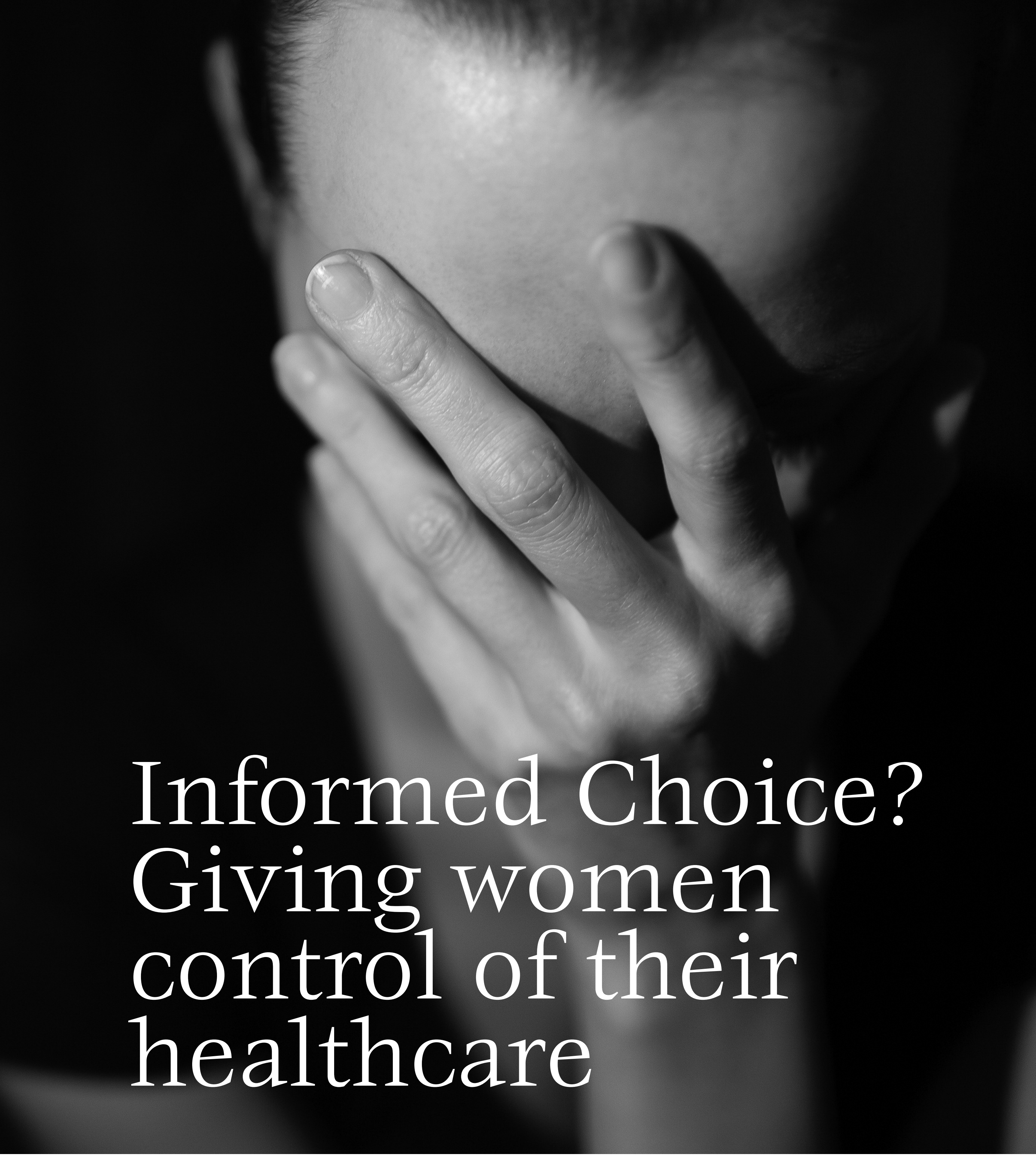

Informed Choice? Giving women control of their healthcare

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ALL-PARTY
PARLIAMENTARY GROUP
ON WOMEN'S HEALTH

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Colleen Fletcher MP, Khalid Mahmood MP, Caroline Nokes MP,
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Contents

Executive Summary

Introduction

The All-Party Parliamentary Group on Women's Health has found that across the country women are not being treated appropriately when it comes to their physical, mental and gynaecological health.

The group surveyed over 2,600 women and sent an FOI to hospital Trusts and found unacceptable treatment for women with fibroids and endometriosis.

The group found that women are not getting the right diagnosis and information about treatments making it extremely difficult for them to decide the best care for themselves.

If women cannot even get the right diagnosis and information about treatments, how can they possible decide what is the best care for themselves? Women deserve every opportunity to take control of their own healthcare and this group is striving to empower women so they have this potential.

The survey carried out for this report identified key issues in regards to:

1) Attitudes

- 42% of women said that they were not treated with dignity and respect.
- 40% of women with endometriosis needed 10 GP appointments or more before being referred.
- 39% of women sought a second opinion.

These statistics show that women are all too often dismissed by healthcare professionals when discussing their symptoms and choices.

2) Information and Choice

- 62% of women were not satisfied with the information that they received about treatment options.
- 67% of women said they got most of their information from the internet.
- Nearly 50% of women with fibroids and endometriosis were not told about the short term or long term complications from their treatment.
- Only 16% of NHS Trusts provide women with written information about Heavy Menstrual Bleeding and pelvic pain.

The fact that women feel the need to seek further advice and they are not satisfied with the information that professionals give them shows that more needs to be done to empower women so they can make these choices. Women should be given the full range of information, in a written format, so they are able to make an informed choice.

3) Costs and short term thinking

- 86% of Trusts could not provide information as to how many diagnostic tests were needed for endometriosis and fibroids diagnoses.
- 40% of those surveyed needed 10 GP appointments or more before being referred to the specialist.
- 12% of women surveyed with fibroids took 1-2 years from their diagnosis to get their treatment.

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, and available in a variety of formats. These leaflets should be endorsed by the relevant clinical bodies and patient groups and the same generic 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) **Wider awareness of menstrual health with the general public and all healthcare professionals, as well as education at schools on these issues** – 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 at the RCGP and RCOG for recognising and treating fibroids and endometriosis.

4) **Encourage multi-disciplinary team working at Trusts** – to ensure access to all treatments for women. Best practice pathway should be followed in this regard.

5) **Where it exists NICE Guidance should be followed for fibroids and endometriosis and for treatments for these conditions.** These should not be implemented variably across the country as is currently the situation.

Welcome and introduction from the Chair of the Women's Health APPG

– Paula Sherriff MP

I am proud to have been Chair of the All-Party Parliamentary Group on Women's Health since June 2016. We have been campaigning for women to have the right to make an informed choice about their own healthcare and are calling for women to be empowered.

Women's healthcare covers a huge arena and affects everyone, either directly or indirectly through someone they love and care about. The Group has heard of areas of healthcare where women receive worse outcomes due to a lack of awareness, such as with stroke, to women who are painfully affected by conditions such as polycystic ovary syndrome, prolapse, premenstrual syndrome, women's health cancers and many others.

All too often I have heard of women being marginalised and side-lined when they try to seek help, dismissed and not taken seriously. This needs to stop. Women have a right to be heard and they deserve to be treated with dignity and respect at all times.

This Group aims to shine a light on little known conditions that have a huge impact, helping to bring women's voices to Parliament and to make a change.

This year the All-Party Parliamentary Group Report is focusing on highlighting the need for informed choice for women. We have chosen to shine a spotlight on two conditions which are prevalent amongst women, fibroids and endometriosis.

These conditions are common in the population and yet there is a chronic lack of awareness, often by healthcare professionals at all levels and frequently in the general public. It is vital that we talk about these conditions, that 'women's problems' are not stigmatised and we learn to talk openly around what is normal pain and what is not. The more we understand conditions and their symptoms, the range of treatments and what can be done, the more women can get the help they need and be offered the choices they deserve so they can make the best decision for themselves.

I was shocked by the stories that I have heard whilst we conducted this inquiry and I am convinced that more can be done easily to change vast numbers of lives for the better.

I am committed to working with my Parliamentary colleagues and others to empower women, to make sure their voices are heard and represented at Parliament, and above all to campaign for change so that women can get the care and choices that they deserve.

Paula Sherriff

Paula Sherriff MP
Member of Parliament for Dewsbury
Shadow Minister (Equalities Office)
(Women and Equalities)

Group Aim

The Group aims to empower women to ensure that they can make an informed choice about the best treatment for them and that they are treated with dignity and respect.

The Report Plan

The group has conducted this inquiry as we want to focus on issues that affect huge numbers of women across the UK. We are looking at two conditions that are extremely common, yet have little awareness by both the general public and with healthcare professionals. These conditions have been chosen because we feel that there is progress to be made in empowering women to ensure that they are able to make informed decisions about their own care.

This report hopes to shine a spotlight on fibroids and endometriosis, to raise awareness of these conditions with healthcare professionals and the general public, and to bring about a positive change to ensure women can access better diagnosis and treatment options across the country. The Group thinks that there are lessons to be learnt that can be replicated across a whole range of women's health conditions, including polycystic ovary syndrome, prolapse and others.

The Group has called for written evidence from a range of influential stakeholders regarding the current state of the NHS for these conditions, and what recommendations can be taken forwards. The Group has also held an oral evidence session to learn from patients and healthcare professionals about their experiences and what best practice might look like. Furthermore the Group opened an online patient survey and sent out a Freedom of Information request to NHS Trusts to gain additional information.

Overview and Impact of Conditions

Both fibroids and endometriosis are widespread amongst women, they both have symptoms identified with pelvic pain, unusual periods and menstruation issues, and are gynaecological issues. The Group believes that it is important to open a more widespread dialogue on these conditions and the whole patient pathway; from presentation to diagnosis to treatment and follow up.

Fibroids and endometriosis are two of the most prevalent conditions that affect women which is why the Group has chosen to focus on these two conditions.

Fibroids:

Uterine fibroids are benign (non-cancerous) tumours of the uterus or womb. They are the most common tumours found in the human body. It is estimated that approximately 20-70% of women have fibroids. Many women never know they have them, and whilst fibroids are thought to affect as many as one in three women, many women do not have symptoms[1]. Fibroids can cause women extreme pain and symptoms and result in surgery and invasive interventions.

Endometriosis:

Endometriosis is the name given to the condition where cells like the ones in the lining of the womb (uterus) are found outside the womb in the pelvis, and occasionally in more remote sites of the body. During the monthly cycle hormones stimulate the endometriosis, causing it to grow, then break down and bleed. This internal bleeding can lead to irritation, inflammation, pain, and the formation of scar tissue (adhesions). Endometrial tissue can also be found in the ovary where it can form cysts[2].

According to current statistics, endometriosis affects 1 in 10 women in the United Kingdom[3]. Endometriosis is the second most common gynaecological condition in the UK[4] and can affect women of reproductive age. Several of the patients we heard from experienced symptoms at a very young age.

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[1] http://www.nhs.uk/conditions/Fibroids/Pages/Introduction.aspx

[2] Endometriosis UK website

[3] Rogers PA, D'Hooghe TM, Fazleabas A, et al. Priorities for endometriosis research: recommendations from an international consensus workshop. Reprod Sci 2009;16(4):335-46.)

[4] University College London Hospitals. General information about Endometriosis.

Patient Testimonials

Case Study:
Amy Maidment, 23, diagnosed at 19, from Oxford

I was diagnosed with endometriosis after my first year at university. The diagnosis process alone was hellish. The laser surgery treatment to the small amounts of endometriosis that was found ('too small to do much', he told me) wasn't a success, and within six months my symptoms started coming back. They were slightly better, though, and I didn't want to face dealing with that system again, so I just decided to grin and bear it. Bad idea.

In March last year, my short daily cramps started to get longer and more severe. I hoped that it was just stress from work, that it'd just pass, but it just kept persisting, gradually worsening over the next couple of months. Management at work were less than sympathetic, with one manager asking to see my entire medical history after I took a day off with crippling period pain. In May, I got a stomach virus, which worsened it to one of the most extreme flares I've ever had. I stopped working at the start of June, because it hurt to breathe when standing on the shop floor. I could barely walk across the hall to the bathroom. I was in utter agony, and because it was a pre-existing long term condition, there was nothing that A&E could do for me when I sat there nearly passing out from the pain.

I was lucky enough to see a brilliant specialist, who listened to me and validated my pain, and told me that we'd find something that would help. He sent me for an MRI, which showed adhesions on my left ovary and down my rectal muscles, as well as in other places – which is exactly where the pain was at its worse. It also showed adenomyosis. He put me on the waiting list for surgery at the JR. I still don't have a surgery date. I'm not sure, since the closure of the Horton and the complexity of the surgery due to where my growths are, when I will get one. I'm too nervous to call and follow it up – what if I nag, have another surgery, and once again it doesn't do anything to help?

However, I have had the Mirina coil inserted in August, and it's been magical. I'm still in daily pain, and sometimes it's awful, but I have my life back a little bit more now.

Case Study:
Sarah Hutchinson

I was first diagnosed by a scan following some severe pain in my side. I was told I had a fibroid pressing on my bladder. My scan never made it to the GP though – and the GP told me firmly that 'fibroids don't cause any problems, and there's nothing you can do about them anyway.'

I spent the next couple of years bouncing between GPs. When my periods became debilitating, I spoke to a GP who told me to take Ibuprofen. I suspect now that my GP made no note of the fibroid on my records. I continued to be treated separately for the various symptoms I was experiencing. I struggled on with the crippling periods that made it difficult to work several days a month, and was exhausted, aneamic, in pain and depressed.

I eventually got help from a nurse practitioner, who gave me time to speak. She listened to my range of symptoms and immediately suggested I had a fibroid. She prescribed Tranexamic Acid which eased my periods immediately.

I was finally referred to a gynaecologist, who told me that because of the size, and because I wanted children, the best option was Myomectomy, though I was given information leaflets about other options.

When I went back to confirm I wanted surgery, I was told that I should wait, but later a nurse told me it was too large to sustain a pregnancy, and suggested asking for a second opinion. I eventually had a successful Myomectomy, removing a single Fibroid 20cm x 20cm x 15 cm - several years after first diagnosis, and a year after the final diagnosis. Looking back, the hardest thing was getting my GP to listen to me - and later, one of the gynaecologists. I knew nothing about fibroids until just before my surgery. My fibroid left me drained and in constant pain - you shouldn't have to fight for treatment when you're that unwell.

Endometriosis

Patient A: She was told that all her pain and symptoms were in her head and the clinician tried to discharge her.

Patient B: The patient involved had been told so many times that nothing was wrong with her that she thought she was 'going mad'.

Patient C: The woman was told at 18 years old to have a hysterectomy and not offered any other solutions, or given any treatment information. She was able to conceive at a later date and now has a child. This patient told us about how she passionately believes in tailoring treatments to individuals based on their pain and their priorities.

Fibroids

Patient D: This patient was told by her gynaecologist that the only treatment option was hysterectomy, she was given no other information and the impact of this procedure was never considered. She fought for more information and finally managed to get the full treatment options explained to her, and had an alternative treatment to hysterectomy.

Patient E: This woman felt that her symptoms were ignored and she was told to just leave the issue. In this time her fibroids grew and became more symptomatic. When she was finally referred she felt that she had less treatment options than if she has been appropriately diagnosed and referred at an earlier stage.

Other patients:

'This disease has such an enormous impact on lives, this is not appreciated by healthcare professionals. The impact of a life lived in pain, compounded by difficult side effects of hormonal treatment, infertility etc is simply not understood. Women feel incredibly alone and unsupported.'

'I was dismissed by my GP so many times over so many years with so many symptoms that added up to endometriosis that I started to even doubt myself. I felt like I was going crazy because no one would take me seriously.'

'It's a debilitating disease which takes over my life at times. More awareness and understanding is required.'

'This illness is devastating, it wrecks lives and there is no real cure.'

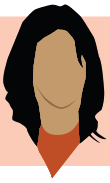
'My life is being ruined by this awful condition.'

'More information available through the internet as no GP or gynaecologist seem to have the time to explain all the facts.'

'I had to fight every step of the way to get treatment for endometriosis and feel in the end the NHS let me down.'

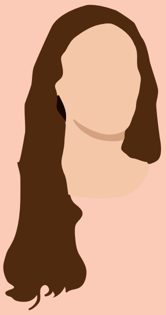
'I was disappointed that I have had to go private to get a correct diagnosis and treatment plan.'

The Patient Survey

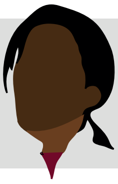


'No information given from hospital, have had to find out everything myself.'

'I read a lot online about what to expect. I knew nothing about fibroids at the time of diagnosis and the hysterectomy was presented as the only option.'

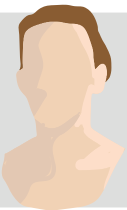


'I told them that I didn't want that, consistently. They then referred me to a Consultant Radiographer. The gynaecologist gave me very little information. I looked into it myself, otherwise I wouldn't have known what could be offered.'



'I was told to either get the operation, or deal with the pain.'

'I was grossly unprepared for the length of recovery.'



'I wasn't given any advice or treatment. My condition wasn't even explained to me.'

'Was never told all the details about treatment options so I had to research myself.'

The WHAPPG opened an internet patient survey asking for women who had suffered from fibroids or endometriosis to share their experiences. Over 2,600 women responded to this request and we have built a picture around their experiences.

Due to the self-selecting nature of this patient survey, the results reflect the women most interested in responding, which will have an impact on the results. It is thought that women who demanded a second medical option, or researched their own treatment options, will have been more likely to complete this survey.

The overall picture that we found showed that the patient pathway current in place, are woefully lacking and are in some cases not followed at all. Women appear to struggle to get a diagnosis with endometriosis, and then with both fibroids and endometriosis this survey shows that women are rarely told about the full variety of treatment options, and are often pushed towards a treatment choice that they might not want, based on their clinician's recommendation. Some healthcare professionals are not aware of certain conditions to a sufficient level, or are not aware of treatment options.

The group has outlined some of findings from the patient survey over the next two pages. 2,604 women responded over a period of 2 and a half months at the start of 2017.

Key findings across both conditions:

- **62% of women were not satisfied with their treatment choice.**

  These findings are supported by the TOHETI Report and FEmISA 2016 report. According to FEmISA, 67% of Trusts take no measures to ensure women are aware of their treatment options and offered choice.

- **42% of women said that they were not treated with dignity and respect.**

  Women deserve to be treated with dignity and respect. Almost 50% of the 2,604 people that responded felt that they were not treated with dignity and respect.

- 67% of women said they first found information out about their condition from the internet.

  The Group was shocked by these high statistics, as it highlights that women are not getting the information that they deserve to make an informed choice about their health and are being forced to turn to the internet for solutions. Furthermore, there is little guarantee that the information provided on the internet is always clinically accurate.

This Group firmly believes that informed choice is a patient's right, and call on all involved to ensure that this happens.

Endometriosis figures:

- 40% of those surveyed needed 10 GP appointments or more before being referred to a specialist and 10% of women took 15 years or more to get a diagnosis from when they first went to a healthcare professional with symptoms.

  These figures highlight the struggle that women with endometriosis can face in getting a diagnosis for their condition. These statistics are truly startling.

- 25% of women received the wrong diagnosis.

  Endometriosis can be difficult to diagnose as there is no simple test. NICE guidelines on diagnosis should be followed by all healthcare professionals.

- Where and how did you first find information on your condition – 68% via the internet, 41% their gynaecologist, 22% from their GP.

  It is disappointing that often healthcare professionals are not providing women with the information that they need and deserve. Instead women have to do their own research, which might not always happen, and often they might not find the right information.

- Anecdotal comments and responses show that many were told these problems were psychological.

  'The first ever GP I saw fobbed me off saying "periods are painful" - at this point I was passing out due to the pain.'

  'I was often made to feel it was all in my

head and that my symptoms were caused by stress and IBS.'

- Over 40% of women sought a second opinion during their diagnosis and treatment.
- 60% of women were not satisfied with their treatment.

Fibroids figures:

- 70% of women were told about hysterectomy, however only 38% received a hysterectomy.

  These figures highlight how women are being pushed towards having a hysterectomy, often without being told about other treatments. This needs to change as more pharmaceutical and non-surgical interventions become safer and should be more commonly available.

- The hysterectomy figures are much higher when compared to the percentage of women who were told about, offered or had other treatment – 47% of women were told about myomectomy, 54% were told about Uterine Fibroid Embolisation, and few were told about pharmaceutical options.
- 43% of women were not satisfied with the information about their treatment choice.

  This is supported by the TOHETI report which stressed that women felt they lacked a voice.

- Over 20% of women sought a second opinion during their diagnosis and treatment.
- Time to treatment from diagnosis:
  - 23% took 1-3 months
  - 20% took 3-6months
  - 11% took 6-9 months
  - 7% took 9-12 months
  - 12% took 1-2 years.

  Given that fibroids can increase in size dramatically some of these waiting times are alarming.

  'The waiting time was unacceptable given my symptoms and I had to pay a lot of money to accelerate my operation.'

- 34% of women were not satisfied with their treatment.

Treatment options

- The breakdown of which treatments women were told about, offered and received is very interesting.

  These findings show that women were all too often more likely to be offered one treatment over others, and that some treatments are much more likely to be discussed with a patient than others.

  The Group believes that all treatment options should be discussed with the patient to ensure that they can make an informed choice about their treatment and they are concerned that this does not appear to be the current situation

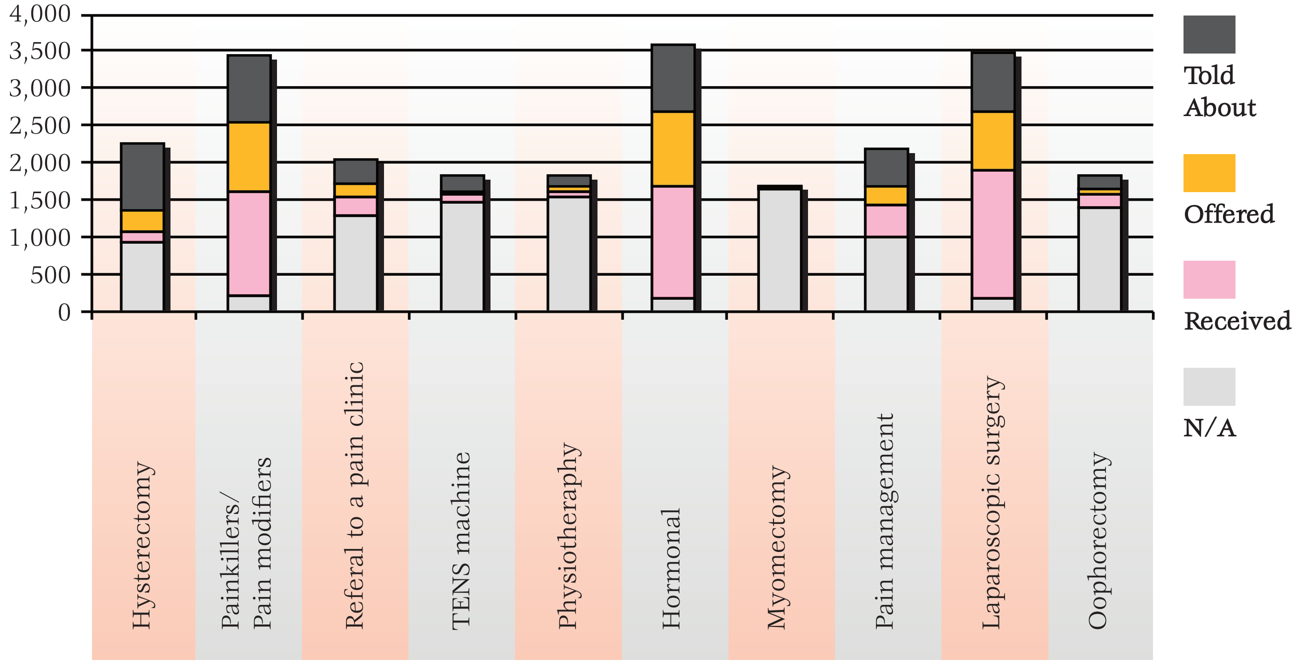
Informed Choice - Endometriosis

On being diagnosed with endometriosis, which treatment options were you (a) told about (b) offered and (c) received? Please tick all that apply.					
Answer Options	Told About	Offered	Received	N/A	Response Count
Hysterectomy	909	283	152	909	1999
Painkillers/ Pain modifiers	910	916	1395	215	2220
Referal to a pain clinic	316	172	268	1273	1814
TENS machine	224	42	97	1464	1758
Physiotheraphy	138	72	102	1518	1737
Hormonal (Combined oral contraceptive pill, Mirena Coil, Progestogens, GnRH analogues, Testosterone derivatives, Danazol, Gestrinone (Dimetriose))	896	996	1524	167	2262
Myomectomy	37	8	13	1624	1669
Pain management	510	257	414	1003	1825
Laparoscopic surgery	774	819	1704	174	2217
Oophorectomy	180	103	152	1402	1713
Other e.g. ulipristal acetate					431
				answered question	2341
				skipped question	26

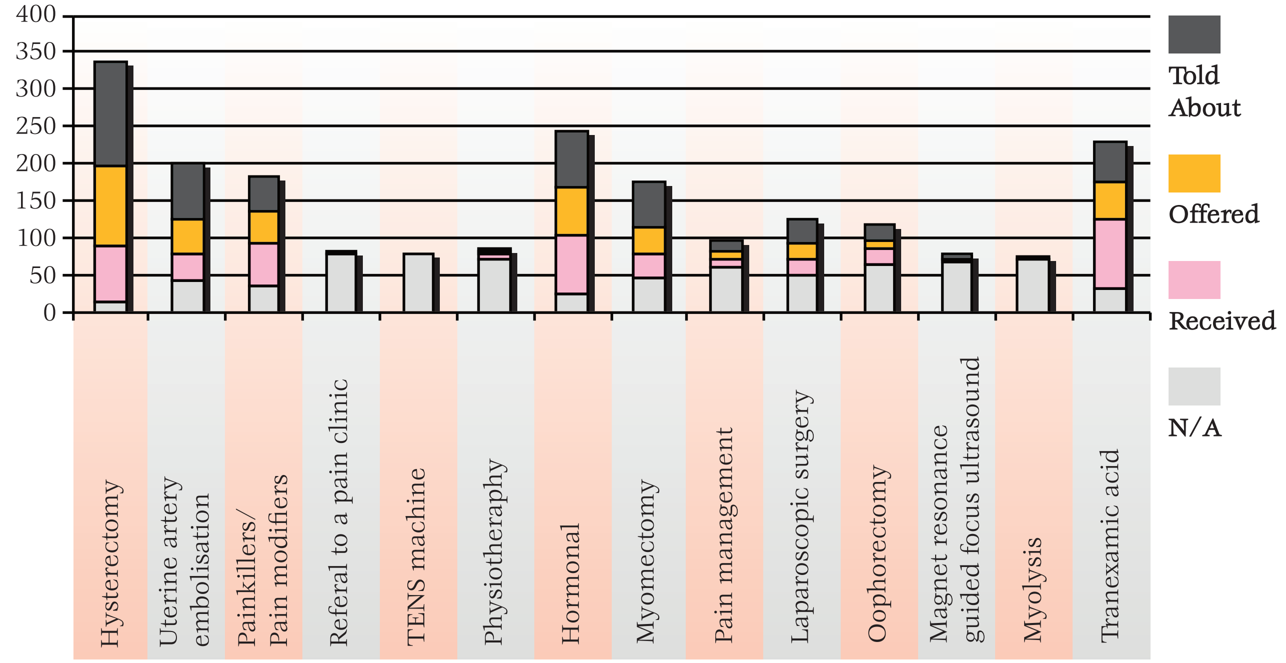
Informed Choice - Fibroids

On being diagnosed with fibroids, which treatment options were you (a) told about (b) offered and (c) received? Please tick all that apply.					
Answer Options	**Told About**	**Offered**	**Received**	**N/A**	**Response Count**
Hysterectomy	143	105	77	13	204
Uterine artery embolisation	78	44	37	42	144
Painkillers/ Pain modifiers	47	43	55	36	128
Referal to a pain clinic	1	0	0	76	77
TENS machine	0	0	0	77	77
Physiotheraphy	2	3	8	70	78
Hormonal (Combined oral contraceptive pill, Mirena Coil, Progestogens, GnRH analogues, Testosterone derivatives, Danazol, Gestrinone (Dimetriose))	76	65	78	25	160
Myomectomy	58	38	31	46	124
Pain management	13	10	10	61	82
Laparoscopic surgery	33	22	22	47	99
Oophorectomy	21	14	20	63	93
Magnet resonance guided focus ultrasound	6	2	4	66	78
Myolysis	1	0	0	72	73
Tranexamic acid - an antifibinolytoc drug used to reduce bleeding	53	50	93	32	151
Other e.g. ulipristal acetate					43
				answered question	233
				skipped question	4

On being diagnosed with endometriosis, which treatment options were you (a) told about (b) offered and (c) recieved? Please tick all that apply.



On being diagnosed with fibroids, which treatment options were you (a) told about (b) offered and (c) received? Please tick all that apply.



Informed Choice - Fibroids

What information were you given about your treatment options?
Please select multiple answers if applicable.

Answer Options	**Response Percent**	**Response Count**
Short-term complications	62.60%	119
Longer-term complications	51.60%	98
Short-term side effects	59.50%	113
Longer-term side effects	40.50%	77
Length of hospital stay	73.20%	139
Time to return to work/normal life	75.80%	144
Death rate	18.90%	36
Home nursing required	11.60%	22
Other (please specify)		46
	answered question	190
	skipped question	37

- Information about treatments and possible side effects and complications given to women when offered a treatment.

  The Group is concerned by evidence shown that when offered or pointed towards a treatment women are often not told about the full impacts of the treatment, or given the full picture of information.

Informed Choice - Endometriosis

What information were you given about your treatment options? Please select multiple answers if applicable.

Answer Options	Response Percent	Response Count
Short-term complications	59.20%	1176
Longer-term complications	46.50%	925
Short-term side effects	62.60%	1245
Longer-term side effects	37.70%	749
Length of hospital stay	53.20%	1057
Time to return to work/normal life	56.40%	1122
Death rate	9.60%	190
Home nursing required	4.00%	79
Other (please specify)		369
	answered question	**1988**
	skipped question	**399**

Anecdotal comments

- Many women had to resort to using private healthcare insurance to get the diagnosis and treatment that they needed/wanted.

  'NHS staff did not take me seriously however private healthcare staff were brilliant and very helpful.'

  'I just wish doctors knew to LISTEN, we know our bodies better than anyone else.'

- Nearly all the comments around treatment choice for fibroids explained that women felt like they were being pushed into getting a hysterectomy.

  'I read a lot online about what to expect. I knew nothing about fibroids at the time of diagnosis and the hysterectomy was presented as the only option.'

- Of the over 1000 plus comments that we received for endometriosis almost every

person spoke about being dismissed by healthcare professionals and having to fight for a diagnosis, information and treatment.

> *'Any attempt to get help takes so long and is often dismissed.'*
>
> *'There is a resistance that you encounter.'*
>
> *'It was distressing having so many GP and walk in centre appointments and feeling that my pain and symptoms were not being taken seriously.'*

These findings are concerning. If women are not even told about, let alone offered, the full range of treatments then how can they be accessing the best care? This Group passionately believes, having spoken to many women, that informed choice is the most important step forward for all conditions.

If women are to make an informed decision about treatment options, they need to fully understand their condition, what treatments are available and what the short and longer term impacts of those treatments are likely to be. This is especially clear when considering that 39% of women surveyed sought a second opinion and 67% of women got most of the information about endometriosis or fibroids from the internet.

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Endometriosis

It is concerning that the patient survey highlighted how hard women struggle to get their diagnosis of endometriosis, and the huge barriers that they had to overcome to finally receive this.

40% of women surveyed had 10 or more GP appointments before being referred to a specialist, which often did not give them the help they needed, and 10% of women took 15 years or longer to get their diagnosis from when they first went to a healthcare professional with symptoms.

Even then, 9% of women had to wait 1-2 years for their first treatment following diagnosis.

Fibroids

Most worryingly for fibroids is the automatic treatment choice which is most commonly offered was hysterectomy, with 70% of those surveyed offered a hysterectomy. There appears to be a variety of reasons for this:

- Gynaecologists used to carrying out their procedure – current culture of practice.
- Gynaecologists are not incentivised to carry out non-surgical and pharmaceutical procedures – culture of what has been the norm.
- Traditionally this was the only option – but not been the case for some time.
- Different tariffs for other procedures –

often benefits reflected in different budgets, or across primary and secondary sectors, provide dis-incentives for procedures other than hysterectomy.

Complications, the short term and long term impact, should all be discussed. Over 40% of women were not told about short term complications and this increases to over 50% for long term complications.

It is telling that many women suffering with fibroids and endometriosis turned to private healthcare insurance to get the diagnosis and treatment that they wanted.

This Group was overwhelmed by the number of responses they received. This is clearly an area where people feel strongly about their experiences and the Group believes that there are clear improvements that can be made.

> *'I have had to get private health cover.'*
>
> *'I had to go private to get anyone to believe me. My friend, a fellow Endo sufferer, was the person who diagnosed me. I was made to think that it was all in my head.'*
>
> *'It is s real shame that I felt I had to go down the private care route and pay for it myself.'*

Scale of the problem – Data from NHS Trusts

The APPG sent out a Freedom of Information Request to all appropriate hospital Trusts (139 Trusts) to determine:

a) What data is collected by Trusts about fibroids and endometriosis

b) How well this is recorded and tracked

c) What procedures are actually being carried out and the costs involved

The APPG was aiming to find out what current practice is and to paint a picture of the current situation. Unsurprisingly many Trusts were unable to answer the questions that we asked in terms of tracking patients with pelvic pain and tracking patients once they received a diagnosis.

The overall response rate from NHS Trusts was 79%, please see the appendix for further information.

Key findings:

- The average number of women diagnosed over the last three financial years for fibroids is 283 people per Trust, the average for endometriosis is 231 people.

- On average over the last three financial years each Trust recorded 91 women received a diagnostics test for endometriosis and 147 for fibroids.

  This number is very low – does this imply a problem with the coding? The Group is concerned that these diagnostic tests not being tracked, or recorded.

- 86% of Trusts were not able to provide an answer as to how many diagnostics tests were needed in the last three financial years to diagnosis endometriosis and fibroids.

  This implies that they appear to not be tracking the cost of misdiagnoses. Trusts therefore have no idea of the cost involved. This also means patients that are admitted repeatedly to A&E for their conditions are not being considered when costs are looked at for these conditions.

- What information is offered to women who present with pelvic pain/heavy menstrual bleeding:

  - Several Trusts list Royal Colleges' information, such as the RCOG leaflet and RCN leaflet. A couple of Trusts referenced other guidelines such as EIDO healthcare leaflets and ESHRE.

  - More Trusts than the Group expected said that they only gave verbal information. Whilst others said they gave information on specific treatments rather than on pelvic pain and Heavy Menstrual Bleeding.

  - Only 16% of hospitals provide women with written information about HMB and pelvic pain.

  The Group was concerned that far too many Trusts do not offer any information, or only offer verbal information. At a consultation women are unlikely to remember everything they are told, let alone the detail that is needed for them to make an informed choice about their condition and potential treatment options.

- Turning to the financial impact of these two conditions we asked each Trust how much is spent on average a year on hospital admissions for:
  - Fibroids was £576,197.58 and for endometriosis £362,241.99

  The Group is concerned that this data might not be accurate, or not tracked appropriately, however these figures are still showing a substantial cost that could be significantly reduced if best practice pathways were followed. A group of Trusts were still unable to answer this question, prompting concerns from the Group over tracking of these patients and their conditions.

- Trusts were asked how many times codes have been logged each year in the last 5 financial years:
  - Hysterectomy – in 2015/16 in total 28,678
  - Fibroids figures – around 250 average – 28,756 in total in 2015/16
  - Uterine Fibroid Embolisation – very low, 11 as average per Trust, 788 in total in 15/16, gone down from 922 in 2013/2014
  - Many Trusts records cannot distinguish between a diagnostic or a treatment laparoscopy – the average number of diagnostics laparoscopy's was 39 per Trust in 2015/16, and 60 laparoscopy's for treatment. These vary from 0 and 1 procedures for Calderdale and Huddersfield NHS Foundation Trust and Kettering General Hospital through to 242 laparoscopy's for diagnosis at Hull and East Yorkshire Hospitals NHS Trust.

  The Group believes that the overall number of laparoscopies is not as high as would be expected from the number of women who report symptoms.

- Trusts were asked how many laparoscopic excision surgeries and hysterectomies (code Q07.1-Q08.9) due to endometriosis/ adenomyosis/fibroids have you carried out over the last three financial years broken down by year – on average 128 for all conditions in 2015/16 – 63% of Trusts could not tell the difference of purpose for the operation.

  These numbers are surprisingly low given the high number of women needing care.

- When Trusts were asked about the number, cost and purpose of hysterectomies, often the Trust could not state what the procedure was for, information received highlighted that:
  - Average cost per Trust in 2015/16 for endometriosis was £277,709
  - Average cost in 2015/16 per trust for fibroids was £297,350
  - 64% of Trusts cannot answer this question.

  Whilst not all hysterectomies will be due to these conditions (anecdotal evidence from FEmISA suggests that approximately 60% of hysterectomies are on fibroids), this direct cost is significant, and does not take into consideration other costs such as the societal costs of needing care for 3 months, being off work for some time, staying in hospital on average for 3 weeks[5] without even considering the emotional cost of having a hysterectomy.

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[5] FEmISA website

- How many uterine artery/fibroid embolization procedures (code RC41Z) have you carried out over the last three financial years, for fibroids, broken down by year – the Group found that some hospitals do not do any, or do very low number.
    - 11 is the average in 15/16

  These are very low numbers considering NICE guidance CG44 around this procedure, and the number of women affected. This is very concerning as it reinforced what the Group found in the patient survey, that all too often women are not being told about all their treatment options. This also highlights the money that Trusts could be saving due to the costs of a) surgery for hysterectomy, b) bed days at the hospital and c) wider societal costs due to the invasive nature of a hysterectomy and recovery time.

In a report published by FEmISA in 2016, the patient group notes that:

‘It is notable that where women have informed choice as at a hospital with a multi-disciplinary fibroid 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.

- The national average is hysterectomy 73%, and UAE 6%. This rather confirms that most women do not have an informed choice about their fibroid treatment.’

Barriers

The Group has heard from a wide range of patients, clinicians and interested stakeholders about what they think some of the barriers are to getting the right diagnosis, treatment and information for patients.

The Group has taken this information and identified the range of barriers below that prevent women from accessing the best services and getting the diagnosis, treatment and follow up that they deserve.

These barriers include: cultural barriers, lack of information, lack of awareness and pathway barriers.

Awareness

Lack of awareness of conditions is hugely worrying, for patients who experience symptoms, but this has also been reported to the group as being sometimes seen through the healthcare professional pathway by patients:

- Lack of understanding of the condition by GPs.

  "It was a traumatic, sad, painful waste of my life and had my GP been more informed think of what a difference that might have made to me."

Combatting barriers

The Group has heard from a range of patients, experts and other stakeholders about what can be changed to help patients.

We have assessed a wide range of suggestions and believe that by implementing these changes, which are a minimum to no cost for the majority, there could be a real and tangible difference made to the lives of patients and we could start overcoming some of the barriers described. These would also help healthcare professionals gather all the information that they need to pass on to patients and make appropriate decisions in the care pathway.

Awareness

- Wider public awareness of endometriosis and fibroids.
- Better awareness of the varied clinical features and manifestations of endometriosis and selection of the most appropriate investigations by healthcare practitioners may reduce delays to diagnosis.[18]
- The ENDOCUL study, which included interviews with healthcare practitioners, reinforces the view that GPs require more information about

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[18] Huntington and Gilmour, 2005; Ballard et al., 2006; Denny and Mann, 2008, in Culley et al., 2013a

- Lack of GP education around what conditions are, and what treatment options are available:
    - In particular there is a lack of GP awareness of interventional radiologists work on embolisation for fibroids which causes a referral delay.
    - Similar concerns around GP awareness of non-surgical treatment options e.g. for drugs and non-surgical interventions.
    - Lack of GP knowledge of BSGE centres for endometriosis and the specialism needed in certain cases.

- Endometriosis and fibroids myths that need to be overcome:
    - Pregnancy will cure your endometriosis.
    - A hysterectomy is the only option for those suffering with endometriosis, and will completely cure the condition.
    - It's not that bad and is something you must live with – period pain
    - You cannot have a non-surgical intervention for fibroids and your first treatment option should be a hysterectomy.

  'I was told I had to live with the pain from endometriosis and to just get pregnant.'

- Lack of awareness that these conditions are debilitating on a monthly basis that has a huge impact if employers do not recognise or take the conditions seriously, from increasing stress, to taking sick leave etc.

endometriosis to assist in timely referral and diagnosis.[19]

- It is necessary to build awareness of these conditions and general menstrual health – what is normal?

  'I had suffered a long time with my symptoms but just thought it was part and parcel of 'being a woman'.'

- Clinicians and Royal Colleges need to work with patient groups to increase understanding and awareness of conditions.

- The profile of newer treatments and non-surgical interventions needs to be raised.

- Translate information leaflets - the ENDOCUL study also highlighted a lack of information available in alternative languages and tailored to different ethnic and cultural groups.[20]

- NHS England and CCGs need to promote NICE clinical guidelines and ensure that any guidelines are brought to the attention of healthcare professionals and used.

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[19] Denny et al., 2010

[20] Endocul study, De Montfort University

Information

- Some Gynaecologists discuss the variety of options readily with their patients, whilst others appear not to do so. The Group believes that in many Gynaecology clinics around England and Wales, such patient focused information is not freely available, nor is the option of referral easily available.

- In the oral evidence session that the Group held, it was repeatedly stressed that there is no standardised information leaflet readily available.

- The Group has found that often there is:

  - Lack of information as to what the condition is.
  - Lack of information over treatment options – clinicians need to explain what all of these are, and the potential risks and benefits.
  - The recommendations from NICE Heavy Menstrual Bleeding Clinical Guidelines are that women should be sent information before her out-patient appointment. According to FEmISA's recent report only 2 Trusts do this[6].

- At the oral evidence session a clinician explained that there are considerable barriers to handing out leaflets to patients.

Information

- National standardised patient information leaflet across the country, to include:

  - Generic information tools used by all providers
  - National patient information leaflet readily available to GPs
  - Better written information to give to patients about different treatment options
  - Up to date information leaflets – endorsed by specialist patient groups and professional societies - RCGP, RCOG, BSGE. Consequently we argue that more information (both verbal and written) about the management, including non-medical- and self-management, of endometriosis should therefore be made available to women, and must be delivered in a helpful format and provided in a timely manner.[21]

- Verbal and written information needs to be evidence based and focus on NICE guidance.

- Commission that all women with a diagnosis of fibroids or endometriosis are given the information they require to make informed choices.

- Information leaflets on conditions in gynaecology clinics. Other formats for leaflets are also important and women need signposting to some excellent leaflets and other resources that already exist, often online. Women

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[6] FEmISA Patient choice and NICE compliance survey on fibroid treatment acute NHS trusts in England, conducted in 2016 Report

[21] Culley et al., 2013a

- The findings of the Group are supported by other evidence. Cox et al., 2003, in Culley et al., 2013a state that women reportedly receive insufficient information at diagnosis, and express a desire for more information about surgery.

- What was most clear from the FOI and the patient survey is that information hugely varies from Trust to Trust, and from consultant to consultant.

- Most patients comment anecdotally in the survey that they have found information from the internet and they receive no paperwork when discussing their diagnosis or their treatment options.

- There is a lack of information about the impact that endometriosis can have on women's daily lives and ways in which they can be supported to manage endometriosis. Women need to be signposted to these resources and offered support by specialist nurses and counsellors.

need time to discuss their personal options once they have been made aware of these, and given time to consider them.

'I just want to stress that I WAS NOT given information about other treatments for fibroids. I was only offered a hysterectomy and, only through my own online research, did I discover the other options out there. I had to ASK for these other treatments.'

Education

- Educate GPs and gynaecologists about gynaecological conditions and about different treatment options that they may not be were of – include these in training programmes and training modules with CPD points for the RCGP and RCOG as there is evidence that a lack of education and training means that they are not in a position to advise women about their suitability.

- Implement guidelines which are endorsed by relevant clinical bodies.

- Ensure implementation and importance of inclusion of pharmaceutical, minimally invasive surgical techniques and non-surgical treatment options in Gynaecology training schemes, and GP training which is given appropriate weighting.

- The school curriculum should include education about normal and abnormal menstruation, this could be included in PSHE lessons. This would help young women to recognise when they need to seek help with symptoms. School nurses could assist with discussing these conditions. It is important that girls know what is normal.

- More needs to be done to encourage women to seek help earlier, through targeted educational programmes in schools and community (supported by TOHETI study).

Pathway barriers and referrals

There are a range of pathway barriers that mean that even once a woman has sought help there can be countless problems. The Group has outlined these below:

Primary Care

- For endometriosis there is a concern around GP failure to refer, which can be for a number of reasons. These findings from our report are supported in a systematic literature review produced by authors from De Montfort University which highlighted a number of barriers to referral at the provider and patient levels.
    - Several papers suggest that prior to diagnosis, women commonly experience repeated visits to doctors where symptoms are normalized, dismissed and/or trivialized, resulting in women

Pathway

- RCGP, RCOG, RCN, BSGE to work with patient groups to reinforce pathways in existence by NICE and ESHRE, agree best pathway, and promote implementation of this across the country. These groups to work together to produce a best practice pathway where needed and encourage implementation. This will follow an evidence based approach with quick referrals to correct specialists with information appropriate for the patient.
- Streamline services to secondary care as appropriate.
- Better information for primary and secondary care clinicians. Utilise the BSGE model of accreditation for endometriosis centres.
- Investment in sexual and reproductive healthcare training in

  feeling ignored and disbelieved.[7]

  - Within the ENDOPART study, the delays amongst the sample were between six months and 28 years, and the average was 9.1 years.[8]
  - The literature review reported studies which showed that some general practitioners lacked knowledge, awareness and sympathy and displayed attitudes that perpetuate myths about endometriosis.[9] The ENDOCUL study, which included interviews with healthcare practitioners, reinforces the view that GPs require more information about endometriosis to assist in timely referral and diagnosis.[10]

    'GPs must take women seriously when they present with endometriosis symptoms.'

  - Delays were found to be common at the primary care level and reflect resistance to referral.[11]

    'I had to wait over 13 years for a diagnosis When I knew I had problems with my period and pain from when I started my periods No real support or help from GP.'

- With endometriosis the history of symptoms, and wide range of symptoms means that a short GP appointment often results in a lack of information being shared, and does not result in a diagnosis. GPs should primary care to enable the primary care workforce to meet the full range of women's healthcare needs and deconstruct the current silos that exist in women's healthcare.

- Clinical practice should reflect NICE guidelines – with access to treatments ranging from medical drugs, to minimally invasive procedures, routinely discussed and offered (TOHETI).

Commissioning Pathway

- CCG campaigns and commissioning:
  - CCGs to understand health, social and economic benefits of non-surgical interventions and drugs for fibroids and endometriosis.
  - Commissioners to commission pathways including onward referral.
  - Improved collaborative working between CCGs and local authorities to better understand the needs of local populations and to ensure that women's health services are commissioned using a system-wide perspective (this will also save CCGs money in terms of reducing the number of hospital referrals for Mirena insertions).
  - Ensure commissioners audit treatment of severe disease and check that such patients have access to, and are referred to, accredited specialist endometriosis centres.

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[7] Cox et al., 2003a, b; Denny, 2004a, b, 2009; Jones et al., 2004; Ballard et al., 2006; Denny and Mann, 2008; Manderson et al., 2008; Markovic et al., 2008, in Culley et al., 2013a

[8] Culley et al., 2013b

[9] Cox et al., 2003b; Denny, 2004b; Jones et al., 2004; Denny and Mann, 2008, in Culley et al., 2013a

[10] Denny et al., 2010

[11] Denny and Mann, 2008; Nnoaham et al., 2011, in Culley et al., 2013a

consider timely referral and offer women support from a practice nurse with specialist training in women's health. Women need support with the psychosocial impact of endometriosis and this is not always readily available.[17]

- There is no simple diagnostic test for endometriosis, and diagnostic tests can be misleading in complicated cases, which means that it is difficult to diagnosis and get all this information.

- More primary and secondary care nurses with specialist knowledge of women's health issues are badly needed. This would free-up GP and consultant time and be an important opportunity to discuss treatment options and managing endometriosis in more detail.

- GPs are often not aware of all fibroids treatment options and sometimes fail to refer on to Interventional Radiologists (IR's) when appropriate.

Secondary Care

- Gynaecologists do not carry out embolisation procedures and they can often be reluctant to refer on for fibroids.

- A close working relationship with gynaecology is important to ensure a sustainable uterine artery embolisation for fibroids service. It is very unusual in the UK for there to be

Pathway – specialist centres and specialists

- BSGE centres
    - BSGE patient information leaflets created with specialist patient groups.
    - The RCOG, its specialist society, the British society for gynaecological endoscopy and the NHS have encouraged the centralisation of the specialist services in endometriosis centres.
    - Forthcoming NICE guidance on endometriosis may also be helpful.

- Specialist centres – for those requiring multi-disciplinary teams for both surgical and non-surgical treatments.

- Multidisciplinary team for fibroids (TOHETI reference) e.g. Guys, Birmingham Heartlands.

- Utilise specialist nurses and encourage recruitment for these positions - not enough specialist nurses.

- Potential for special women's health nurses at a GP level to reduce the demand on GPs and who have more of a specialty.

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[17] Culley et al (2013) Endometriosis: improving the well-being of couples. De Montfort

joint clinics where both a Gynaecologist and an IR are both available for assessment of gynaecological conditions such as fibroids. There exist few multi-disciplinary teams.

- FEMISA - NICE Heavy Menstrual Bleeding Guidelines state that patient selection should be carried out by a multi-disciplinary team. Only 8 Trusts offer this and women report that it is very difficult to access UAE or to see an Interventional Radiologist who performs UAE.[12]

- Not all centres offer UFE or MRgFUS.

  'It took ages to even find out that UAE was available, and locally.'

- Ensuring a referral to an interventional radiologist, even if patients are aware of this treatment option for fibroids, can be difficult.

- Gynaecologists can also be a barrier for treating endometriosis, particularly if they do not have a specialty in endometriosis:
  - Culture of treating endometriosis with surgery
  - Patients have reported having their symptoms dismissed if other test show that everything is normal without having a laparoscopy
  - Short appointment means that there is no chance to discuss options

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[12] FEmISA Patient choice and nice compliance survey on fibroid treatment acute NHS trusts in England, conducted in 2016 Report

- Short appointment times and difficulty getting appointments means that patients often are forced to make a decision on the spot without consulting family members, and without adequate information.

- Referral to a specialist centre can be complicated for endometriosis.
    - There are BSGE centres, (The BSGE is a specialist society and a charity with over 1,000 members. The BSCE accredits specialist centres for the treatment of severe endometriosis).
    - Can be long delays and long distances to travel to reach BSGE centres.

- Not enough endometriosis specialist nurses or endometriosis specialists in general.

- Lack of consistency in care from hospital to hospital.

- There is also an issue with doctors with referrals to second care cross-nationally. In Northern Wales patients are often being referred to Cardiff at a much more significant distance to travel, rather than across the border to Chester.

General Barriers

- Failure of standardisation of a minimum acceptable level of patient information across Trusts, both in Primary and Secondary care. Information often not carried over.

- Barriers to certain treatments:
    - For non-surgical interventions there are perverse incentives in place
    - For drugs to shrink fibroids there are barriers between primary and secondary care commissioning
    - For embolisation and other minimally invasive procedures the tariffs do not accurately reflect the benefits to these procedures.
- Regional variation in access to specialists and treatments.
- A number of women in our survey said they received the wrong diagnostic test for endometriosis.
- NICE guidelines are not mandatory which means that Trusts do not always implement evidence based guidelines for managing these conditions.
- Women often did not feel that they were fully included in decision-making about their treatment or offered a full range of options. Treatments were felt to be restricted based on a clinician by clinician basis.

    'It seems that only by asking questions and searching for different gynecologists that you can have a range of options available without the default hysterectomy.'

Commissioning barriers:

- Tariffs and CCG commissioning for medication, such as Ulipristal acetate, and non-surgical interventions are often barriers.

- At the oral evidence session an example was given of how medication can be used to treat fibroids. The issue of prescribing this sort of treatment is that a gynaecologist is able to prescribe it to patients for the first month in secondary care, however a GP is required to prescribe it going forwards. Often GPs are not allowed to prescribe this by their CCG in primary care setting due to cost – a prescription is around £100 a month. It was highlighted that the cost of a hysterectomy is £3,600, whereas four courses of the medication is much cheaper at £1,200. The silo nature of secondary and primary care budgets was highlighted as an issue.

- Barriers to access to Mirena coil for gynaecological reasons – commissioning barriers due to fragmented funding and commissioning, problems with training and maintenance of skills.[13] New data from November 2016 reveals a 0.38% fall in Mirena fittings, suggesting that barriers to access for women such as complex commissioning structures are having a tangible impact on uptake of this effective contraceptive and gynaecological intervention.[14]

- Waiting times for referral to secondary and specialist care and specialist care can be lengthy.

- There is a NHS England specialised commissioning specification (E10a) for severe endometriosis but it is not fully delivered.

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[13] Faculty of Sexual and Reproductive Healthcare

[14] IMS Health, XBPI, Units data, MAT November 2016

Support and after care

- No follow up post procedure appears to be standard, whether for fibroids or endometriosis. Often women have had serious surgery or intervention and there is a need for healthcare professional engagement after treatments across the country.

- These conditions can have significant effects on the emotional well-being of women and their families and many would benefit from being able to discuss issues such as sexual relationships with trained professionals (Culley et al 2013). Support groups can offer help to women and partners and healthcare professionals should inform women about such organisations.

- Depression, anxiety and emotional distress are not uncommon among women with endometriosis, though there is often a lack of awareness of these impacts and how to respond to them (Culley et al 2013).

- Often no reference to fertility concerns (De Montfort University).

Support and Aftercare

- Follow best practice care pathways and ensure that this is available.

- Emotional counselling and support groups signposted to patients. Women (and partners) should be offered counselling or other psychosocial interventions if they are having difficulties living with chronic conditions such as endometriosis. Patient support groups offer support and women should be made aware of the resources currently on offer from groups such as Endometriosis UK. Information should be available in audio-visual format as well as written format. Information, support and resources should be culturally and linguistically appropriate for a diverse society.

- Better follow up after procedures/appointments and joined up through primary, secondary care and discharge.

'There is no dignity, and no support for women in constant pain.'

'The after care is poor. No one tells you anything at all and there is little information available.'

'The thing that shocked me was how little support was given after the hysterectomy.'

Culture

- Women have a lack of awareness of what is normal regarding menstruation and period pain – due to this they may put off seeking help.
- Women may be put off seeking advice due to the stigma that persists around gynaecological issues.
- Women failing to get a diagnosis when they seek initial help at their GP – women have frequently been told 'it's all in your head' or 'it's just period pain'.
- The perception of menstrual irregularities as 'normal' and the perception of menstrual pain as something to be endured also contribute to delay in seeking help[15], particularly for adolescents.[16]
- Several people submitted evidence referencing how those from lower socio-economic background do not seek help and are less likely to get the help they need once going to their GP.
- There are also concerns about the lack of access to appropriate services for minority ethnic women with endometriosis as the ENDOCUL study showed. African-Caribbean women also have a higher incidence of fibroids than white women.

  'I wish my doctor was more sympathetic and helpful.'

  'I feel that it is commonly dismissed as 'bad periods' and hence 'not significant'.'

Culture

- Treat all patients with dignity and respect – culture surrounding 'period pains' needs to be addressed.
- Empower women to make a choice by giving them all the information they need to make an informed choice.
- More research needed into treatments for endometriosis.
- DWP update to ensure that where appropriate severe endometriosis is classified and taken into consideration as a debilitating disease.

  'It is very difficult to discuss the disease in the workplace, the impact of being stuffed full of painkillers and covered in heat patches a few days every month while having to work is really challenging and completely exhausting.'

  More needs to be done to help employers deal with endometriosis.'

  It's 2017 and women are beyond fed up with the way we are being treated. Just listen and believe them.'

  'Girls' need to be informed and empowered so that they can lead a full life on their own terms.'

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[15] Cox et al., 2003b; Denny, 2004b; Ballard et al., 2006, in Culley et al., 2013a

[16] Manderson et al., 2008; Markovic et al., 2008, in Culley et al., 2013a

Addressing the barriers

This Group has laid out a list of recommendations that we believe will benefit patients, clinicians and the wider NHS.

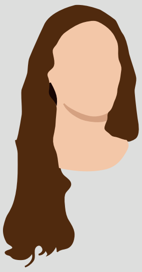
We can see clearly that there is a strong economic argument for early intervention.

- Endometriosis can has a severe impact on women's lives including their working lives. Speedier diagnosis and treatment might help to ameliorate some of the distress that women experience and reduce the economic impact.
- Minimally invasive procedures for fibroids have a much quicker recovery time resulting in less time in hospital, at a high cost, and less time out of work and contributing to the economy.
- Severe pelvic pain, fainting, heavy menstrual bleeding and other symptoms of these two conditions can result in repeat admissions to A&E which put a strain on the NHS and increase costs.

What getting the correct information and treatment means.

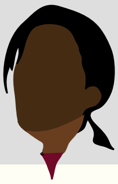
'We have been silenced by society for too long.'

'I have Endometriosis on my bowel, bladder, kidneys, urethra and ovaries and still have pain (still menstruating) but I appreciate the care I have received for many years and it shows that good care does make a difference to quality of life/fertility/conception.'



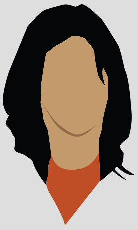
'My experience of my second laparoscopy for excision surgery and the after care excellent however I was fortunate not everyone is aware of how to/able to get referred to a top endometriosis specialist on the NHS.'

I 'really feel like I had good treatment and care from a specialist who understood the condition.'



'I feel my care was excellent with all options explained by all professionals I came into contact with.'

I asked my gynaecologist to give me ulipristal acetate again. She let me take it for 3 months and kept giving me repeat prescriptions. It worked every time to stop my periods completely and give me my life back.



Recommendations

Improve patient experience by:

1 Patient information leaflets (endorsed by the RCOG, BSGE, RCGP , RCN and RCR/BSIR and created in conjunction with specialist patient groups) to be used in GP practices, gynaecology clinics and for the general public in a generic format:

- These should cover information on the condition and information on all treatment options – from hormonal contraception and pharmaceutical solutions, minimally invasive surgery and major surgical intervention.
- Information should be available for patients and also for families. Information resources should be available, including in multiple languages, audio-visual materials and online website, blogs and testimonies.
- This information should also cover coping with the emotional stress of these conditions, how to access support outside the NHS, and offer support to partners and families. Also information needs to be specially prepared to be age relevant. Not all treatment are appropriate for younger women, or women who have not had children etc.

2 Public awareness on gynaecological concerns focusing on what is normal menstrual health and pelvic pain and what is not.

3 Treat all patients with dignity and respect and empower women to make a choice by giving them all the information and access to the specialist services they need.

Improve awareness by:

4 Multi professional training and education opportunities to be supported by RCN, RCGP and RCOG – which have CPD points on endometriosis and fibroids.

5 PSRE education and SRE to include menstrual health at secondary schools.

6 Where NICE guidance exists it should be followed – Trusts and CCGs need to be made aware of this.

Improve patient pathway:

7 Simple best practice pathway endorsed and mandated across the country – a clear patient pathway agreed and rolled out for endometriosis and fibroids.

8 Ensure appropriate incentivisation for treatment through payment mechanisms.

9 Encourage multi-disciplinary team working at Trust – to include interventional radiologists, gynaecologists and others.

10 Access to a clinical specialist nurse is an important way to improve patient understanding and patient care.

Patient case studies

Marie Turner

2009 was a pivotal year for me. I had just started university, I'd moved out of my childhood home, and I first started noticing the pain.

It felt like blisters. One A&E visit (of several that year) ascertained I had Chrohns. A barium meal scan, 2 isotope scans, ultrasounds, MRI scans, endoscopies - all ruled that out. I was then told I had IBS in 2010, that I was an "anxious person" (the consultant had never met me before this meeting) and to go away and take some tablets.

Back again in 2012, in agony. Another endoscopy. Nothing. It was getting worse. I remember sitting at the bus stop going home from uni in tears because the pain was so incredible I didn't think I'd make it home conscious. I went back. IBS again. Go away. I'd lost a year of university already.

In 2014, I went to my local NHS walk-in center after fainting on the train home from work. The GP at the walk-in center was concerned and sent me to the OB-Gyn department at the hospital. Hours in A&E, throwing up, eventually given a bed at 3 am in the Gynae ward. I sobbed as my dad walked out of the doors.

I knew I had a cyst. I met a doctor who was insistent I was constipated. I wasn't. I begged them to do an ultrasound, which they did the next day - lo-and-behold, a 5cm cyst on my left ovary.

I was assigned to a Gynae consultant, who over the next 2 years, would reluctantly see me every month or so, tell me I didn't have Endometriosis, find yet another cyst, and insist that I didn't need surgery.

I got a second opinion last year resulting in an ablation laparoscopy which gave me a diagnosis of stage 4 Endometriosis. I was relieved. I was told my pain was made up for 7 years. I had adhesions on my left ovary, my bladder and uterus were stuck together via my Pouch of Douglas.

That was October last year. The pain is back. I've been told to have children in the next 5 years or to have Prostrap, a menopause injection which has been proven in many studies to have no effect on Endometriosis. I'm now being referred to a specialist in Birmingham, who can excise all Endometriosis.

All it would have taken is just one person to believe me. One person. I've lost 7 years to pain.

Anne Little

I went to see my GP due to problems with bleeding whilst exercising. She examined me and diagnosed fibroids. This was later confirmed by ultrasound scan. I was told my options were to do nothing and wait for the menopause to kick in during which time the fibroid would be likely to shrink naturally. Alternatively, I could have surgery to remove the fibroid.

My GP explained in detail what a fibroid but to be honest, I was offered very little information and surgery was the most commonly cited option available to me. I was very concerned about having a hysterectomy as it seemed such an invasive option with a long recovery period too which would have a massive impact on my work – I run a business delivering exercise classes in the community.

I was a part time Higher Education lecturer at the time and therefore lucky to be aware of and have access to NICE guidelines. After a great deal of time researching the topic and considering the options available to me, I became aware of the options for non-invasive treatment of fibroids. It was at this time that I approached Trevor Cleveland at Sheffield to discuss the feasibility of fibroid embolization. At that stage a CT was also undertaken to check suitability of my fibroid for UFE but GP's at my local practice seemed to know little about the procedure.

Before agreeing to have UFE I went to see a gynaecologist as NICE guidelines recommend a gynaecologist be involved in the decision making process. The gynaecologist was adamant I should have a hysterectomy and both ovaries removed. Very scary!

Trevor Cleveland and his team at Sheffield were amazingly supportive and patient. I decided to go with UFE. I have not looked back since.

Best practice

Patient F: An example of what a best practice experience would look like is highlighted in the experience of Patient F. Patient F was aware that the symptoms that she was experiencing were not usual and went to her GP. Her GP recognised that there was a gynaecological concern and referred her to a gynaecologist to carry out further investigations. After further investigation her gynaecologist correctly identified her condition and set out a range of options that were available, with written information. The woman was then able to go away and consider these treatments before choosing the option which was right for her. The patient was aware of patient group support networks and used these following her treatment. The Group believes that this is more what best practice should look like.

Conclusion

In conclusion the WHAPPG believes that change is needed in the way that fibroids and endometriosis are diagnosed and treated. There needs to be an agreed and accredited best practice pathway rolled out across the UK. NICE guidance needs to be followed across the UK to try to reduce unacceptable regional variation.

Women's health conditions appear all too often to be dismissed and women not getting the care that they need as a result. NICE guidance, where it exists, needs to be followed across the UK to try to reduce unacceptable regional variation.

Appendix

Number of Trusts FOI'd: 139 NHS Trusts asked, of those 29 did not answer – response rate of 79%

FOI response rate – 79% response rate

Patient survey completion – 2,367 responses to the endometriosis survey, 237 to the fibroids survey

Written evidence numbers – 175 responses

Oral evidence minutes/speakers – published on the WHAPPG website

Relevant guidelines:

- RCOG guideline on endometriosis
- European Society of Human Reproduction and Embryology (ESHRE) guideline on Management of women with endometriosis
- NICE guideline on Endometriosis – due to be published shortly
- Endometriosis UK information
- RCN factsheet on endometriosis
- NICE Clinical Guidelines on Heavy Menstrual Bleeding CG44 200, which is currently out for consultation
- NICE QS47 2013 – QS on heavy menstrual bleeding, being updated – CG44
- TOHETI patient leaflet on fibroids and patient video

Bibliography and Footnotes

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5 FEmISA website

6 FEmISA Patient choice and NICE compliance survey on fibroid treatment acute NHS trusts in England, conducted in 2016 Report

7 Cox et al., 2003a, b; Denny, 2004a, b, 2009; Jones et al., 2004; Ballard et al., 2006; Denny and Mann, 2008; Manderson et al., 2008; Markovic et al., 2008, in Culley et al., 2013a

8 Culley et al., 2013b

9 Cox et al., 2003b; Denny, 2004b; Jones et al., 2004; Denny and Mann, 2008, in Culley et al., 2013a

10 Denny et al., 2010

11 Denny and Mann, 2008; Nnoaham et al., 2011, in Culley et al., 2013a

12 FEmISA Patient choice and nice compliance survey on fibroid treatment acute NHS trusts in England, conducted in 2016 Report

13 Faculty of Sexual and Reproductive Healthcare

14 IMS Health, XBPI, Units data, MAT November 2016

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21 Culley et al., 2013a

Abbreviations

APPG –	All-Party Parliamentary Group
BSIR -	British Society of Interventional Radiology
BSGE -	The British Society for Gynaecological Endoscopy
CCG –	Clinical Commissioning Group
ESHRE -	European Society of Human Reproduction and Embryology
HMB –	Heavy Menstrual Bleeding
MRgFUS -	Magnetic Resonance-guided Focused Ultrasound
NICE –	The National Institute for Clinical Excellence
RCGP –	Royal College of General Practitioners
RCOG –	Royal College of Obstetricians and Gynaecologists
RCN –	Royal College of Nursing
RCR –	Royal College of Radiology
TOHETI -	The Transforming Outcomes and Health Economics Through Imaging (TOHETI) programme, funded by Guy's and St Thomas' Charity
UFE –	Uterine fibroid embolization
UAE –	Uterine artery embolization
WHAPPG –	Women's Health All-Party Parliamentary Group

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