'yo**U**r **F**irst choic**E**' – the provision of and access to UFE

yoUr First choicE: A Review of the provision of, and access to, Uterine Artery/Fibroid Embolisation, a less invasive treatment for Fibroids for women in England

Uterine artery/fibroid embolisation (UAE/UFE) treatment[i] is a non-surgical interventional radiology treatment which is a less invasive alternative to hysterectomy, preserving the uterus, with faster recovery time.

The Medical Technology Group conducted a Freedom of Information survey, with backing from FEmISA and Ian Liddell-Grainger MP, Chair of the All Party Parliamentary Group on Improving Patient Access to Medical Technology, to explore the provision of and access to UFE treatment in England. Women's views were also sought about the information and choices they were given about treatment for their fibroids via a patient survey on FEmISA's website.

The limited FOI survey results show:

- **significant variation among the PCTs and Acute Trusts who responded in the numbers of woman undergoing UFE as a treatment for fibroids.**
- **in a number of PCT areas in England UFE is not being routinely commissioned for women.**
- **some PCTs were unaware of new Best Practice Tariff for UFE and there is currently a lack of patient group involvement in commissioning fibroid treatments.**

The FEmISA patient survey shows:

- **that many women did not feel that they had been given enough information about treatment choices or options for their fibroids from their GP or gynaecologist.**

A set of recommendations for the Government, NHS commissioners and healthcare professionals have been developed to address the challenges identified by this survey.

1.The Report's Authors:

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FEmISA – Fibroid Embolisation: Information, Support & Advice; a UK based patient support group, run by volunteers and funded by group members. It was set up by women whose fibroids were successfully treated by embolisation. FEmISA works to support women with fibroids and ensure that they are informed about their treatment options.

Ian Liddell-Grainger MP - Chair of the All Party Parliamentary Group on Improving Patient Access to Medical Technology .

2.Key words in the report

UFE, UAE, embolisation, uterine fibroids, Primary Care Trusts, acute trusts, patient information, patient choice, NICE clinical guidelines.

3.Background to the report

Uterine fibroids are one of the most common gynaecological problems among women in the UK, with at least one in four women developing them at some stage in their life[ii]. Fibroids are benign tumours which usually develop during a woman's reproductive years and most often occur in women between 30 to 50 years old. Fibroids tend to develop more frequently in women who are of Afro-Caribbean origin.

Fibroids may be associated with debilitating gynaecological problems such as heavy menstrual bleeding (HMB) and pain and may cause infertility and miscarriage. As information provided by NICE states, "Some women with fibroids may not have any symptoms, while others may experience heavy bleeding, urinary incontinence, and pressure or pain in the abdomen. Fibroids can sometimes make it difficult for a woman to conceive or to carry a pregnancy to term"[iii].

Fibroids have traditionally been treated by hysterectomy, myomectomy (surgical removal of the fibroid), or drugs, but a newer minimally invasive treatment, uterine artery/fibroid embolisation, has been available for over ten years, and has been approved as safe and efficacious by NICE[iv]. NICE has also issued positive clinical guidelines (NICE clinical guideline 44: Heavy menstrual bleeding) - see Appendix 1.

Despite the NICE clinical guidelines, and UFE treatment having the additional benefits of decreased lengths of hospital stay, potentially retaining a woman's fertility and faster rehabilitation (normally

1-3 weeks compared with 2-3 months for abdominal hysterectomy), the UFE procedure is often not offered to women by clinicians and overlooked by commissioners as a treatment for fibroids. A large number of the 39,000 hysterectomies performed each year in England in the NHS[v] are for fibroids. Hysterectomy remains the 'default' treatment, perhaps due to a combination of clinical conservatism, a lack of multidisciplinary team working between gynaecologists, providing surgery and interventional radiologists providing UFE, a reluctance to take up new technology and perhaps too few women being aware of their options.

4. Methodology

4.1. Freedom of Information Survey – PCTs and Acute Hospital Trusts

The Medical Technology Group, FEmISA and Ian Liddell-Grainger MP undertook a survey of all Primary Care Trusts (PCTs) to determine what services were commissioned by PCTs in England for women with symptomatic fibroids. The survey also looked at what services were provided for such women by acute trusts in England. The survey took the form of a Freedom of Information (FOI) request sent to PCT and NHS Acute Trust Chief Executives. See Appendix 2 for the FOI questions.

The data was collected between July and September 2011. Ninety-seven PCTs responded, a response rate of 70 %. Ninety acute trusts responded, a response rate of 58 %. However limited data was collected as, for example, only 36 PCTs provided quantitative data on the diagnosis of fibroids and 30 PCTs provided data on numbers of treatments in answer to Questions 1-4, and only 49 acute trusts provided quantitative data in answer to questions 1-6.

4.2. FEmISA on-Line Patient Survey

In parallel with the FOI survey, FEmISA, as a member of the MTG, undertook an on-line patient survey on what information women with symptomatic fibroids were given about treatment options by their GPs and their gynaecologists (see page 6).

5.The FOI survey responses give the following headline findings[vi]:

Limited access

- Six PCTs (of the 77 who responded to question 5) suggested that they did not routinely commission UFE. One PCT responded: **"We commission hysterectomy, myomectomy but not uterine artery/fibroid embolisation. The latter is a Procedure of Limited Clinical Value and is covered under this policy."**

Significant Variation in uptake

- According to responses from the PCTs:
    - 36 PCTs were able to provide data on the number of women diagnosed with symptomatic fibroids in the last 2 years; this ranged from 142 to 2,009, with an average 537 (but the population and demographic profile of each PCT will vary considerably). The percentage of women diagnosed with symptomatic fibroids undergoing in-patient treatment in the last 2 years, who underwent UFE treatment for fibroids was 11% compared with 64% by abdominal hysterectomy, 12% for vaginal hysterectomy, 7% for myomectomy and 6% for laparoscopic hysterectomy. These figures are based on the information provided by the 30 PCTs who provided data in answer to questions 1 to 4 of the FOI request.
    - The number of women who underwent UFE treatment for fibroids in the last 2 years varied in English PCT areas, ranging from none to 309. These figures are based on information provided by the 30 PCTs who provided data in answer to question 3.
    - The number of women who underwent a hysterectomy for the treatment of fibroids in the last 2 years varied, ranging from 50 to 635. These figures are based on the information provided by the 30 PCTs who provided data in answer to questions 1 and 2 of the FOI request.
    - 36 PCTs who responded were unable to provide any figures at all for the treatment procedures they commissioned for fibroids.
- According to responses from the acute trusts:
    - 90 acute hospital trusts responded to the survey. Of those surveyed 19 (21%) did not have any data, 71 (79%) sent some data, but a full analysis could only be carried out on 49 (54%), where there was sufficient data. Of those who responded and did not provide UFE, 34 (38%) have referral pathways to Trusts that do provide the treatment.
    - Of those women diagnosed with fibroids who received hospital in-patient treatment – only 10% received UFE, 61% abdominal hysterectomy, 6% laparoscopic, 6% vaginal and 16% myomectomy. These figures are based on 49 acute trusts who answered questions 1-6.
    - The number of women who underwent UFE treatment in the last 2 years varied between acute trusts, ranging from none to 304. These figures are based on information provided by 49 acute trusts who answered question 2 and question 5 and who offer UFE treatment.

- The number of women who underwent a hysterectomy for the treatment of fibroids in the last 2 years varied between acute trusts, ranging from 61 to 841. These figures are based on the information provided by the 46 acute trusts who answered questions 2 and 4.

- In The Heart of England NHS Trust, 61% of women who received in-patient fibroid treatment had UFE. This compares with an average of 10% of women having in-patient fibroid treatment being treated with UFE, and 61% receiving abdominal hysterectomy across those trusts that provided data. It should be noted however, that this hospital has many referrals for UFE from other surrounding hospitals and PCTs.

- Note: The data was analysed on the basis that PCTs and acute trusts had provided accurate responses. Any codings or groupings used by PCTs to classify diagnosis, treatment or procedures were not checked by the authors. Where there was any obvious doubt about whether data related to the treatment of fibroids, it was excluded from the analysis. It should also be noted that the population and demographic profile of each PCT will vary considerably.

Quality of patient information

- Acute trusts were asked about what information was provided to women to ensure they were fully and objectively informed about their treatment choices. The limited responses showed some good examples of best practice, with women being provided with a wide range of information, but a few acute trusts did not have written information, or only provided it if requested.

Lack of data

- A low number of PCTs (36) and acute trusts (49) provided full data in response to the FOI request. The data should not therefore be regarded as an accurate reflection of national trends but shows variations in the provision of and access to UFE.

6. FEmISA Patient Survey Findings

- In parallel with the FOI survey, FEmISA as a member of the MTG, undertook an on-line patient survey on what information women with symptomatic fibroids were given about treatment options by their GPs and their gynaecologists. We would like to thank the 120 women who responded.

- GPs are the first port of call for women with symptomatic fibroids and fibroids are one of the most common gynaecological problems. The survey results suggest many GPs did not fully discuss treatment options with women when their fibroids were diagnosed, although GPs may not be in a position to discuss options before full diagnosis. From the survey, 43% of women did not discuss treatment options with their GP, and while 42% of GPs mentioned hysterectomy only 14% mentioned fibroid embolisation and 19% myomectomy (32% mentioned drug treatments, 13% endometrial ablation which can be used to treat small fibroids <3cm and heavy menstrual bleeding and 3% MR-guided ultrasound, which is a newer treatment for small fibroids). Illustrative comments from women who responded to the patient survey included, ***"I discussed this with my consultant, GP didn't know much"***.

- When seeing their gynaecologist, 73% of the women who took part in the survey said they were told about hysterectomy and 51% offered it. This contrasts with 44% being told about fibroid embolisation and 35% offered it (as regards other treatment options, myomectomy 42% were told about myomectomy and 20% offered it, 36% were told about drug treatment and 20% offered it, 17% were told about endometrial ablation and 11% offered it, and 4% were told about MR-guided focused ultrasound and 2% offered it).

- These findings raise questions about whether women are being given the opportunity to make informed decisions about their treatment options. Of the women taking part in the survey, 59% of women felt they had not been given sufficient information about treatment options and their advantages and disadvantages. Asked what additional information they would have liked 73% responded, "about treatment choices" (75% wanted to know about UFE and over 50% about all the other treatments apart from hysterectomy; this may be because women had been better informed about hysterectomy originally). These concerns are backed up by comments made by women in the on-line survey:

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

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

- The anecdotal results of the patient survey seem to indicate that NICE clinical guidelines are not always being followed. NICE clinical guidelines also state that a woman with HMB referred to specialist care should be given information before her outpatient appointment. The authors strongly recommend that all such women should be given a copy of NICE's written information (Understanding NICE guidance) which clearly sets out all treatment options.

7. Discussion[vii]

UFE treatment

The picture that emerges is that in some PCT areas no women, or only a handful, are having UFE as a treatment for fibroids. For example, in NHS Coventry no women underwent UFE treatment for fibroids in the past 2 years although 308 women were diagnosed as having symptomatic fibroids requiring treatment. Similarly, in South Tyneside PCT no women underwent UFE treatment although 149 women were diagnosed with symptomatic fibroids requiring treatment. In NHS Mid Essex only one woman had UFE treatment, despite 298 women being diagnosed with symptomatic fibroids requiring treatment. In NHS Wakefield District only three women had UFE treatment despite 544 women being diagnosed with symptomatic fibroids requiring treatment.

This compares to other PCT areas where the numbers of women undergoing UFE treatment were significantly higher. For example in Liverpool PCT, where 637 women were diagnosed with having symptomatic fibroids requiring treatments, 309 underwent UFE treatment over the past two years. And in the Birmingham and Solihull Cluster PCT, where 394 women were diagnosed with having symptomatic fibroids requiring treatment, 154 underwent UFE treatment.

As regards the numbers of women undergoing hysterectomy for the treatment of fibroids, the PCT with the highest number of hysterectomies was NHS Leicestershire and County Rutland where 1,123 women had hysterectomies. However, this PCT did not state how many women were diagnosed with symptomatic fibroids. The PCT where the smallest number of women underwent a hysterectomy was NHS Calderdale; 142 women were diagnosed with symptomatic fibroids requiring treatment, of which 50 women had hysterectomies.

Over 100 acute hospital trusts offer UFE treatment in the UK[viii]. Where UFE was not offered as a treatment by a responding hospital many had a referral procedure in place to a near-by hospital which did UFE.

However, the findings raise questions about why there is such a wide variation in the numbers of women having UFE treatment in different PCT areas in England, and whether all women are being offered the full choice of treatment options.

Patient Choice and Compliance with NICE Clinical Guidelines

NICE clinical guideline 44 states that when surgery for fibroid-related heavy menstrual bleeding is felt necessary then UAE, myomectomy and hysterectomy must all be considered, discussed and documented. UAE is recommended for women with HMB associated with uterine fibroids and who want to retain their uterus and/or avoid surgery (see Appendix 1). NICE clinical guidelines are based on the best available evidence.

PCTs were asked about what treatments they commissioned for women with fibroids greater than 3cm in diameter (question 5). Answers to this question indicate that in some PCTs the choice of treatment available to women may be restricted:

- **"We commission hysterectomy, myomectomy but not uterine artery/fibroid embolisation. The latter is a Procedure of Limited Clinical Value and is covered under this policy."**
- **"Currently UFE is not routinely commissioned and if the patient opts for UFE the clinician needs to apply for exceptional funding"**
- **"Treatments are provided on the basis of clinical decision. If a clinician wished to seek funding for UFE a request for this would be directed through the PCT's Individual Funding Request Panel"**
- **"Hysterectomy and myomectomy commissioned. Guidelines only so can determine local commissioning policy"**
- **"We are compliant with NICE guidelines with the exclusion of UAE/UFE"**
- **"Hysterectomy and myomectomy are commissioned where appropriate. Uterine artery/fibroid embolisation is not routinely commissioned as NICE guidelines do not cover the clinical and cost effectiveness of that procedure, only the safety and efficacy".**

If this procedure is not being routinely commissioned it calls into question whether women are being offered real choice. Specifically:

- Are women being given the chance to consider and discuss with clinicians the full range of treatment options for fibroids?
- Why in some areas is UFE not routinely paid for by the PCT?
- For what reasons is UFE regarded as a 'Procedure of Limited Clinical Value' when NICE has approved it as safe and efficacious[ix]?
- If UFE is regarded as clinically appropriate, why should women have to ask their clinician to make a special funding application on their behalf?
- Is UFE mistakenly regarded as an inappropriate treatment for women with larger fibroids when outcomes have been shown to be good?[x]

Two PCTs included responses that highlighted that they had recognised the benefits of UFE treatment; **"we actively encourage alternatives to hysterectomy as we feel less invasive treatments are a better option for any women"** and, "**discussed the treatment of heavy menstrual bleeding with local gynaecologists, and will do so again shortly, as our rates of hysterectomy are higher than expected. In line with the "Right Care" approach we would like to reduce the number of hysterectomies that are carried out"**.

NICE clinical guidelines are recommendations on appropriate treatment based on best available evidence; they aim to improve the quality of healthcare. Yet it is clear that there is not a consistent approach to the implementation of NICE clinical guidelines, with regional variation across the NHS.

Best Practice Tariff: DH incentives

Eight PCTs stated that they were not aware of the new Best Practice Tariff for UFE which started on 1st April 2011 and allows for a more appropriate payment for providers for carrying out this minimally-invasive treatment for fibroids.

Best practice tariffs were introduced in 2010-11 by the Department of Health to help the NHS improve quality, by reducing unexplained variation and universalising best practice. In April 2011, best practice tariffs were extended into new service areas including interventional radiology, to incentivise techniques including UFE. The Payment by Results Guidance for 2011-12 states, "The benefits of minimally invasive procedures such as those facilitated by interventional radiology include decreased lengths of stay, reduced risk of hospital acquired infections, and faster rehabilitation. These procedures are an alternative to open surgery, but do not represent best practice in every circumstance because clinical considerations and patient choice may make open surgery alternatives legitimate". It goes on to state that "NICE guidance states that UFE as a "first-line treatment can be recommended" where clinically appropriate"[xi].

In the new NHS the focus is on choice, quality and better outcomes for patients, whilst providing value for money. The Department of Health has recognised the benefits of new treatments such as UFE. If initiatives by the Department of Health to meet these ends, and incentivise quality, are not embraced by commissioners of care and treatment, it will not be possible to improve quality in this area of care.

Best practice tariffs are also to help the NHS deliver productivity gains. The financial benefits of UFE include:

- A lower tariff price: the tariff for UFE is lower than for hysterectomy (in the April 2011 Payment by Results tariff the payment for UFE is £2,500 compared to £2,736 for hysterectomy and £2,736 for myomectomy).

- With a lower tariff price UFE is less expensive to the NHS than hysterectomy. However the most common surgical treatment for fibroids is hysterectomy. Purely for illustrative purposes only, if approximately 30,000 hysterectomies are carried out for fibroids in the UK[xii], this would equate 25,140 in England, based on the population of England accounting for 83.8% of the UK total[xiii]. There is no benchmark for how many of those hysterectomies might have been appropriate for UFE treatment. Purely hypothetically, if 50% of those hysterectomies were instead UFE[xiv], the savings to the NHS could be in the region of £2,966,520[xv].

- The recovery period after UAE is significantly less than following surgery; the reduction in length of hospital stay from the 5-7 days expected post hysterectomy to 1-2 day post UAE has the potential to bring significant cost savings to the NHS (as well as being preferable to the majority of patients)[xvi].

- Hysterectomy, as a major surgical operation, usually requires 2-3 months convalescence. UFE patients are usually advised to take 2 weeks off work[xvii]. There will therefore potentially also be wider costs savings to the economy and employers via fewer lost working days and reductions in the benefits bill due to the faster, shorter recovery time associated with UFE.

Patient involvement

PCTs were asked whether they had involved any patient groups in commissioning for fibroid treatments. A number of PCTs did involve patient groups and lay members in commissioning but 39 simply said "no".

At the heart of the proposals in Health and Social Care Bill currently before Parliament is putting patients at the centre of the NHS; patients should be more involved in decisions about their treatment and care; the message is 'no decision about me without me'. Through the new local Healthwatch, there should be increased accountability for patients and the public; patients should have more influence over what services are commissioned in their local area by Clinical Commissioning Groups. It is essential that PCTs and the new Clinical Commissioning Groups recognise and give patients a stronger voice in what services should be commissioned.

Patient information

Acute trusts were asked what information they provided to women to ensure they were fully and objectively informed about their treatment options. Many good examples of best practice were found with acute trusts having patient information leaflets, national patient leaflets from the Royal College of Obstetricians and Gynaecologists, and the patient's section from the British Society of Interventional Radiology Website, and providing patients with NICE guidelines. However a few trusts said that they did not have written information or that information was provided if requested:

- **"Unfortunately we do not have patient information leaflets available, but as described above, the information is integral to each clinical consultation and all women are fully informed by their Consultant":**
- **"The Trust gives oral information during the consultation and consent process. The current patient information leaflet is being developed".**
- **"Patients are informed by consultants. If they wish to see further information, nurses will print off leaflets about fibroids from the "Patients.co.uk" website":**

It is essential for there to be good communication between healthcare professionals and women. As NICE clinical guideline 44 states, "Face-to-face communication should be supported by evidence-based written information tailored to the woman's needs".

The trusts responses did however differ widely from the responses from women in the FEmISA patient survey where 59% of women felt that they were given insufficient information about their treatment options and treatment.

8. Recommendations

There is a wide variation in the number of woman having UFE as a treatment for fibroids in certain areas of England. NICE clinical guideline 44 makes clear that, “HMB has a major impact on a woman’s quality of life. Treatment and care should take into account the woman’s needs and preferences. Women with HMB should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals”. Women cannot make informed decisions if there are restrictions on them accessing a particular treatment.

Women deserve access to the most appropriate treatment. The benefits of UFE have been recognised by the Department of Health and NICE. Commissioners must recognise those benefits too.

The report authors therefore make the following recommendations to improve access to UFE treatment:

1. The listing of certain procedures such as UFE as of ‘limited clinical value’ risks eliminating procedures and preventing decision-making by clinicians and patients, based on the best available evidence of appropriate treatment. The authors urge the Department of Health to clarify whether they are supportive of this form of 'non-clinical rationing' and to issue robust guidance that urges PCTs, and the new clinical commissioning groups, to follow NICE clinical guidelines.

2. Women should be given routine access throughout England to UFE treatment (when clinically appropriate). The new NHS Commissioning Board should issue full and comprehensive commissioning guidance to clinical commissioning groups to ensure clinical commissioning groups are guided to commission all treatment options for fibroids and putting an end to regional variation in access.

3. Women should routinely be given high quality information about their treatment options both by their GP and by specialist clinicians. The authors call for a central source of bespoke high quality patient information to be available online and through printed materials, for example on the NHS Choices website.

4. GPs, as the first port of call, need to keep themselves up to date to be able to advise their patients and commission care in the future. The authors call on the Royal College of General Practitioners to ensure continued improvement in the education and training of GPs about common conditions such as fibroids.

5. Treatment options for fibroids can have a major impact on a woman’s life; there is no chance of having a child after a hysterectomy. Women must be able to make informed decisions about treatment options; specialists must ensure that, in accordance with NICE clinical guideline 44, where surgery for fibroid-related HMB is felt necessary, the full range of options, UFE, myomectomy and hysterectomy, must all be considered, discussed and documented**.** The authors call on the Royal College of Obstetrics and Gynaecology to ensure their members are aware of this.

6. NICE proposes a multi-disciplinary team approach. In some hospitals joint fibroid clinics have been set up so women can be fully informed by interventional radiologists and gynaecologist about all their treatment options, ensuring choice and optimal health outcomes. The authors strongly recommend that interventional radiologist and gynaecologists should work together as a team and interventional radiologists should have admitting rights and their own dedicated beds, for UFE.

7. The proposed list of healthcare topics for new Quality Standards to be developed by NICE[xviii] includes Heavy Menstrual Bleeding. A new NICE QS on HMB should be commissioned to ensure a framework that provides for high quality care and choice of treatment for women with fibroids.

8. The Department of Health and the new NHS Commissioning Board should ensure that all commissioners and acute trusts are aware of new best practice tariffs to ensure the benefits of minimally invasive techniques such as UFE are fully taken on board by local commissioners of care and treatment.

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[i] The terms UAE and UFE are both used to describe the embolisation treatment procedure. UAE is a less specific term and may be used for conditions other than fibroids (eg to stop severe pelvic bleeding caused by trauma or haemorrhage after childbirth). UFE is a specialized form of UAE for treating symptomatic fibroids. In this report the authors have used the term UFE.

[ii] http://www.nhs.uk/Conditions/Fibroids/Pages/Introduction.aspx

[iii] http://www.nice.org.uk/nicemedia/live/11025/51707/51707.pdf

[iv] See NICE Interventional procedure guidance 367 Nov 2010
http://www.nice.org.uk/nicemedia/live/11025/51706/51706.pdf

[v] The figure 39,000 comes from Hospital Episode Statistics 2009-2010

[vi] Full FOI data can be found on the MTG website. The FEmISA patient survey can be found on the FEmISA website.

[vii] Discussion focuses on key findings from the FOI survey however other findings (around diagnostic pathways and lack of data) are discussed in Appendix 3 to the Report.

[viii] FEmISA research; see http://www.femisa.org.uk/

[ix] See NICE Interventional procedure guidance 367 Nov 2010
http://www.nice.org.uk/nicemedia/live/11025/51706/51706.pdf

[x] PCT responses included, "the ethnic diversity of our population means that we have relatively high rates of hysterectomy for very large fibroids (20 week uterine size) because this is the most appropriate treatment"; however studies have shown that the size of uterus or fibroids is not a limit on UAE and UAE should be offered to women with large fibroids and uterine volumes. See Pron, G, Cohen, M, Soucie, J, et al. The Ontario Uterine Fibroid Embolization Trial, Part 1 Baseline patient characteristics, fibroid burden and impact on life. Fertility

and Sterility, January 2003. Pron, G, Bennett, J, Common, A, et al. The Ontario Uterine Fibroid Embolization Trial Part 2. Uterine fibroid reduction and symptom relief after uterine artery embolization for fibroids. Fertility and Sterility, January 2003.

See also *Does Size Really Matter? Analysis of the Effect of Large Fibroids and Uterine Volumes on Complication Rates of Uterine Artery Embolisation*; A. A. Parthipun, J. Taylor, I. Manyonda, A. M. Belli; Springer Science+Business Media, LLC and the Cardiovascular and Interventional Radiological Society of Europe (CIRSE) 2010

[xi] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_126157.pdf

[xii] see http://www.fibroids.co.uk/fibroid_embolisation/alternatives.html.

[xiii] Population of UK taken as 61,827,200, population of England as 51,809,700

[xiv] Making a 50% assumption is purely for illustrative purposes and does not take into account factors such as clinical appropriateness or patient choice.

[xv] This sum has been calculated by using the current tariff prices; the cost of 50% of the 25,139 treatments by way of UFE (£31,425,000) was subtracted from the cost of 50% hysterectomies (£34,391,520). The illustrative saving does not take into account that symptom relief may not be achieved in some women, and that further procedures may be required.

[xvi] British Society of Interventional Radiology: UK Uterine Artery Embolisation for Fibroid Registry 2003-2008.

[xvii] see http://www.fibroids.co.uk/fibroid_embolisation/alternatives.html

[xviii] http://www.nice.org.uk/getinvolved/currentniceconsultations/NQBEngagement.jsp

Appendix 1

NICE clinical guideline 44 – Heavy menstrual bleeding

1.7. 1 For women with large fibroids and HMB, and other significant symptoms such as dysmenorrhoea or pressure symptoms, referral for consideration of surgery or uterine artery embolisation (UAE) as first-line treatment can be recommended.

1.7.2 UAE, myomectomy or hysterectomy should be considered in cases of HMB where large fibroids (greater than 3 cm in diameter) are present and bleeding is having a severe impact on a woman's quality of life.

1.7.3 When surgery for fibroid-related HMB is felt necessary then UAE, myomectomy and hysterectomy must all be considered, discussed and documented.

1.7.4 Women should be informed that UAE or myomectomy may potentially allow them to retain their fertility.

1.7.5 Myomectomy is recommended for women with HMB associated with uterine fibroids and who want to retain their uterus.

1.7.6 UAE is recommended for women with HMB associated with uterine fibroids and who want to retain their uterus and/or avoid surgery.

Appendix 2

Freedom of Information Questions for PCTs :

1. How many women in your area were diagnosed with symptomatic fibroids, requiring treatment in the last year 2 years?

2. How many women underwent a hysterectomy for the treatment of fibroids in the last 2 years? Of these how many were abdominal, laparoscopic, vaginal?

3. How many women underwent UFE treatment for fibroids in the last 2 years?

4. How many women underwent myomectomy in the last 2 years?

5. What treatments do you commission for women with fibroids >3cm? NICE Guidelines state that they must be offered hysterectomy, myomectomy and uterine artery/fibroid embolisation? Do you commission all these treatments? If not, why not?

6. What processes have you put in place to ensure that commissioning for fibroid treatment is compliance with NICE guidelines on Heavy Menstrual Bleeding [NICE Clinical Guidelines 44 Jan 07]?

7. In the last years did you involve any patient groups in commissioning for fibroid treatments? If yes, how?

8. What processes do you have in place to ensure that all women are offered an alternative to hysterectomy?

9. What processes do you have in place to ensure that women are fully informed about all the treatment options for symptomatic fibroids so they can make a fully informed choice of the treatments available?

10. Are you aware of the new Best Practice Tariff for uterine fibroid embolisation starting on 1st April this year which will allow for a more appropriate payment of this minimally-invasive option to treat fibroids and, if yes, have you increased the number of UFE commissioned to hospital providers as a result?

Freedom of Information Questions for Acute Trusts

1. How many women were seen by your Trust for heavy menstrual bleeding and dysmenorrhoea in the last 2 years?

2. How many had fibroids fully diagnosed? How many did not have the cause fully diagnosed?

3. How many women were diagnosed with symptomatic fibroids, requiring treatment in your hospital in the last 2 years?

4. How many women underwent a hysterectomy for the treatment of fibroids in the last 2 years? Of these how many were abdominal, laparoscopic, and vaginal?

5. How many women with fibroids underwent UFE treatment in the last 2 years? If this service is not offered in your Trust, what arrangements are in place for referrals and where do you refer?

6. How many women with fibroids underwent myomectomy in the last 2 years? If this service is not offered in your Trusts, what arrangements are in place for referrals and where do you refer?

7. What is your normal diagnostic pathway for women with heavy menstrual bleeding, menorrhagia, dysmenorrhoea?

8. NICE Clinical Guidelines 44 Jan 07 on “Heavy Menstrual Bleeding” state that all women with fibroids >3cm must be offered uterine artery embolisation, myomectomy and hysterectomy. What processes do you have in place to ensure that all women are fully informed of these treatment options and given alternatives to hysterectomy?

9. What information do you provide to women to ensure they are fully and objectively informed about their treatment options – please send examples of patient information leaflets and links to your web site.

Appendix 3

Acute trusts were asked about their normal diagnostic pathway for women with heavy menstrual bleeding, menorrhagia, dysmenorrhoea.

The authors were encouraged to see many examples of good practice (for example: "Currently women referred for assessment of menstrual disorder are seen in the general gynaecology outpatient clinic. Individual decisions regarding further assessment and treatment are made in the clinic with the patient. Options for non-medical treatment of women with fibroids would include embolisation, myomectomy and hysterectomy and the final decision regarding treatment made with the patient. We now have a local service for embolisation if this treatment is selected. We provide information leaflets for embolisation and hysterectomy, but not specifically for myomectomy. In relation to treatment of women with menstrual disorder we follow the national guidance produced by the Royal College of Obstetricians and Gynaecologists and NICE").

The authors would strongly recommend that all acute trusts use the care pathways as set out in the NICE Quick reference guide - Clinical Guidelines on Heavy Menstrual Bleeding.

Lack of data

PCTs were asked to provide data about the numbers of women in their area diagnosed with symptomatic fibroids requiring treatment, the number of women who underwent a hysterectomy for the treatment of fibroids, the number who underwent UFE treatment for fibroids and the number who underwent myomectomy (see Questions 1-4).

Many PCTs stated that they did not hold the information or have the level of detail to answer any of these questions. It was often stated that the inquiry should be directed to hospital providers (the acute trusts) for answers. However 18 acute trusts did not hold data about the number of women undergoing treatments for fibroids.

This raises general questions about the current NHS information infrastructure. The OPCS procedural codes for UFE are very long and would be difficult for PCTs to access, but hospitals should know the number of procedures they carry out. If this information is not held or cannot be readily extracted, how can PCTs understand their local disease burden from fibroids, and make planning and commissioning decisions supporting patient choice? Without good quality data how can acute trusts as providers of care properly monitor their activity, efficiency and performance?