 7 - answers

Q7 How many complaints has your Trust received in the past 2 years about lack of compliance with NICE Guidelines?

Answered: 77 Skipped: 7

#	RESPONSES
1	none
2	unknown
3	2
4	1
5	1
6	0
7	0
8	unknown
9	unknown
10	unknown
11	unknown
12	unknown
13	unknown
14	2
15	2
16	0
17	unknown
18	unknown
19	2
20	unknown
21	4
22	0
23	0
24	0
25	2
26	unknown
27	unknown
28	0
29	3
30	unknown
31	unknown
32	1
33	unknown
34	1
35	0
36	unknown
37	0

38	2
39	unknown
40	unknown
41	1
42	1
43	0
44	unknown
45	0
46	unknown
47	unknown
48	0
49	2
50	0
51	unknown
52	unknown
53	0
54	1
55	unknown
56	1 otherwise not recorded
57	0
58	unknown
59	Unknown
60	0
61	0
62	Unknown
63	0
64	unknown
65	0
66	0
67	4
68	Unknown
69	None recorded
70	None recorded
71	unknown
72	None recorded
73	We categorise complaints into categories including 'lack of information, improper treatment, unavailability of equipment and incorrect information given'. However complaints within these categories may not relate specifically to lack of compliance with NICE guidelines. In order to establish which of these complaints fall specifically under 'lack of compliance with NICE guidelines' would require manual review of these complaints which would exceed the appropriate time limit. The Trust has taken into account the cost attributable to the time spent in locating, retrieving and collating the information. We have therefore applied exemption Section 12 (4)(b) of the Freedom of Information Act 2000-beyond appropriate time limit. The appropriate limit is set at £450.00 (18 hours at £25 per hour.)
74	4 complaints, 2 not upheld, one upheld, 1 currently in resolution
75	Unable to provide this information
76	Information not held.
77	2

APPENDIX 5

Question 12 – 'Other' Answer details

Q12 NICE Clinical Guidelines on Heavy Menstrual Bleeding (CG44 Jan '07), whichincludes uterine fibroids, states that all women with fibroids >3cm requiring hospitaltreatment must be offered hysterectomy, uterine artery embolisation and myomectomy.How does your Trust ensure that all women are given the choice of all 3 treatments and that there is no age discrimination in treatment choices given to women? [Please tick all that apply]

Answered: 77 Skipped: 7

#	OTHER (PLEASE SPECIFY)
1	We have a patient information leaflet available on the external UHS website relating to uterine fibroid embolisation
2	the Trust audits compliance against all NICE guidance
3	We offer patient information packs, leaflets, booklets to complement the clinician's recommendation for a treatment or intervention
4	We only give information once the patient has been assessed for suitability for treatments

5	The Trust participated in the Royal College of Obstetricians and Gynaecologists National Audit, 2013. All gynaecologists within the Trust inform women of all appropriate treatments as they are all signed up to follow guidelines which reflect NICE guidance. 13
6	We can confirm EKHUFT offers all treatment modalities including uterine artery embolisation within the Trust and refer suitable women who wish to consider UAE to the Consultant Interventionalogy Team
7	Barnsley Hospital NHS Foundation Trust or Royal College of Obstetrics and Gynaecologists (RCOG) websites)
8	We do not offer all choices to all women as not always clinically appropriate. We do have a gynae care pathway. Leaflets provided as appropriate
9	Patients are given the information that the gynaecologist thinks appropriate at their outpatient appointment.
10	We survey gynae patients regularly to ensure they are properly and fully informed and given all the treatment choices. - Patient Surveys approx. every 2-3years
11	Patients are offered all three treatments and there is no age discrimination
12	MCHFT does not have an interventional radiologist with special interest in Uterine Artery Embolisation. All women who wish to access this treatment option are referred to UHNM.
13	The TRust can offer all treatments in NICE guidlines, but the choice is determined between the patient and her doctor and while age may be a factor we do discriminate
14	We do not routinely off all women with fibroids >3cm requiring hospital treatment hysterectomy, UAE and myomectomy. This is not age discrimination but rather clinical judgement requiring treatment to be tailored to the individual. For example it would not be appropriate to offer a 15 year old nulliparous girl with a 3 cm fibroid a hysterectomy, nor would it be appropriate to offer a post-menopausal patient with large symptomatic fibroids a myomectomy, due to the high associated morbidity and lack of requirement to preserve fertility
15	Information to follow but not received
16	Pathway with primary care
17	Although the Trust does not actively monitor advice given it is routine for all clinicians to offer the choice of all 3 treatments. In accordance with our equality and diversity policy we do not deny treatment to patients solely on age
18	Clinicians adhere to NICE guidance where appropriate. UAE is available at Frimley Health. Clinicians are aware of age legislation discrimination, but health needs differ at different stages of life and this fact takes priority in clinical discussion.
19	Not applicable - This is a specialist procedure and not offered at Ealing Hospital. Appropriate cases are referred to Hammersmith Hospital
20	part of the consent procedure for hysterectomy
21	We have a 'Gynae MDT' to discuss cases and agree on treatment in complex cases
22	Our Gynaecologist inform women of all appropriate treatment and offer information leaflet after their clinic consultation
23	We discuss with patients all available options in the clinic. Patients are provided with verbal and written information. Gynaecologists have the expertise to carry out hysterectomies and myomectomies. We refer UAE to Exeter.
24	Please see attached enclosure 04: Management of Pelvic Inflammatory Disease
25	Other - we are part of the HMB audit undertaken by RCOG & we have a video on You Tube
26	FOIAs 40 personal data
27	UAE not offered by the Tryst

APPENDIX 6

Question 13 – 'Other' Answer details

Q13 NICE Guidelines on Heavy Menstrual Bleeding state that "1.3.1 A woman with HMB referred to specialist care should be given information before her outpatient appointment." How does the Trust ensure compliance? [Please tick all that apply]

Answered: 75 Skipped: 8

#	OTHER (PLEASE SPECIFY)
1	We have a patient information leaflet available on the external UHS website relating to uterine fibroid embolisation
2	we audit the compliance to all NICE guidance and include audit where required. Depending upon how the GP has referred the patient this may influence what information is sent out prior to clinic appointment. An assessment is undertaken at outpatients and information would be provided and the patient given time to consider all treatment options.
3	We offer patient information packs, leaflets, booklets to complement the clinician's recommendation for a treatment or intervention
4	MCHFT does not have an interventional radiologist with special interest in Uterine Artery Embolisation. All women who wish to access this treatment option are referred to UHNM.
5	the GP should have provided the information prior to referral. For pts referred to the Hysteroscopy clinic, specific information is sent out beforehand
6	Patients are directly booked for appointments by the GP and due to very short waiting times for appointments, patient's referral letters may not be seen by consultants until shortly prior to their clinic appointment.
7	Information to follow but not received
8	We have a leaflet with all options given to all HMB patients
9	Please see attached enclosure 04: Management of Pelvic Inflammatory Disease In addition, the Trust has a number of patient information leaflets available on its website at this link: http://dc.eidohealthcare.com/library/eido_english
10	Information given by Primary Care
11	FOIAs 40 personal data

APPENDIX 7

Question 14 – 'Other' Answer details

Q14 NICE Interventional Procedures Guidance on Uterine Artery Embolisation (IPG 367Nov '10) states that - 1.3 Patient selection should be carried out by a multidisciplinary team, including a gynaecologist and an interventional radiologist.How does your Trust ensure multidisciplinary team working between gynaecologists and interventional radiologists to ensure women have access to all fibroid treatment recommended by NICE? [Please tick all that apply]

Answered: 74 Skipped: 9

1	Don't know
2	the Trust does not carry out Uterine Artery Embolisation
3	Other - We provide an outpatient hysteroscopy service that helps with the diagnosis and management of fibroids but not access to interventional radiologists locally. Fibroids can then be resected transcervically under GA or managed alternatively with embolization usually referred to Leicester, Northampton or Birmingham
4	EKHUFT can confirm patients undergoing uterine artery embolisation are cared for jointly by the gynaecologists and interventional radiologists and are followed up following the procedure by both consultants
5	All patients with fibroids will be seen by Gynaecologists who then discusses the feasibility of embolization based on the size, location and patients' wishes have access to the interventional radiologists who carry out fibroid embolisation (UAE) to discuss this option with them
6	We offer the service and refer to our Royal Bournemouth Hospital interventional radiology colleagues when patients want to discuss embolisation".
7	Information to follow but not received
8	All patients with fibroids that express a wish for UAE undergo MRI for attention of IR who carries out procedure and determines whether suitable
9	UAE not performed at this Trust
10	Frmley Park offers UAE
11	We do not have a fibroid clinic. We no longer have a menstrual clinic, patients are seen in general gynae clinics. We have been offering patients UAE for 10 years
12	Interventional radiology is at different hospital and we access them through referral pathways
13	n/a
14	We do not have this information
15	patients are seen in Gynaecology and there is a monthly fibroid MDM where women are discussed

APPENDIX 8

Question 15 – 'Other' Answer details

Q15 NICE Guidelines on Heavy Menstrual Bleeding (HMB) states that - 1.10.1 All those involved in undertaking surgical or radiological procedures to diagnose and treat HMB should demonstrate competence (including both technical and consultation skills) either during their training or in their subsequent practice. How does the Trust ensure all gynaecologists receive adequate training on UAE?

Answered: 76 Skipped: 7

#	RESPONSES
1	unknown
2	Not applicable
3	This is through the appraisal system & revalidation process
4	We do not perform UAE
5	Training is included with along with other areas and offered face to face and via e-learning
6	All gynaecologists are aware of UAE as treatment option for fibroids. All patients where UAE is considered are referred to interventional radiologists. Patient are seen by interventional radiology consultants who assess, decide suitability and then counsel patients about the procedure. If a joint UAE and myomectomy is performed, gynaecologists and interventional radiologists work together closely
7	We run a centralised service under one consultant, thereby continued training process
8	UAE performed by Radiologists not Gynaecologists Surgical procedures performed by Gynaecologists, consultants demonstrate competence through appraisal system as with other surgical procedures. Our Nurse Consultant practice is accredited by British Society for Gynaecological Endoscopy (BSGE) with a 3 year audit of practice with re-accreditation if accreditation criteria is reached
9	only one gyane who runs the fibroid clinic
10	Our service is provided by the radiologists
11	We refer patients requiring UAE to Northampton General Hospital where they are seen and counselled by a designated Interventional Radiologist who will provide the patient with further information and assess their suitability for the procedure
12	Although the Trust does not offer UAE, UAE training is part of mandatory standard training for all gynaecologists ¬A Staff attend additional courses ¬A The medical staff revalidation procedure requires consideration of ongoing competence
13	We can confirm EKHUFT have regular presentations at Trustwide audit and educational meetings. Recent audit on UAE was presented in October 2015 at a joint meeting
14	Two radiologists on the Barnet site are carrying out these procedures. They also carry out other types of interventional procedures and have received training before they started providing this service. They have kept up to date by attending educational events in relation to UAE. Gynaecologists, who perform myomectomies, both open and hysteroscopic are uptodate with their CPDs and appraisals
15	Barnsley hospital offers 1) Myomectomy & 2) Hysterectomy . Uterine Artery embolization not offered locally as NO interventional radiologist on site. They are referred to Northern General Hospital, Sheffield.
16	Not performed at this trust
17	not in place at the moment
18	Uterine embolisation is only carried out by our radiologist and is not performed by the gynaecologists
19	The gynaecologists do not carry out UFE - this is performed by the radiologists who have discussed the procedure, risks and benefits with the patients

20	All consultants who are involved in the management of fibroids are aware of the need for the above as our guideline is in line with the NICE guideline concerning the management of HMB
21	The Trust does not offer UAE
22	Audit and Training
23	service not provided
24	It is expected that all gynaecologists at Poole Hospital NHS Foundation Trust follow the HMB guideline and surgical competence will be checked at annual appraisal.
25	n/a
26	Our Gynaecologists do not have any formal training in UAE. It is undertaken by the Radiologists. However our Gynaecologists are expected to be aware of the procedure, the indications for it (and contra-indications) and how it is carried out, plus any side-effects, risks and complications. It is up to individual Gynaecologists to familiarise themselves with the procedure, particularly if they are going to be offering it to patients as a treatment option. This is all part of Good Medical Practice. The process of enlightening Gynaecologists about the procedure should be part of each Gynaecologist's CPD - this is an area that is monitored through the appraisal process
27	Gynaecologists attend educational sessions in UAE by the interventional radiologists, who actually perform these procedures.
28	Our Gynaes do not perform UAE
29	The Trust does not undertake UAE
30	Gynaens are trained as per RCOG guidlines
31	This is part of their general Gynaecological training (see RCOG logbooks). This is achieved through educational supervision.
32	Interventional radiologists (IR) who undertake UFE comply with NICE guidance and see patients for consultation and discuss options, risks and benefits. They have performed these procedures as part of competencies during IR fellowship training and attend regular IR meetings such as BSIR and CIRSe to keep skills up to date. We will audit outcomes of our procedures with follow up imaging and unless referred by gynaecologist (most are, and hence follow up patient) we will follow up patient to see resolution of symptoms.
33	Gynaecologists are aware that the service is available and to whom they should; they do not undertake this procedure. Audit of the use of UAE has been presented at one of the audit meetings
34	Information to follow but not received
35	Annual Multi-disciplinary Rolling Half Day with a presentation by the interventional radiologist. Guidelines on intranet that are updated regularly
36	Junior doctors have to follow the training matrix of the RCOG. Senior doctors have to follow the RCOG CPD programme.
37	CPD
38	n/a
39	Only radiologists do UAE.
40	UAE is performed by radiologists
41	Through appraisal and documentation of competence – procedure undertaken by an interventional radiologist
42	Not applicable, Ealing Hospital gynaecologists do not undertake UAE
43	Gynaecologists at this Trust do not perform UAE – it is done by Interventional Radiologists
44	Individual instruction / teaching of trainees by gynaecological consultants. This is supplemented by RCOG / RCR national guidelines
45	n/a
46	The Trust does not offer UAE
47	we had a meeting with interventional radiologists
48	UAE is performed by the interventional Radiologists and not the Gynaecologist. Every women going through this procedure is seen and counselled by the Consultant Radiologist who is well trained to perform such procedure.

49	The gynaecologists are all up to date with RCOG CME requirements (as evidenced by annual appraisals) which includes a section on UAE
50	Part of speciality training syllabus
51	This is not applicable to our Trust
52	At present, there is no formal training.
53	national expert with experience of intercventional radiologywith auditable outcomes
54	Gynaecologists do not perform UAE
55	there is no process
56	n/a
57	The Trust's gynaecologists do not receive training specifically, but it is knowledge based. Patients are referred to the interventional radiologist for assessment.
58	As part of their training, junior doctors observe procedures and complete competency documents which are signed by their clinical supervisors. Any training needs are identified at appraisal.
59	Our Gynaecologists are not trained to undertake UAE, this procedure is done solely by the interventional radiologist.
60	We do not have this information
61	Our Trust does not offer (UAE), but we inform all patients about it and refer them to another hospital
62	don't do UAE
63	Consultant gynaecologists all possess a certificate of completion of training and are on the specialty register. We would refer you to the training syllabus of the Royal College of obstetricians and gynaecologists. Junior doctors all work under consultant supervision and discuss these cases with the relevant consultant.
64	All permanent staff are in Consultant posts and therefore holds CCT in Gynaecology. These skills and knowledge are required to gain CCT. There are no Specialist Nurses or Specialty Doctors managing HMB at Salford Royal NHS Foundation Trust
65	Specialist training via interventional radiologist
66	All fibroid embolisations are undertaken by 2 consultant interventional radiologist. The interventional consultants have worked with gynaecologists and anaesthetists at the Trust to develop a pathway and treatment programme.
67	Gyanecologists do not perform UAE they refer patients to radiologists
68	information leaflet and staff meetings
69	UAE not provided at YDH - referred to Royal Devon and Exeter NHS Foundation Trust
70	they don't
71	Not applicable Gynaecologists do not perform UAE
72	This is part of core training for all of our trainees. Our Consultants keep up-to-date through CPD.
73	UAE is provided by our interventional radiologists, not our gynaecologists.
74	No formal training at WGH
75	Quarterly MDT between Radiologists & Gynaecologists where UAE teaching / dissemination of new information would be discussed. Self-directed learning also applicable Annual appraisal should highlight any deficiencies in training / maintaining competencies.
76	N/A as not offered by PAHT however clinicians are expected to remain up to date on all relevant treatments in their area of specialism

APPENDIX 9

Q16 How is the training of gynaecologists about UAE monitored and recorded?

Answered: 76 Skipped: 7

#	RESPONSES
1	unknown
2	Not applicable
3	Consultants comply to royal college guidance for accreditation & monitored through appraisal process
4	We do not perform UAE
5	We use the Trust-wide database for training records to record a wide range of subjects appropriate for the needs of our patients and staff
6	There is no formal recording of this training
7	n/a
8	Through NICE guidelines disseminated through governance process, recorded via minutes
9	through CPD
10	Training recorded by way of log book for trainees
11	n/a
12	Yearly Personal Development plan
13	EKHUFT can confirm training is recorded at Educational meetings. Doctors in training receive specific education with regard to UAE as part of their benign gynaecology module and this is recorded in their learning portfolio
14	See previous answer. At the Trust level, regular auditing of women who underwent UAE are analysed and data is presented at the Trust Audit meetings to share the findings and embed it for future reference
15	n/a
16	n/a
17	not in place
18	n/a
19	The gynaecologists are not specifically monitored re UFE
20	There is no formal record of training for UAE within the Trust for our gynaecologists. Additional point: We have just set up a service delivery for UAE within the Trust. The business case and the clinical template have all been approved. We are hoping to start the service in the coming financial year
21	Trust doesn't offer UAE
22	Attendance at audit and teaching record of doctors in training
23	n/a
24	Information not recorded
25	n/a
26	as abovr
27	Training is monitored in training logs, on Continuing Professional Development data files for individual gynaecologists, and by the meeting attendance register
28	n/a
29	n/a
30	Gynaes do not perform UAE
31	As above

32	Please note that whilst interventional radiologists undertake UFE, we can confirm that Gynaecologist perform in the accredited RCOG CPD programme
33	This is completed by the Radiologists.
34	Information to follow but not received
35	Via attendance at RHD and logged on training records.
36	Junior doctors' logbook of training and senior doctors' appraisal and CPD portfolio.
37	Revalidation and appraisal
38	n/a
39	Only radiologists do UAE.
40	UAE is performed by radiologists
41	Personal portfolio of evidence
42	Not applicable, Ealing Hospital gynaecologists do not undertake UAE
43	Gynaecologists at this Trust do not perform UAE – it is done by Interventional Radiologists
44	Not recorded by the Trust per se. Individual StRs are taught about UAE by their gynaecology consultant colleagues. This training will be indicated in the trainees RCOG training log.
45	n/a
46	n/a
47	n/a
48	In our Trust, the Gynaecologists do not perform UAE at all. They only explain that option as one of many treatment options provided in our Hospital. The patients are provided as well with the relevant information leaflets as required
49	Audit. A review of all UAEs performed in the Trust was presented in 2014 by an interventional radiologist to all consultant gynaecologists.
50	On the college log book
51	Our Gynaecologists do not receive training in this aspect
52	At present, there is no formal training
53	it isn't
54	Gynaecologists do not perform UAE
55	there is no process
56	n/a
57	n/a
58	Training is monitored and recorded at appraisals and by clinical supervisors.
59	Our Gynaecologists are allocated time for continuous personal development. They are expected to maintain a record with the RCOG and we review this at their annual appraisal sessions.
60	don't know
61	not monitred
62	Not
63	none
64	Specialty trainees working in the service train using the RCOG curriculum with includes management of HMB. Their progress is reviewed by their educational supervisor during each placement and annually by the School of Obstetrics and Gynaecology of HENW.
65	n/a
66	We have a data base for all UAEs performed. There is internal audit and a comprehensive follow up for all patients.
67	n/a
68	regular meeting in place lead for gynae and IR
69	UAE not provided at YDH - referred to Royal Devon and Exeter NHS Foundation Trust

70	they don't
71	Not applicable Gynaecologists do not perform UAE
72	This is monitored at annual appraisal
73	N/A
74	N/A
75	Possibly not fully compliant would depend on degree of scrutiny by appraiser.
76	N/A as UAE not offered by PAHT

APPENDIX 10

Q27 If 'No' where are patients wanting UAE referred?

Answered: 31 Skipped: 52

#	RESPONSES
1	Neighbouring organisations
2	They are referred to the Royal Free Hospital
3	Northampton
4	we refer to local specialist centre.
5	They are referred to Northern General Hospital, Sheffield
6	Local University hospital
7	Our Trust does not offer (UAE), but we inform all patients about it and refer them to another hospital Hospital of patient choice
8	Royal United Hospital, Bath
9	es, we have done over 200 cases
10	Heart of England NHS Trust
11	The Royal Bournemouth & Christchurch Hospitals
12	UHNM
13	Bolton
14	Royal Devon & Exeter
15	Norwich or Addenbrookes
16	Hammersmith
17	Royal Victoria Infirmary, Newcastle
18	St Marys & UCL
19	This information is not recorded on our Clinical Coding system and would be hand written in patient records
20	don't know
21	unknown
22	Northern General Hospital
23	Aylesbury/Bedford
24	Interventional Radiology at Leeds
25	University Hospital of South Manchester NHS Foundation Trust. 28
26	Central Manchester Foundation Trust or University Hospital of South Manchester Foundation Trust
27	Royal Devon and Exeter NHS Foundation Trust
28	N/A
29	St Michaels Hospital, Bristol. UHB
30	n/a
31	Not Known as not referred by PAHT

APPENDIX 11

Q29 Does your Trust provide beds for UAE patients on a regular basis - say once a week, as are provided for hysterectomy patients?

Answered: 57 Skipped: 26

#	OTHER (PLEASE SPECIFY)
1	Beds are booked on the gynaecological ward as required (same process as for hysterectomy)
2	Beds are provided for both UAE and hysterectomy patients
3	Have access to beds but not ringfenced for gynae
4	When a patient is booked for UAE by the radiologist, a bed is arranged on the gynaecology ward similar to a day case elective procedure or if the patient requires an overnight stay.
5	Other (please specify) - Beds are provided as needed in the post-operative surgical ward
6	as required
7	The service always provides beds for patients after UAE treatment. However we do not treat patients once a week.
8	unknown
9	Other - We seldom recover UAE patients on the ward, however, if a UAE patient requires a bed, there will be one readily available
10	N/A
11	Yes (as required – but that's less frequently than once a week)
12	N/A

APPENDIX 12

Trusts providing beds for UAE on a regular basis

- University Hospital Southampton NHS Foundation Trust
- The Royal Wolverhampton NHS Trust
- Heart of England NHS Foundation Trust
- Calderdale and Huddersfield NHS FT
- Cambridge University Hospitals NHS Foundation Trust
- The Royal Free London NHS Foundation Trust
- Lancashire Teaching Hospitals NHS Trust
- Epsom and St Helier University Hospitals NHS Trust
- University Hospitals Coventry and Warwickshire NHS Trust
- King's College NHS Foundation Trust
- Countess of Chester Hospital NHS Foundation Trust
- Kingston Hospital NHS Foundation Trust
- Frimley Health NHS Foundation Trust
- Ipswich Hospital Trust
- Medway NHS Foundation Trust
- Royal Devon & Exeter NHS Foundation Trust
- Mid Yorkshire Hospitals NHS Trust
- Surrey and Sussex Healthcare NHS Trust
- Oxford University Hospitals NHS Foundation Trust
- Royal United Hospital Bath
- Royal Berkshire NHS FT
- Nottingham University Hospitals NHS Trust
- Hull and East Yorkshire Hospitals NHS Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- North Tees and Hartlepool NHS FT
- UCL
- Gateshead Health NHS Foundation Trust

- Buckinghamshire Healthcare NHS Trust – (however gynae patients are given preferential treatment over UAE patients and UAE patients have their procedure cancelled in favour of patients having hysterectomy)

APPENDIX 13

Q30 Do your interventional radiologists have admitting rights and named consultant status?

Answered: 61 Skipped: 22

#	OTHER (PLEASE SPECIFY)
1	Admission would usually be in conjunction with the treating consultant, patients would then be admitted under the consultant who referred them
2	The patients are co-admitted under the Gynae Cons of the week
3	Patients admitted under care of gynaecologist managing patient
4	Patients remain under the referring gynaecologist
5	There are no interventional radiologsist
6	We don't have any interventional radiologists and none of our radiologists have admitting rights
7	No admitting rights, but named consultant status
8	don't know
9	They admit in conjunction with a gynaecologist

APPENDIX 14

HOSPITALS NOT GIVING ADMITTING RIGHTS TO CONSULTANT INTERVENTIONAL RADIOLOGISTS OR NAMED CONSULTANT STATUS

- University Hospitals Bristol NHS Foundation Trust
- Peterborough and Stamford Hospitals NHS Foundation Trust
- University Hospitals Coventry and Warwickshire NHS Trust
- King's College NHS Foundation Trust
- South Tees Hospitals NHS Foundation Trust
- Southend University Hospital NHS Foundation Trust
- Countess of Chester Hospital NHS Foundation Trust
- The Dudley Group NHS Foundation Trust
- Kingston Hospital NHS Foundation Trust
- Medway NHS Foundation Trust
- Royal Devon & Exeter NHS Foundation Trust
- Hillingdon Hospitals NHS FT
- Milton Keynes
- Oxford University Hospitals NHS Foundation Trust
- Dartford and Gravesend – (*no admitting rights, but Interventional Radiologists have names consultant status)*
- Royal Berkshire NHS FT
- Nottingham University Hospitals NHS Trust
- Northumbria Healthcare NHS Foundation Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- North Tees and Hartlepool NHS FT
- UCL
- North Cumbria University Hospitals NHS Trust
- Wirral University Teaching Hospital NHS Foundation Trust (WUTH)
- Buckinghamshire Healthcare NHS Trust
- Gateshead Health NHS Foundation Trust
- Lancashire Teaching Hospitals NHS Trust

- The Royal Free London NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust
- Derby Teaching Hospitals NHS Foundation Trust
- West Hertfordshire Hospitals NHS Trust
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