



Understanding the needs of women with fibroids

Introduction

Fibroids are benign tumours that develop in the smooth muscle cells of the womb. They are the most common form of tumours found amongst women with an estimated 30 – 40% of women between the ages of 25-45 expected to develop them.

Research, however, has shown that fibroids are more common in black women with an estimated 55-80% of black American women affected. In addition, black women are known to develop fibroids at a much younger age, are more likely to develop larger, multiple fibroids, and tend to develop more severe symptoms. The reason for this is currently unknown, but it is thought to be a combination of genetic, environmental and lifestyle factors.

The Lake Foundation is a registered charitable incorporated organisation that aims to improve the health and wellbeing of the black community. Through our interactions with black women we have anecdotally found that whilst fibroids are very common, there seems to be a lack of information and support for women who are affected. To explore this issue further, we conducted a survey to explore the needs of women with fibroids and this report summarises our findings and outlines how these findings will inform the development of our fibroids information and support programme.

Overview of the Survey

The Lake Foundation launched its fibroids survey on 1st July 2014 and this remained opened until 30th September 2014. Twenty-eight women between the ages of 25 and 64 completed the survey and all but one participant was from an African-Caribbean background.

The survey explored four main areas:

- The level of knowledge of fibroids prior to diagnosis
- Treatment and diagnosis
- The effect of fibroids and its treatment on quality of life
- The availability of support and information

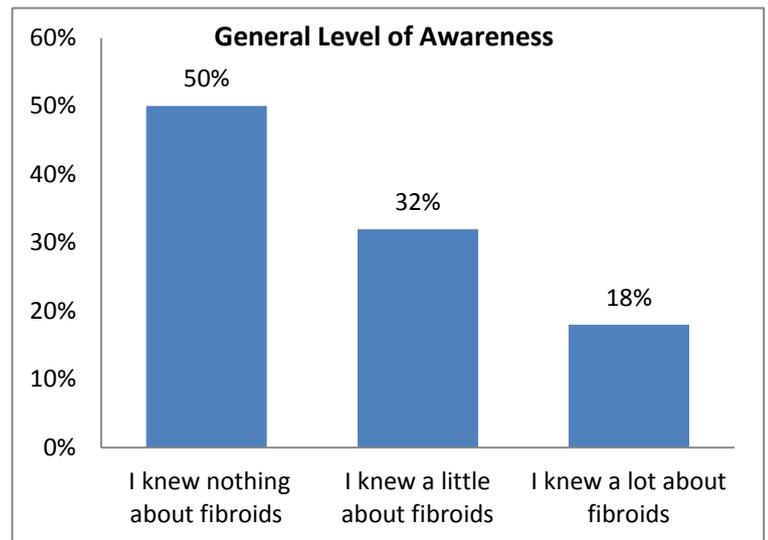
The survey questions were developed in collaboration with InFaction, a research management organisation, and were reviewed by our target group to ensure they were clear, easy to understand and explored the key issues faced by women with fibroids.

Survey Results

1. Awareness of fibroids prior to diagnosis

General Level of Awareness

The first area this survey explored was the level of awareness of fibroids prior to diagnosis. The majority of women, 50% of participants, stated that they knew nothing about fibroids before being diagnosed, 32% stated that they knew a little about fibroids and 18% felt that they knew a lot about fibroids before their diagnosis.



Awareness of Signs and Symptoms

Whilst the majority of women stated that they knew nothing or very little about fibroids before their diagnosis, there was a fairly good level of awareness of some of the symptoms. Seventy-one percent of participants stated that before their diagnosis they were aware of heavy periods as a symptom, 42% were aware of abdominal pain as a symptom and 39% recognised painful periods as a symptom.

Knowledge of other symptoms was fairly low with a small percentage of women being aware that frequent urination (18%), constipation (14%), pain during sex (25%), lower back pain (18%), miscarriages (7%), infertility (18%) and haemorrhoids (4%) were symptoms associated with fibroids. Additionally, 18% of participants were not aware of any of the symptoms of fibroids.

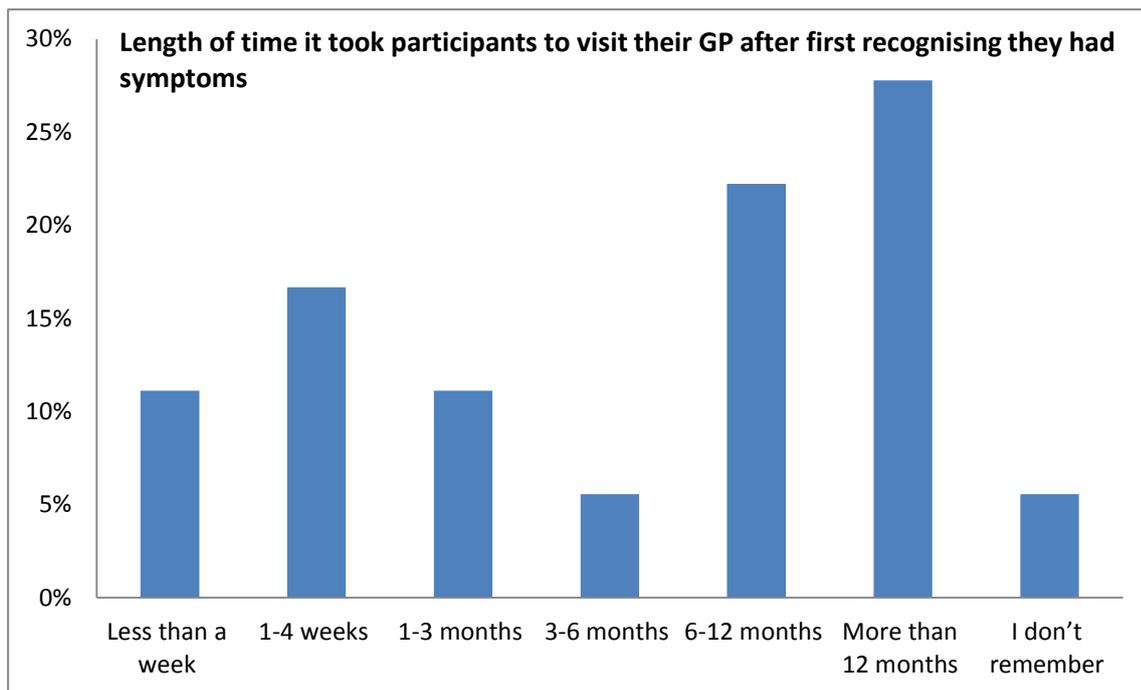
Awareness of Risk Factors

When risk factors were explored, a significant number of participants (43%) stated that before being diagnosed they did not know what factors could increase a woman's risk of developing fibroids, but a significant number of participants, 46%, recognised that being from an African or Caribbean background increased the risk.

2. Route to Diagnosis

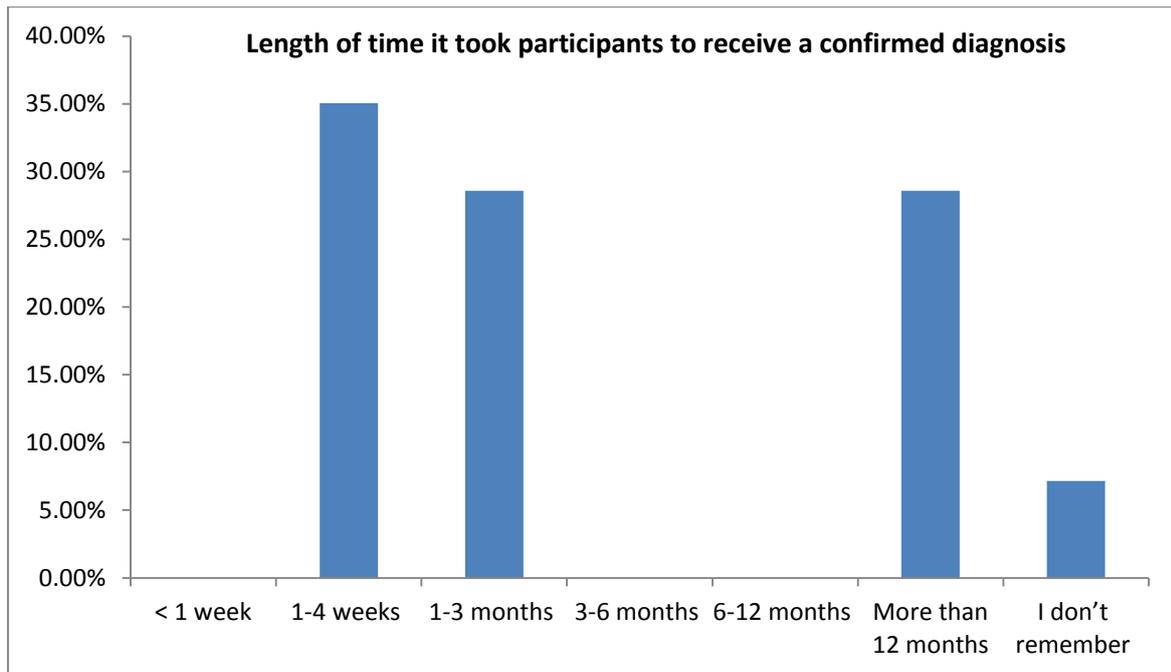
Symptom Recognition and Help Seeking

The first step in a woman's route to diagnosis is recognising symptoms and then taking action. Fifty-four percent of participants stated that when they first developed symptoms they didn't think that it could be fibroids. Furthermore, the survey found that most women delayed seeing their General Practitioner (GP). Forty-five percent of women said they waited six months or more, after first noticing their symptoms, to visit their GP.



Receiving a Confirmed Diagnosis

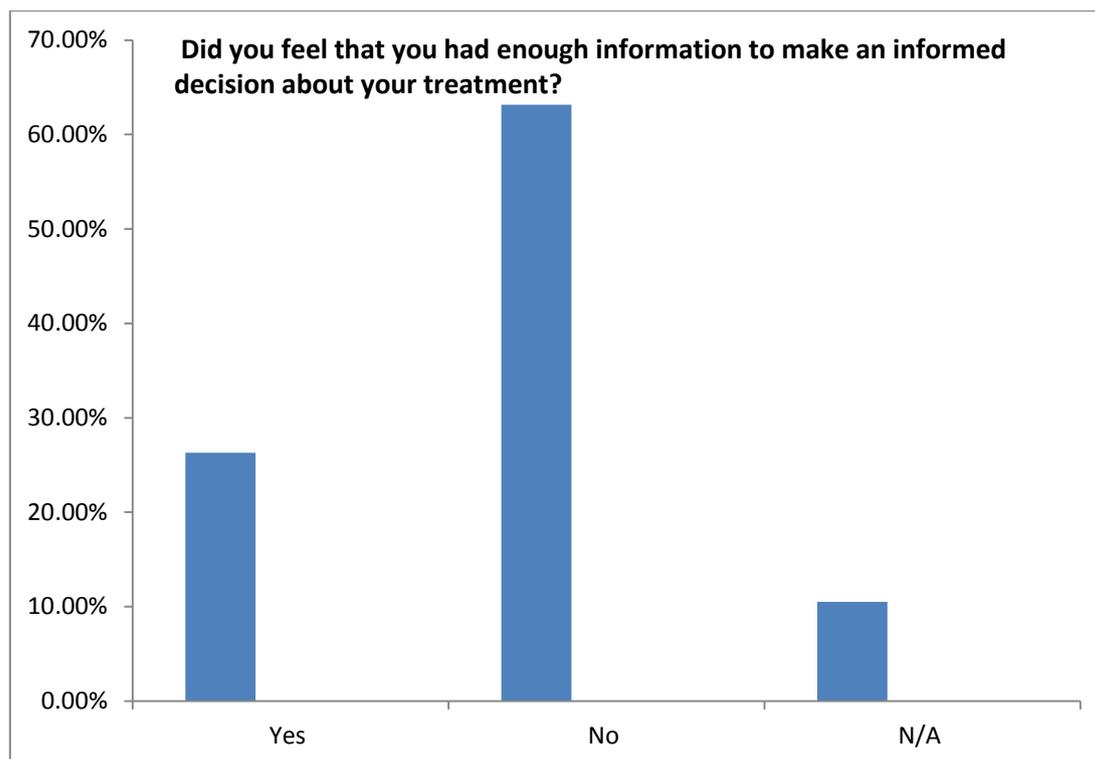
Once patients had visited their GP, over a third of patients (36%) received a confirmed diagnosis of fibroids within 4 weeks, but in some cases there were very long delays with 29% of patients saying it took 12 months or more for them to receive a confirmed diagnosis, and 28% of patients receiving a confirmed diagnosis 1-3 months after first visiting their GP.



3. Treatment

When looking at treatment, the survey first explored the discussions that women had with their GP about treatment options and how useful those discussions were. Fifty-three percent of women said that surgery or a medical procedure was discussed with them, 31% said their GP talked to them about observation (wait and see/regular monitoring), 21% had a discussion with their GP about drug treatment, and 21% stated that their GP didn't discuss any options with them. Of those that didn't have a discussion with their GP, 50% said they had these discussions with a gynaecologist.

We then explored how useful those discussions were and found that despite speaking to their GP about their treatment options, 63% of women didn't feel that they had enough information to make an informed decision about their treatment.



When it came to the treatment that patients actually received, we found that 42% of women had surgery or a medical procedure, 32% were kept under observation, 16% received drug treatment and 21% didn't have any treatment.

For those patients who received some form of treatment (surgery, a medical procedure or drug treatment), we explored whether they were satisfied with their follow-up/after-care plan. Twenty-five percent were very satisfied with their aftercare plan with participants saying:

"I was very satisfied"

"It was amazing."

Seventeen percent of respondents stated that they were somewhat satisfied with their aftercare plan, and 33% stated that they were not at all satisfied. Those participants who were not satisfied stated that the following would have improved their after-care plan:

"A more realistic recovery time. I was told I should be back to work within days, but just recovering from GA took long and surgery weeks."

"More one-to-one meetings. Self-help groups"

"More information"

"Regular check-ups"

4. The Effects of Fibroids and its Treatment on Quality of Life

Side effects of treatment

We asked women who had surgery, a medical procedure, or drug treatment, what short-term and long-term effects they have experienced. Fifty-five percent of participants reported having short and long term effects. These included: numbness in the lower abdomen, heavy bleeding, being unable to conceive, abdominal itching, vague pains, headaches, fatigue, nausea and mild dizziness. Twenty-four percent of the participants said that they didn't feel well-supported to address these issues.

The impact of living with fibroids

Participants who were living with their fibroids, or awaiting treatment, reported that their fibroids had a significant impact on their emotional well-being, with participants stating that their condition resulted in them developing depression and a sense of fear. Respondents described the root cause of their depression and fear as follows:

"Depression from feeling that my only options were drugs or surgery – neither of which could cure it and which could reduce my fertility further"

"Fear of not being able to have children"

"Just a constant fear of what they could become. A lot of uncertainty as they were dismissed as not being an issue yet. I do wonder if they do become an issue how would I know"

Additionally, participants reported that they regularly experience physical symptoms, some of which have a significant impact on their day-to-day life.

"I try not to go out because of the heavy bleeding (flooding)"

"Heavier periods."

"Regular pain"

"Occasional immobility"

"I look pregnant"

Forty-seven percent of women said that they didn't feel well-supported to address these issues.

The most difficult aspect of their experience with fibroids

Participants were then asked to describe the most difficult aspect of their journey with fibroids.

Many described the physical symptoms as being the most difficult aspect of their experience with fibroids. Several participants mentioned pain as a major challenge, with one participant describing it as *“intense pain”*. Others felt that *“heavy bleeding”, “heavy periods and flooding”, “hard lumps”, “anaemia”* having a *“large stomach”, “feeling exhausted all the time”, “constipation”, “fullness”* and *“people thinking I am pregnant”* were particularly difficult to deal with.

Infertility and complications during pregnancy were also seen as major challenges. In particular, there was a *“fear of infertility and the feeling that there was nothing I (or the doctors) could do about it”*. There was also disappointment at *“not being able to conceive when I wanted to”* and *“now not being able to have children”*. Another participant described her most difficult moment as:

“When I was pregnant with my child, I experienced complications and intense pain and a larger than normal uterus. I was 3 months along and looked like I was 6 months pregnant. “

Others felt that a major difficulty was the lack of information and conflicting information about fibroids. For example, one participant said, *“there is not enough information, particularly with regards to surgery alternatives and diet changes.”* Whilst another felt that it was challenging *“learning what caused them and learning what I could do to prevent them from happening again, there is a lot of conflicting information out there.”*

Some participants felt that the emotional impact was the most challenging aspect of having fibroids. They felt that fibroids created *“stress”,* and a feeling of *“uncertainty”* and *“fear”*. One participant stated that *“I have hated life at times because of fibroids. I feel like I am being punished for something.”*

Finally, two participants described their most difficult moment as their unease with the recommendation of a hysterectomy as a treatment option. They stated:

“Resisting doctors performing hysterectomy in my early 30s. Fighting for new, but less invasive and life changing procedures. I strongly feel as a woman of African descent there was a constant battle with medical practitioners to resist removal of my uterus as simply a malfunctioning organ as you would a faulty car component. They had no awareness between the mind and body in such a primeval area of being a human being, essentially a female. I often felt a degree of misogyny amongst some when I questioned their approach. Furthermore, I felt Black women's fertility was regarded as something to curb, rather than preserve, especially the less educated ones. This is based on years of experience at The Soho Women's Hospital, later EGA.”

“The most difficult was for my long-time gynaecologist to only suggest hysterectomy as an option. Thanks to the Internet, I knew there were other options. I sought out other doctors for help. I have recently learned that there are dietary options and I’m looking into these seriously - but horrified that a lot of what I have been doing/eating/using may have contributed to the condition and I would have kept on doing these from diagnosis to now as the GPs clearly do not have the knowledge/interest to share this basic information (even if unproven, it will only benefit my body as a whole) with sufferers.”

5. The Availability of Information and Support

The availability of information

In the final section of the survey, we explored what support participants needed and what was actually available to them. We first focused on information and found that 67% of participants were given information about fibroids, including diagnosis and treatment, but a significant number of women, 33%, did not receive any information.

Those participants that did receive information received this as a leaflet, through a one-to-one discussion with their GP, nurse, or consultant or via a website.

The availability of support

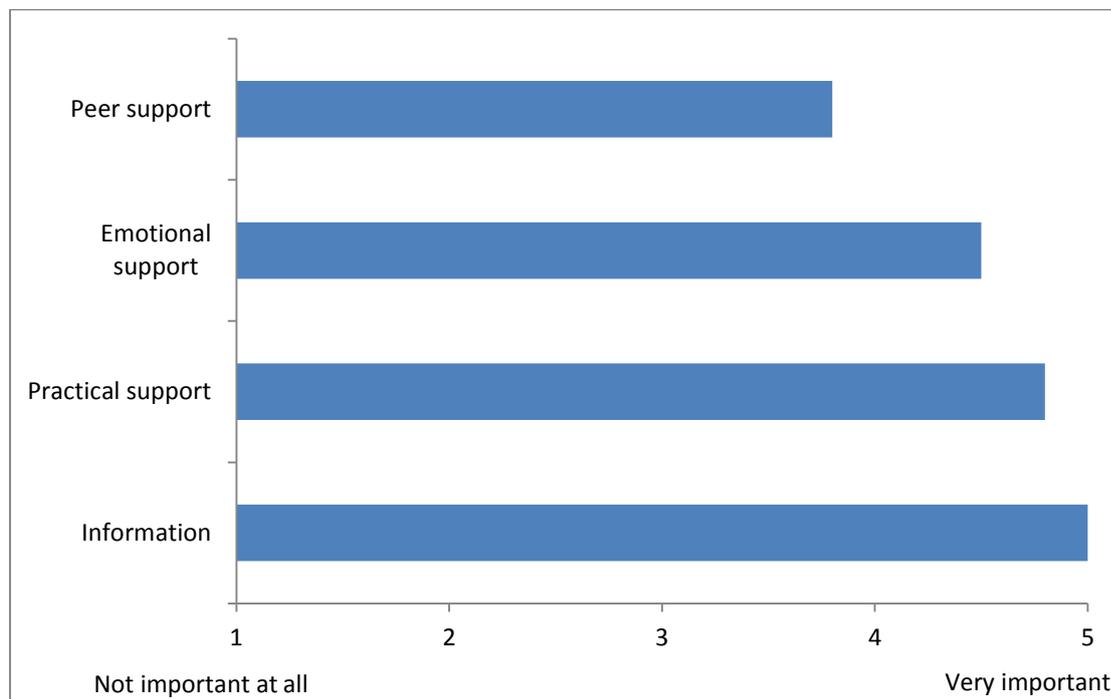
All women who took part in this survey stated that they needed some form of support. In the table below we compare the support that participants needed with what was actually available to them. We found that the biggest gaps in the availability of support were in information and peer support, with a small gap in emotional support. Specifically, 80% percent of participants stated that they needed information but only 53% said that this was available to them. Additionally, 67% of respondents said they needed peer support (support from other women with fibroids) but only 40% of women said that this was available.

Type of support	Percentage of women who stated they needed this type of support	Percentage of women who said this type of support was available
Emotional	47%	40%
Practical	33%	33%
Information	80%	53%
Peer	67%	40%

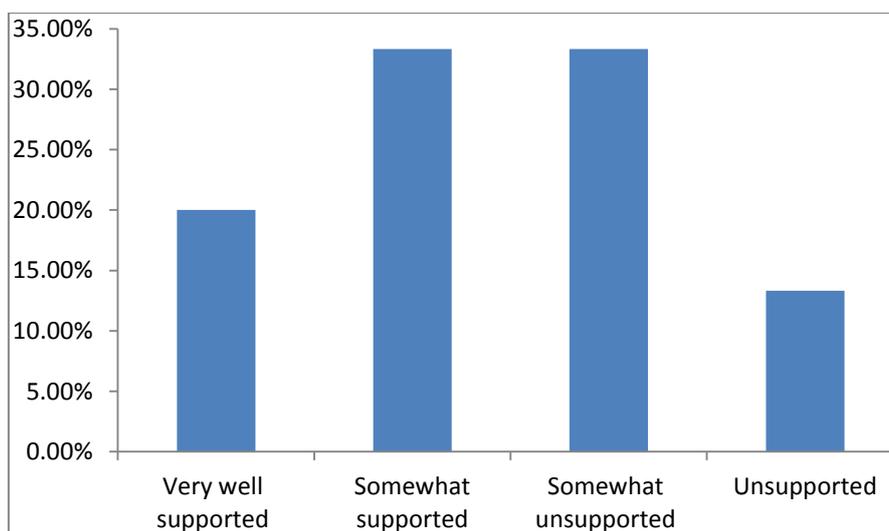
Finally, 27% of women said that no support was available to them and 6.7% said they weren’t sure what support was available.

Participants were asked, based on their experience with fibroids, to rate the importance of the different types of support. All Participants unanimously rated information as very

important (average score of 5, with 5 being very important), practical support was found to be the second most important type of support (average rating of 4.8), followed by emotional support (average rating of 4.5) and then peer support (average rating of 3.8).



Overall, women had a variety of experiences when it came to feeling supported, with some women feeling well supported (20%), somewhat supported (33%), somewhat unsupported (33%) and others feeling unsupported (13%).



Conclusions from the Survey

The Lake Foundation’s fibroids survey explored five main areas and our key findings are as follows:

1. Awareness of fibroids prior to diagnosis

- There was a general low level of awareness of fibroids amongst participants prior to their diagnosis.
- There was a good level of awareness of some of the main symptoms of fibroids but a low level of awareness of other symptoms.
- Participants were aware that ethnicity was a risk factor for fibroids but less aware of other risk factors.

2. Route to Diagnosis

- The majority of participants delayed seeing their GP for six months or more after first noticing symptoms.
- After visiting their GP, most women received a confirmed diagnosis within 4 weeks but over a quarter stated that it took 12 months or more to receive a confirmed diagnosis.

3. Treatment

- Despite the fact that 79% of participants had a discussion with their GP about treatment options, 63% stated that they didn't feel that they had enough information to make an informed decision about their treatment.
- The majority of participants (42%) had surgery to treat their fibroids.
- A quarter of respondents were very happy with their follow-up and aftercare whilst 33% stated that they were not at all satisfied.

4. The Effect of Fibroids and its Treatment on Quality of Life

- Participants reported that fibroids and its treatment significantly affected their quality of life, affecting them not just physically, but emotionally.
- Many participants did not feel like they had enough support to assist them in managing or overcoming the emotional, physical and medical impact of fibroids.

5. The Availability of Information and Support

- The biggest gaps in the availability of support were in information and peer support with a small gap in emotional support.

Next Steps

The survey suggests that a significant number of women with fibroids do not have access to the support and information that they require. The Lake Foundation will focus its efforts on addressing the gaps in the availability of information and support by developing a relevant support system for women, particularly black women, with fibroids.

Specifically, we will focus on obtaining funding for the following:

The development of clear, accurate information on fibroids through the development of:

- A fibroids Ask the Expert panel.
- A fibroids booklet – this will provide an overview of fibroids, symptoms, diagnosis, treatment and information on how to deal with symptoms and the side effects of treatment.
- Short information guides on specific topics. This will include:
 - Treatment options.
 - Fertility and fibroids.

The development of a support programme for women with fibroids that will explore the following:

- Fibroids support line.
- Online support through a live web-chat.
- A structured support group.
- An annual fibroids information day.

Thank you

The Lake Foundation would like to say thank you to everyone who took part in this survey.