



‘It’s not in my head!’

Patient experience of
Fibromyalgia

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Disclaimer

This report relates to our findings taken from our survey and from the individuals we spoke to at the Fibromyalgia Friends Together Group. Our report does not represent the experiences of all patients with Fibromyalgia but only those who contributed by completing our survey.

Foreword

Fibromyalgia is a chronic and debilitating condition that causes pain all over the body.

It is difficult to diagnose because the symptoms vary and fluctuate and sometimes this can be mistakenly attributed to another condition. What emerges clearly from our findings is that Fibromyalgia impacts a person's ability to function as it interferes with their day-to-day living and has a long-term impact on their quality of life. As a long-term condition, there needs to be long-term care and support.

We hope that the findings of this report will be used to provide support, information and improve access to, treatments and therapies which help patients to better manage their condition and also raise public awareness of Fibromyalgia.

Rick Moore, Chair
Healthwatch Leicestershire

Acknowledgements

We are extremely grateful to all the patients who shared their experiences of Fibromyalgia with us.

Thank you to the Fibromyalgia Friends Together Group at Shuttlewood Clarke Foundation for allowing us to attend and speak to the group.



Executive Summary

Fibromyalgia, is a long-term condition that causes pain all over the body, is not uncommon but relatively few people know about it or understand the symptoms.

At Healthwatch Leicestershire (HWL) we were made aware that services for local people with Fibromyalgia are not meeting their needs.

We designed this study to capture the experiences of people diagnosed with Fibromyalgia and the treatment they receive alongside information and support.

We received 950 responses of which 247 respondents were residing in Leicestershire, 43 in Leicester City, 1 in Rutland and 650 had UK postcodes including Scotland, Wales and Northern Ireland.

When we reviewed all the responses we found that Fibromyalgia impacts on individual's quality of life and limits their chances for education, employment and social life. Fibromyalgia also impacts on the individual's ability to perform routine chores and look after personal care needs such as eating, bathing and dressing.

The length of time taken for a diagnosis contributes to their isolation and frustrations. Despite waiting a long time for a diagnosis, there were contradictory views on individual experiences with their GP. When broken down by Clinical Commissioning Group (CCG) areas across Leicester, Leicestershire and Rutland (LLR) and the UK, findings were very similar. Over a quarter of individuals across all areas including the UK reported that their GP was neither knowledgeable nor supportive. However, a higher percentage of individuals reported that their GP was both knowledgeable and supportive.


When asked about misdiagnosis, the findings were very similar across LLR and UK respondents. The majority of respondents had not experienced misdiagnosis.

It was concerning however that over half of respondents from LLR and the UK were not offered information by the NHS on living with Fibromyalgia. If patients are not provided with reliable information from a health care professional they may turn to the internet and the quality and accuracy of information gained online is not always reliable.

Generally, respondents visited their GP monthly, bi-monthly, or quarterly regarding their Fibromyalgia. It is worth noting however, that nearly a quarter of LLR respondents and almost a fifth of UK respondents stated that they did not see their GP regarding their Fibromyalgia, this is because they feel their GP is not supportive or knowledgeable of their condition.

Whilst the findings regarding GP services seemed to be positive, experience of secondary services was less favorable. The majority of individuals from LLR and the UK reported that non-specialist hospital staff do not have much knowledge of or understand Fibromyalgia. We received a number of qualitative comments from individuals across LLR and the UK stating that, doctors and medical staff in hospitals do not see Fibromyalgia as a "real thing" and their symptoms are dismissed. There is a clear lack of understanding of Fibromyalgia both in primary and secondary health services and this may prevent individuals from reaching out and accessing services when they are in need of help.

Individuals in LLR and the UK would like to see local specialist clinics and services for Fibromyalgia which are easy to access as well as more awareness of the condition to the public and health care professionals along with information on support groups, exercises and nutrition which will allow them to better cope with Fibromyalgia.



“There are very few times I go out but I end up in bed for the week. I enjoy doing crafts but finding motivation is difficult, especially with having severe depression”

(Female, 35-44, Chamwood)

Introduction

The purpose of this study was to gather the experiences of patients who have Fibromyalgia and access local services. We also wanted to understand what matters most to patients with Fibromyalgia and to identify key health and care issues.

Context and Background

In January 2016 Healthwatch Leicestershire (HWL) launched a consultation exercise to understand what areas of health and social care people consider a priority for informing HWL's work plan. The responses were analysed and categorised into themes. Twenty-five respondents talked about the lack of a Fibromyalgia clinic and the need for a specialist nurse in Leicestershire.

In February 2016, The Shuttlewood Clarke foundation asked us to meet with the Fibromyalgia Friends Together Group (FFTG) following a response to a question put to University Hospitals of Leicester (UHL). As part of the discussion, members of the group spoke about their wish to have a service where they can receive help and advice over the telephone by a Fibromyalgia specialist. They also talked about the need for a local service for people with Fibromyalgia, as the closest clinic to Leicestershire is in London.

We met with the FFTG again in April 2016 and through discussions it was decided that we would co-produce a survey with feedback from the FFTG and promote it widely to gather the experiences of local patients with Fibromyalgia.

The survey was subsequently designed with feedback from the FFTG and launched on Monday 26 September 2016 and was closed on Wednesday 28 December 2016. We also facilitated a meeting between the FFTG and a representative from UHL.

The meeting was held in November 2016. At the meeting, we gave an update on some key headlines from the findings of the survey and members shared some of their experiences with the Patient and Public Involvement Membership Manager from UHL.

The outcome from the meeting, included an offer from the UHL representative to circulate a leaflet and information produced by the FFTG across the Trust to raise awareness of Fibromyalgia, (see page 27).

Update from the FFTG, May 2017:

"The Shuttlewood Clarke Foundation Fibromyalgia Friends Together are pleased to be working with Healthwatch to raise awareness of fibromyalgia and improve the services for people living with fibromyalgia. Following a meeting with a representative from the NHS, facilitated by Healthwatch, we have produced our TOP 10 TIPS for living with fibromyalgia which is to be circulated to 28,000 people including 12,000 health professionals; this will certainly help to raise awareness of Fibromyalgia."

Support Services Manager, Shuttlewood Clarke Foundation

What is Fibromyalgia?

We recognise that not everyone is familiar with understanding what Fibromyalgia is, and we hope that the following explanation is helpful to the readers of this report.

Fibromyalgia is a condition that is characterised by chronic widespread pain, fatigue and a combination of associated symptoms. The experience of pain varies for each individual, it can be felt as an ache, a burning sensation often described as head to toe or a sharp stabbing pain. The pain is sometimes continuous and other times it will come and go; the severity of the pain will also vary. Fatigue experienced by individuals ranges from feeling tired to exhaustion and drained of energy. Fatigue can also come and go¹.

As well as widespread pain and fatigue, individuals with Fibromyalgia may also have:

- Increased sensitivity to pain
- Headaches and migraines
- Non-refreshing sleep
- Stiffness
- Irritable Bowel Syndrome (IBS)
- Fibro-fog – cognitive disturbances including lack of concentration and trouble with learning and remembering new things
- Anxiety and depression
- Painful menstrual cramps

The exact presentation of Fibromyalgia is very variable and this can lead to a delay in diagnosis and frustration on the part of both the patient and clinician. Although Fibromyalgia is not necessarily a degenerative condition, it does often have a very significant impact on the quality of life of the patient and their family and friends². Individuals can find themselves unable to work and experiencing difficulty in performing everyday tasks and chores. As a result of muscle pain and fatigue many Fibromyalgia patients limit their activities including exercise. Consequently, making them physically unfit and making their symptoms worse³.

The exact cause of Fibromyalgia has not yet been found, however it is thought that Fibromyalgia often develops after some sort of trauma which seems to act as a trigger; this could be a fall, accident or injury, childbirth, an operation or an emotional event. This however is not always the case and sometimes Fibromyalgia begins without any obvious trigger.

Diagnosis of Fibromyalgia has always been difficult because the condition cannot be identified in standard laboratory tests or x-rays.

Moreover, many of its signs and symptoms are found in other conditions as well, such as Chronic Fatigue syndrome or Rheumatoid Arthritis⁴. As Fibromyalgia is a difficult condition to diagnose, it is not clear as to how many people are affected by the condition. The NHS estimates that nearly 1 in 20 people may have Fibromyalgia to some degree and the condition affects around seven times more women than men⁵.

There is currently no cure or universally agreed treatment for Fibromyalgia. There are no specific NICE guidelines regarding Fibromyalgia in the UK⁶. Referrals to specialists and treatments depends largely upon the individual's GP. This may lead to inconsistent access to treatment within a local authority area, which can result in poor clinical care and inefficient use of resources⁷.

There are however, a variety of different treatment approaches that can help, and it is important that GPs are aware of the range of options and are able to discuss strategies for improving symptoms with their patients. The present, treatment for Fibromyalgia focuses on symptom control rather than cure. Mainly, treatment aims to reduce pain and improve sleep. The treatments offered will depend on the severity of the patient's condition and may include physiotherapy, pharmacological pain relief, counselling and cognitive behavioral therapy, dietary and exercise advice and self-management programs⁸.

¹ <http://www.fmauk.org/2-uncategorised/52-what-is-fibromyalgia>
² <http://journals.sagepub.com/doi/abs/10.1177/1755738016638865>
³ <http://ukfibromyalgia.com/what-is-fm.php>

⁴ <http://www.fmauk.org/2-uncategorised/52-what-is-fibromyalgia>
⁵ <http://www.nhs.uk/conditions/Fibromyalgia/Pages/Introduction.aspx>
⁶ <https://www.nice.org.uk/guidance/conditions-and-diseases>
⁷ Chronic widespread pain, including fibromyalgia: a pathway for care developed by the British Pain Society.
⁸ <http://www.bupa.co.uk/health-information/directory/f/fibromyalgia>

Methodology

We worked together with the Fibromyalgia Friends Together Group (FFTG) to design a survey to gather the experiences of patients who have Fibromyalgia.

The questions were designed to gain both quantitative and qualitative data on patient's experiences of local services and of living with symptoms and suffering with Fibromyalgia.

We had three overarching aims:

- **Identify key health and care issues experienced by patients with Fibromyalgia**
- **Understand what matters most to patients with Fibromyalgia**
- **Identify gaps in support services**

The survey was made available online and promoted via the HWL E-news, website and Twitter. It was also cascaded to all HWL contacts and was promoted on the FFTG Facebook page. A member of the FFTG, also shared the survey with Fibromyalgia Action UK, who promoted it on their Facebook page to over 10,000 followers. We believe the latter resulted in a higher response rate than we expected as outlined in this report.

We therefore had to spend more time analysing the comments and feedback. We plan to disseminate the report to a wider audience than originally planned, to include Healthwatch England and other stakeholders.

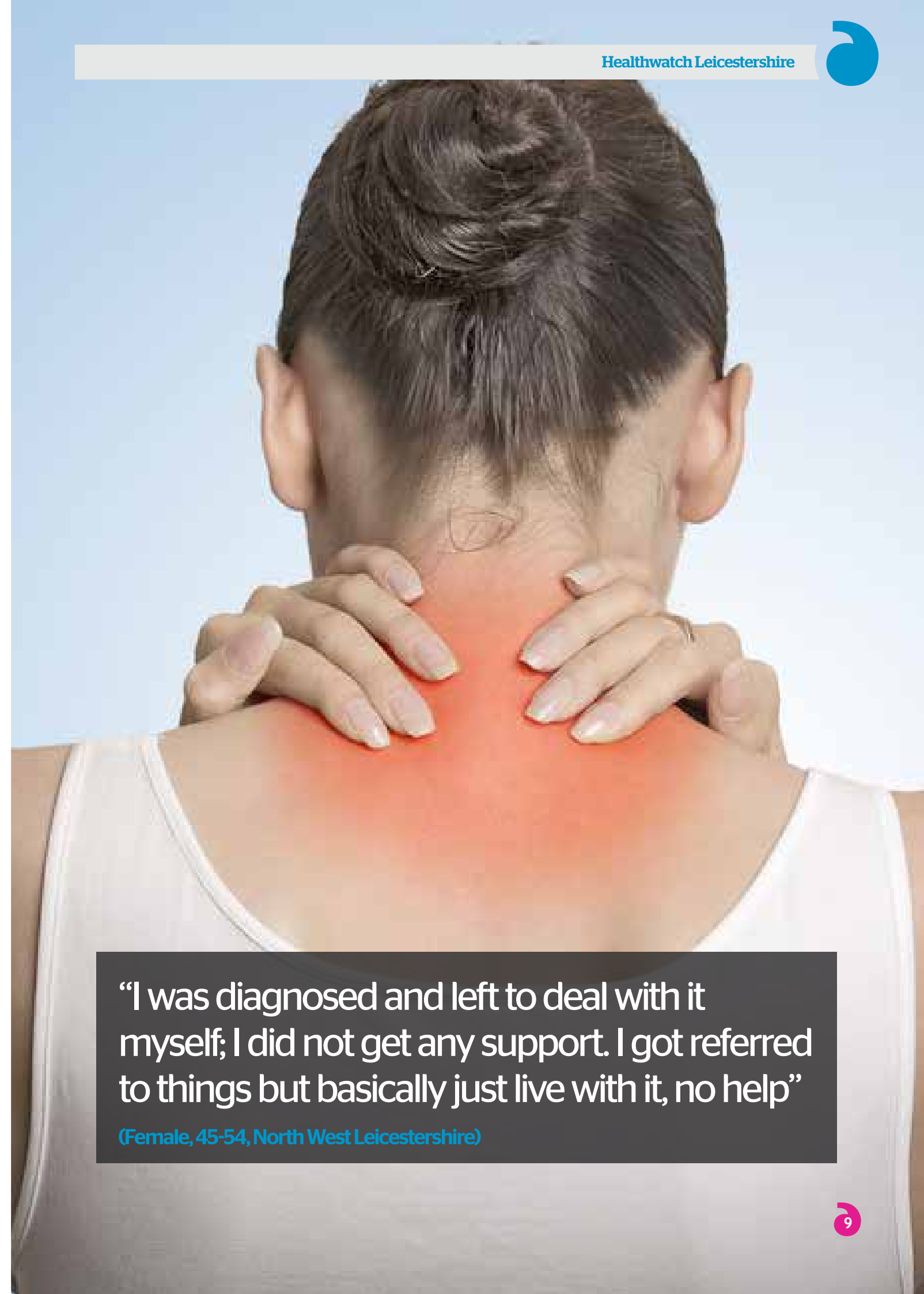
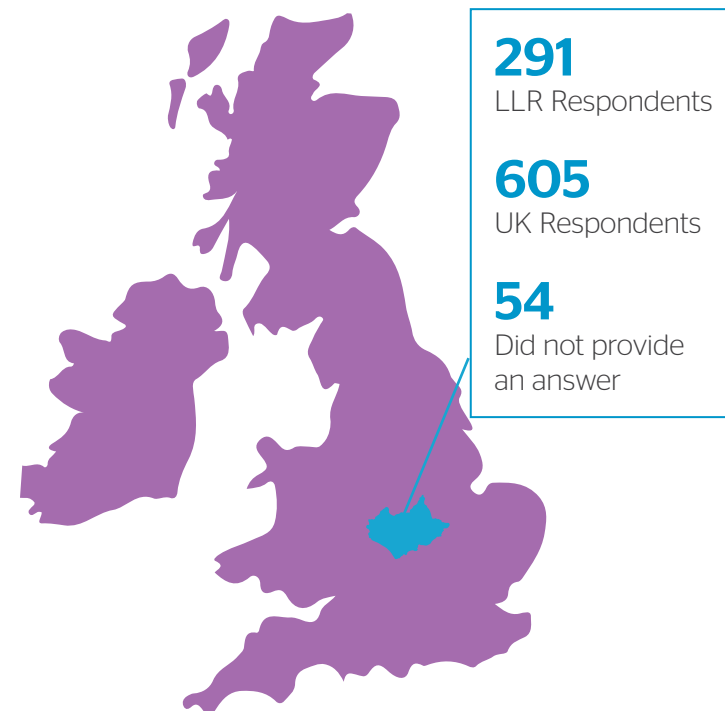
As part our research on Fibromyalgia, we read the reports from Healthwatch Gloucestershire and Healthwatch Trafford to inform our approach.

(<http://tinyurl.com/n4zpy3l> - December 2016)

Who we spoke to



We received a surprising number of responses to this survey with an overall total of 950. A third of which were from respondents living in Leicester, Leicestershire and Rutland (LLR) and others were 'out of area'. Those individuals who were 'out of area' were asked to provide us with a postcode; we received a postcode from 594 respondents from individuals living all across the UK.



“I was diagnosed and left to deal with it myself; I did not get any support. I got referred to things but basically just live with it, no help”
(Female, 45-54, North West Leicestershire)

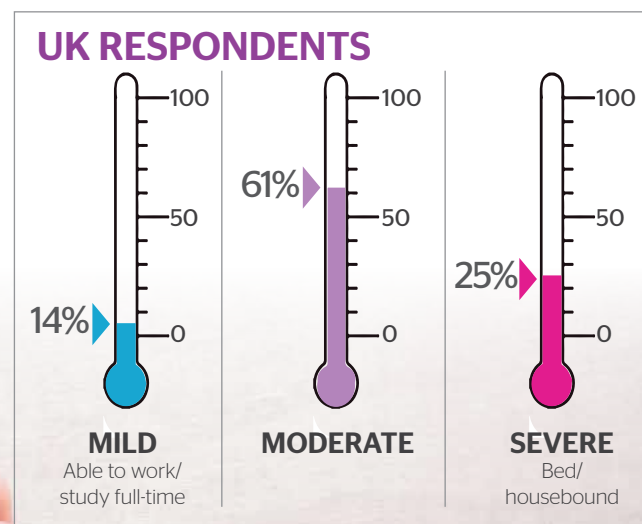
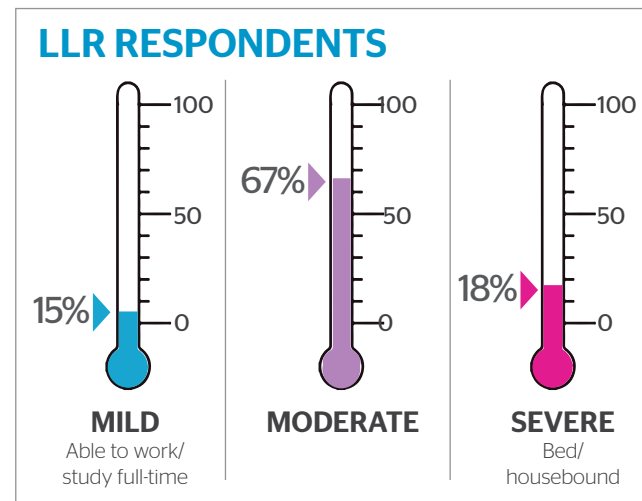
Main Findings

From our initial analysis, there was not much difference between the local LLR response and those from rest of the UK. For this reason, we present the comparative findings with quotes from individuals to support the emerging themes and recommendations.

How would you describe your current level of Fibromyalgia?

Across LLR, over two thirds of respondents said their level of Fibromyalgia was moderate which meant they were unable to work or study full time. Nearly a fifth of respondents said that their level of Fibromyalgia was severe and thus were bed/housebound. The remainder said that their level of Fibromyalgia was mild, which allowed them to work or study full time.

This was also consistent with those living elsewhere in the UK. Just under two thirds of respondents said their level of Fibromyalgia was moderate and a quarter said their Fibromyalgia was severe and therefore were bed/housebound. The remainder said that their level of Fibromyalgia was mild, allowing them to work or study full time.



If you have a formal diagnosis of Fibromyalgia, who diagnosed you?

Our analysis shows that, a formal diagnosis by a Rheumatologist was the most common from respondents across LLR and also for those living elsewhere in the UK.

LLR RESPONDENTS

Own GP	22%
Another GP at my practice	5%
A Specialist Fibromyalgia Clinic	3%
Rheumatologist	47%
Private doctor or paid service	4%
Physiotherapist	0%
I do not have a formal diagnosis	4%
Other	15%

UK RESPONDENTS

Own GP	16%
Another GP at my practice	3%
A Specialist Fibromyalgia Clinic	3%
Rheumatologist	64%
Private doctor or paid service	1%
Physiotherapist	1%
I do not have a formal diagnosis	1%
Other	11%

How long did it take from first visiting your GP with symptoms to getting diagnosed?

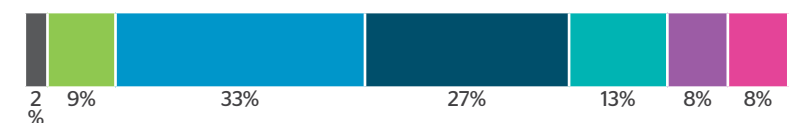
As Fibromyalgia is largely a diagnosis of exclusion, it can take time to carry out tests and receive the results to rule out other conditions. This can explain some of the delay in patients receiving a diagnosis.

Our findings show that respondents across LLR and the UK waited long periods of time living with the symptoms of Fibromyalgia before a proper diagnosis was made.

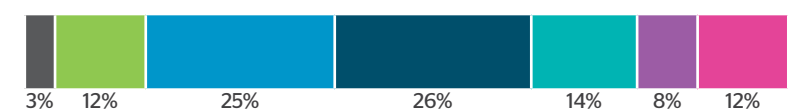
The pattern locally and nationally appears to be similar.

LENGTH OF WAIT FOR DIAGNOSIS

LLR RESPONDENTS



UK RESPONDENTS



KEY:

- Less than 12 months
- 1-2 years
- 2-5 years
- 5-10 years
- 10-15 years
- 15-20 years
- 20 years or more



What are your symptoms?

We wanted to understand more about the type of symptoms individuals experienced. A list of symptoms was compiled when co-designing the survey with the FFTG. Individuals were given the list of symptoms and asked to select all that apply to them.

The findings for LLR and UK respondents was the same for this question. The most common symptom experienced by individuals was pain; followed by fatigue and 'fibrofog'.

	SYMPTOM	LLR	UK
	Pain	289	598
	Fatigue	277	588
	'Fibrofog' - loss of concentration	256	563
	Depression	202	428
	Insomnia	197	439
	Irritable bowel syndrome	181	416
	Restless leg syndrome	172	390
	Other (please specify)	91	204

Those individuals who also selected 'Other' were asked to specify the symptom. The list below represents some answers from both LLR and UK residents.

- Dizziness
- Blackouts
- Numbness
- Anxiety
- Panic attacks
- Weight gain
- Hypersensitivity
- Headaches
- Vertigo
- Raynaud's syndrome

The following are quotes from respondents, which highlight some of the difficulties experienced by individuals with Fibromyalgia and to what extent.

"Unable to cope with more than one thing at a time"
 (Female, 25-34, Blaby)

"I feel like I'm not human, like I'm going to cave in literally!"
 (Female, 45-54, North West Leicestershire)

"I regularly have fluid cysts in my breast which need to be aspirated. I also lose my balance and fall easily."
 (Female, 45-54, Northamptonshire)

"Appetite changes and I actually have days where I just collapse as my body will not physically hold me up"
 (Female, 25-34, Burton-on-Trent)



"I have recently ended a relationship due to not wanting to be a burden"
 (Male, 45-54, Sheffield)



In which ways, if any, has Fibromyalgia affected your daily life?

It is important to understand what extent an individual's life is affected by their Fibromyalgia to be able to design and implement interventions to help them. Individuals were given a choice of eight statements and asked to select all that applied to them. The table below shows the amount of times each statement was selected by respondents living in LLR and the UK.

Statement	LLR	UK
Ability to enjoy recreational hobbies	250	536
Ability to perform routine chores (such as household chores, shopping or getting around)	243	552
Ability to socialise with family/friends	237	530
Ability to work/study (including voluntary work)	233	514
Ability to look after personal care needs (such as eating, bathing, dressing or getting around the house)	138	346
Other (please specify)	43	74
Divorce or separation from spouse	23	62
None of the above	9	4

Nearly all respondents living in LLR and the UK, said that Fibromyalgia had affected their quality of life in some way. A very small number of individuals selected 'None of the above' from the list of statements, suggesting that Fibromyalgia affects the majority of patients in one way or another.

Those who selected 'Other' were asked to specify the ways in which their daily lives were affected. The list below represents some answers from both LLR and UK residents.

- Affects my caring role
- Disturbed sleeping patterns
- Isolation
- Limited driving and mobility
- Parenting duties affected
- Unable to exercise
- Lack of libido

The following are quotes from respondents, which highlight to what extent their Fibromyalgia impacts on their daily lives.

"Relationships with family & friends has been affected as they don't understand Fibromyalgia"
 (Female, 45-54, Charwood)

"I work one day a week then it takes about 4 days to recover"
 (Female, 35-44, Harborough)

"I simply exist now, I no longer have a life"
 (Female, 35-44, Stafford)

"Whilst my children were growing up I missed out on having energy to play and take them to events also day to day care of them was exhausting so I was unable to enjoy my motherhood and their childhood"

(Female, 35-44, Charwood)

“A locum suggested I may have it (fibromyalgia) but my own GP at that time said ‘you don’t even want to go there’. Was only when having physiotherapy for something else she suggested getting checked for it, got referred. Eventually got to fibro specialist in pain clinic who diagnosed me”

Female, 45-54, Wokingham

How does your GP talk about Fibromyalgia?

Individuals were asked how their GP talks about Fibromyalgia and they were asked to choose from 4 statements. 286 individuals living in LLR answered this question.

We present the findings by Clinical Commissioning Group (CCG) area.

286
LLR responses to this question

KEY: MY GP IS:

■ Knowledgeable AND supportive
■ Not knowledgeable BUT supportive
■ Knowledgeable but NOT supportive
■ Neither knowledgeable/supportive

The findings across all 3 CCG areas are not hugely different. Over a quarter of respondents across all 3 areas reported that their GP is neither knowledgeable nor supportive. However, in certain areas a higher percent of respondents reported that their GP is both, knowledge and supportive.

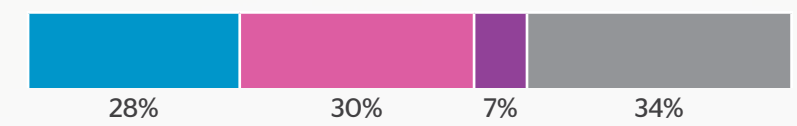
We also looked at the responses from individuals living in the UK, to see whether there were any noticeable differences. Interestingly, the findings were similar to individuals living in LLR.

As the number of respondents from each CCG area and the UK is different, we are unable to compare and contrast findings directly between them.

The overall findings suggest that in some areas of LLR and the UK, GP’s are knowledgeable, supportive and understand the impact of Fibromyalgia on their patients. However, in other areas it appears that there is a general lack of understanding of the condition by GP’s and this is concerning as patient’s may feel that they have nowhere to go for help. CCG’s should consider providing more training and information for GP’s who are not very knowledgeable about Fibromyalgia and as a result appear to not be supportive.

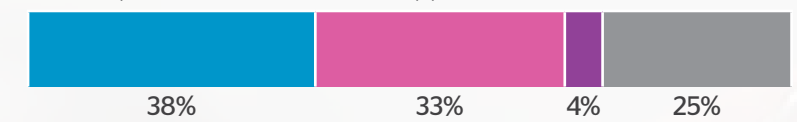
West Leicestershire CCG -

189 respondents answered, 3 skipped



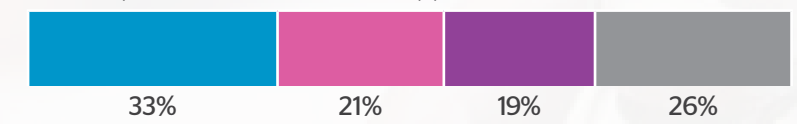
East Leicestershire & Rutland CCG -

55 respondents answered, 1 skipped



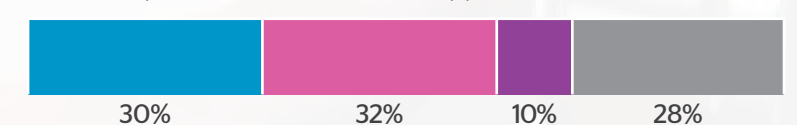
Leicester City CCG -

42 respondents answered, 1 skipped



UK Respondents -

596 respondents answered, 9 skipped



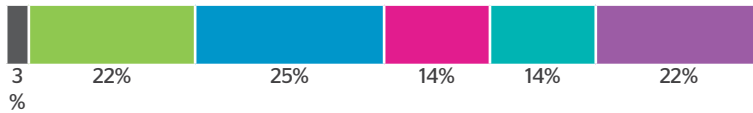


Regarding your Fibromyalgia, how often do you see your GP on average each year?

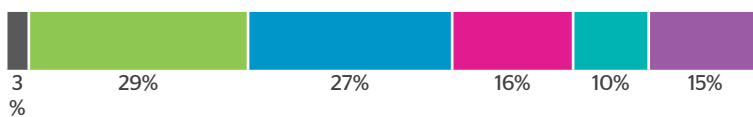
Overall, respondents visited their GP on a monthly, bi-monthly and quarterly basis regarding their Fibromyalgia. There is a small number of individuals both locally and nationally who visit their GP on a weekly basis. Nearly a quarter of LLR respondents and almost a fifth of UK respondents reported not visiting their GP regarding their Fibromyalgia.

VISITS TO THE GP

LLR RESPONDENTS



UK RESPONDENTS



KEY: HOW OFTEN I VISIT MY GP

- Weekly
- Monthly
- Every 2 months (bi-monthly)
- Once a quarter
- 1-2 times a year
- I don't see my GP about Fibromyalgia

"I had to 'fight' for pain clinic referral"
 (Female, 55-44, Charnwood)

Regarding your Fibromyalgia, which specialist services, if any, has your GP referred you to?

Our findings showed that LLR respondents were mostly referred to Rheumatology, followed by Pain Management and Physiotherapy. Similar findings were also reported by UK respondents. Individuals were allowed to select more than one option for this question.

A number of people from LLR (78) and the UK (104), said they had not been referred to any specialist services by their GP.

REFERRAL TO SPECIALIST



Rheumatology

LLR	UK
147	317



Pain Management

LLR	UK
116	207



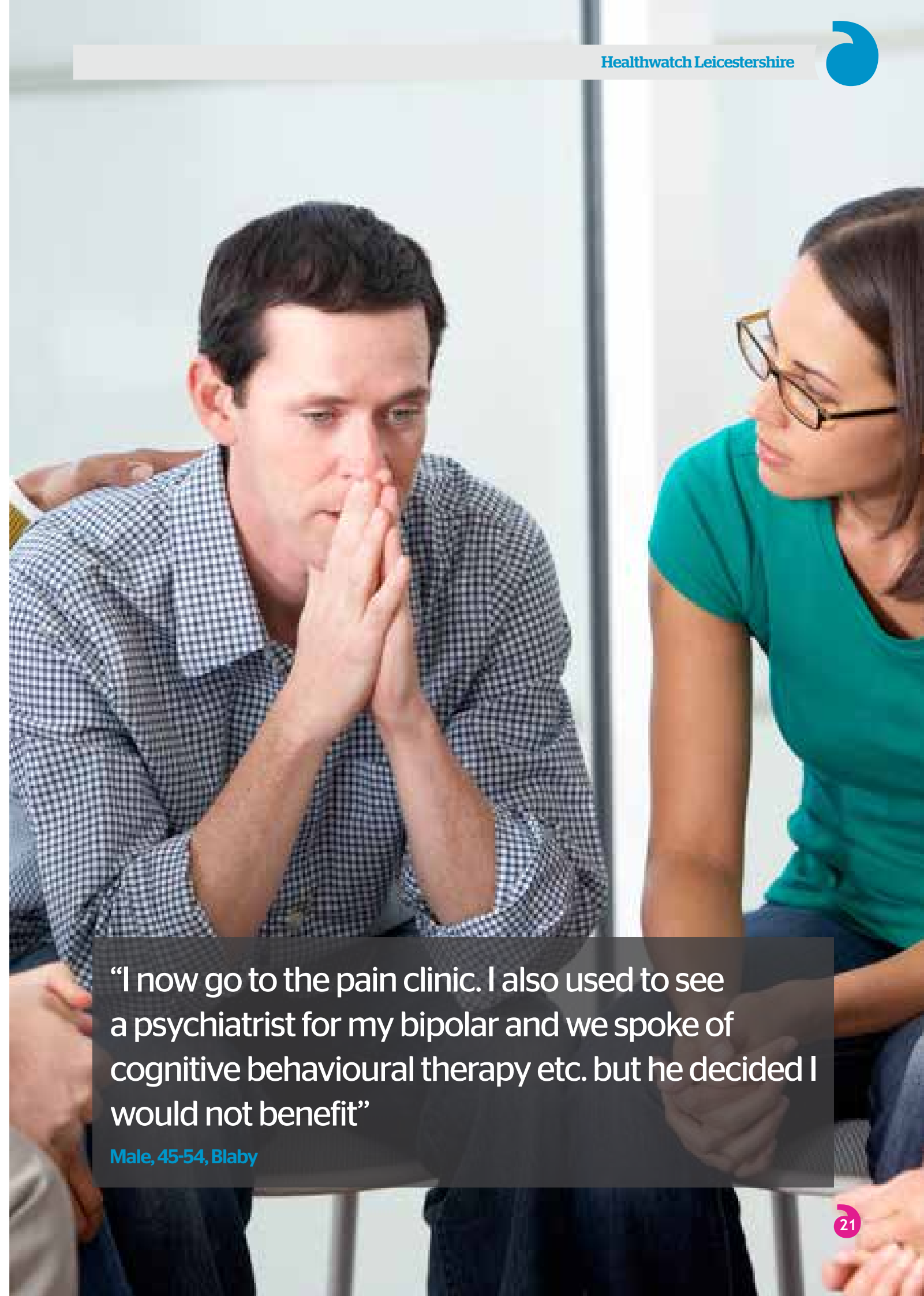
Physiotherapy

LLR	UK
111	258

The following are quotes from respondents who selected 'Other' and highlight some of the difficulties they experienced to get a referral to a specific clinic or specialised treatment.

"I was never asked to see anyone, and was just given pills and left to get on with it"
 (Female, 45-54, North West Leicestershire)

"Guy's hospital were helpful, but the referrals they suggested were not followed up by GP practice"
 (Female, 55-64, Harrow)



"I now go to the pain clinic. I also used to see a psychiatrist for my bipolar and we spoke of cognitive behavioural therapy etc. but he decided I would not benefit"

Male, 45-54, Blaby



Do you find that (non-specialist) hospital staff have knowledge of Fibromyalgia and understand your condition?

We asked respondents how they felt about the knowledge and understanding of non-specialist hospital staff regarding Fibromyalgia. Nearly a fifth of respondents in LLR and outside of LLR said that they feel non-specialist hospital staff understand Fibromyalgia, treat them appropriately and have some knowledge of the condition.

In both cases however, the majority of respondents in LLR and the UK reported that non-specialist hospital staff do not have much knowledge of or understand Fibromyalgia. This is concerning and suggests that there is a lack of knowledge in primary and secondary services across LLR and rest of the UK.

In respect to your Fibromyalgia, is there anything else about hospital services that you would like to mention?

We received over 250 responses to this question. The majority of the comments were negative. The following are illustrative examples of individual experiences and opinions regarding hospital services.



LLR respondents



UK respondents

“Most hospital A&E doctors simply laugh at the suspected fibromyalgia- to them it’s a ‘made up’ condition”
(Female, 16-24, Hinckley & Bosworth)

“I think they just tell you anything to get rid of you. They tell you it’s not real it’s all in your head that you are imagining it”
(Male, 25-34, Merseyside)

“I was diagnosed and left to deal with it myself; I did not get any support. I got referred to things but basically just live with it, no help”
(Female, 45-54)

“It doesn’t seem to be taken seriously by the majority of medical staff I’ve met”
(Female, 55-64, Harborough)

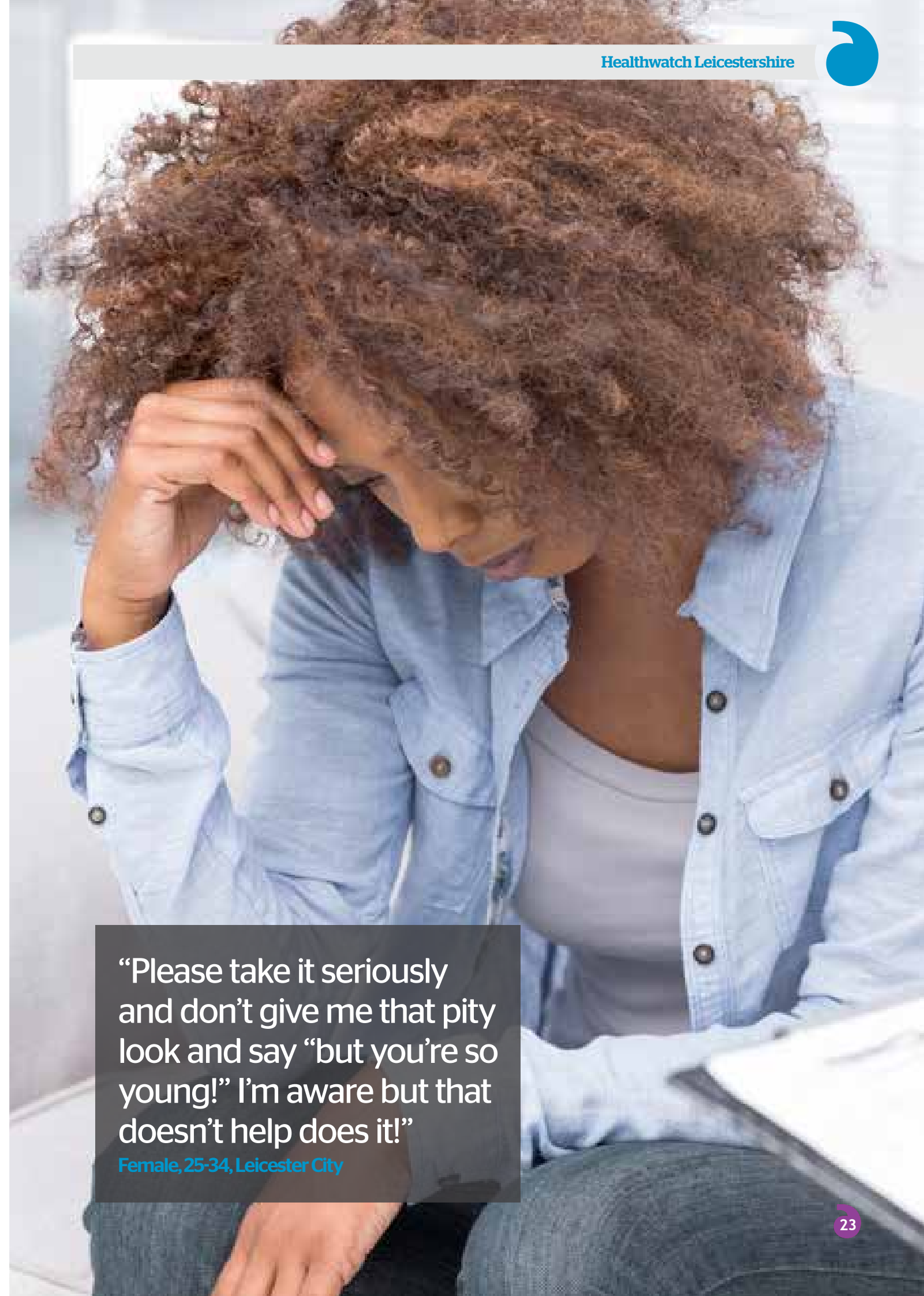
“Since 1998 I have had nothing but disbelief about my pain now i feel like a cripple most days, walking about my flat in pain and confusion with no support from any agencies whatsoever”
(Male, 45-54, Sheffield)

“My GP didn’t recognise my symptoms so I paid privately for a referral to see a Rheumatologist who was mortified I had been suffering for so many years”
(Female, 45-54, North Lincolnshire)

“There should be more support groups and more knowledge about this condition. More help and clinics also a support nurse we could ring when need be”
(Female, 65-74, Charnwood)

“Please take it seriously and don’t give me that pity look and say “but you’re so young!” I’m aware but that doesn’t help does it!”

Female, 25-34, Leicester City




Are you currently having any treatments for the condition?

The overwhelming majority of respondents are receiving treatment for their condition. This reflects the frequency of visits to the GP for prescriptions and on-going treatment.


LLR respondents

 **56%** respondents stated that they are currently receiving treatments.

 **44%** said they are not currently receiving treatments.

UK respondents

 **62%** respondents stated that they are currently receiving treatments.

 **38%** said they are not currently receiving treatments.

What treatments are you having now or had previously?

This question gave respondents the opportunity to provide a qualitative answer.

We organised the feedback by type of medication, treatment and therapies in order to gain a better understanding of ways in which Fibromyalgia patients cope and manage their condition.



LLR respondents



UK respondents



Fibromyalgia Specific Meds

Savella
Duloxetine



Anti-depressants

Fluoxetine
Mirtazapine
Sertraline



Simple Analgesia

Paracetamol
Ibuprofen
Co-codamol
Nurofen
Ralgex spray



Strong analgesia

Morphine
Oxycontin
Oramorph Sulphate
Zomorph
Ligocaine Infusion
Tramadol



Neuropathic analgesia

Amitriptyline
Gabapentin
Pregabalin



Steroids

Betnovate ointment
Steroid injections



Other medication

Zolmitripan
Calcium tablets
Lansaprazole
Sleeping pills
Thyroid medication



Medical therapies (GP referral)

Pain management course
Stem cell treatment
Cognitive Behavioural Therapy
Complementary therapies
Physiotherapy
Rheumatology



Alternative Holistic therapies

Acupuncture
Hydrotherapy
Reflexology
Full body massage (private)
Tens machine

What difference (if any) are the treatments having on your condition?

We gave respondents the opportunity to tell us what difference, if any, their medication or treatment has had on their Fibromyalgia. We received similar responses from LLR and UK respondents.

We have listed below the recurring themes from the qualitative comments.

- Manages depression and anxiety
- Eases pain temporarily
- Aids sleep

- Less nausea
- Eases fatigue temporarily
- Weight gain
- Helps a little with mobility
- Acupuncture relaxes muscles
- No difference, worsens symptoms
- Effects of medication wear off quickly
- Hydrotherapy is very relaxing
- "Takes the edge off"

What support locally would you like to see for Fibromyalgia sufferers?

We asked respondents what support they would like to see locally for individuals with Fibromyalgia. As this question allowed respondents to provide a qualitative response, all responses were analysed and grouped into the below categories.



Services/Facilities

- Local specialist clinics
- Specialist Fibromyalgia Nurse
- Home visits from GP
- Helpline with specialist support
- Transportation services
- Annual/ monthly review of symptoms and medication



Support and information for Patients

- More public awareness campaigns
- Local support groups
- Fitness classes
- Domestic services
- Education on nutrition
- Protection in workplace
- Availability of treatments on NHS
- Support for spouses/family
- Lectures from health professionals



Support and information for Professionals and Employers

- Guidance for employers
- More awareness of the condition for employers
- Less judgement from health professionals

"A lot of health care staff don't understand and a lot of the times when I explain I have Fibromyalgia it gets brushed off as if it wasn't a real health issue."

(Female, 25-34, North West Leicestershire)



Recommendations

The findings from our report will be presented to a range of stakeholders who are responsible for commissioning, providing services and the education and training of Doctors. There are some simple and practical steps that can be taken to make life easier for Fibromyalgia sufferers and their families, such as:

1. A **tool kit** that includes a list of local GPs both private and NHS who specialise in Fibromyalgia within LLR, including information about Fibromyalgia, the types of treatment that may be beneficial and what alternative therapies are available.
2. Provide **support** for families and carers of individuals with Fibromyalgia for example, developing a local support group or a local online forum which would allow patients to participate from the comfort of their home.
3. More **education and training** to existing GPs and those in training regarding Fibromyalgia symptoms and impact on quality of life for the patient, their families and carers. Part of the training should include increasing awareness of local specialist services that GPs can refer patients to including pain management services, hydrotherapy, hyperbaric oxygen therapy, counselling and cognitive behavioural therapy to enable patients to cope better with this debilitating long-term condition.
4. To address both health and social care needs, commissioners should explore a **multi-disciplinary** approach to diagnosis and service provision for patients, their families and carers.
5. More **information** to be made available about Fibromyalgia that includes using online platforms and social media to raise public awareness led by public health, commissioners and providers.

Conclusion

There are clear issues with diagnosis, pain management and support that impacts on the lives of Fibromyalgia sufferers and their well-being. This invariably has a knock-on impact for their family and wider relationships.

Fibromyalgia sufferers are a seldom heard group suffering in silence, who are patiently waiting for their voices to be heard and it is not something that is 'in their head'.

We hope that the findings of this report will be used to provide support, information and improve access to, treatments and therapies which help patients to better manage their condition and also raise public awareness of Fibromyalgia.

Fibromyalgia Friends Together

Fibromyalgia is a recognised illness. The main symptoms of Fibromyalgia are widespread pain, profound fatigue, headaches, depression, increased sensitivity, fibro fog and irritable bowel.

These are our **Top 10 Tips** for living with fibromyalgia.

- 01 Support Group -** Join a Fibromyalgia support group such as Fibromyalgia Friends Together, it is really useful to talk to people who understand what you are going through.
- 02 Pace Yourself -** Take time to come to terms with your diagnosis and learn to manage your symptoms. Organise and prioritise your workload as you won't be able to do as much as you used to. Be kind to yourself and accept help from wherever possible.
- 03 Health Professional -** Try to find a GP that understands and recognises fibromyalgia. Keep a food and pain diary and take it with you to all appointments. Ask for a referral to a rheumatologist, pain clinic, physiotherapist or dietitian and be persistent
- 04 Treatment -** Fibromyalgia is different for everyone, so it's important to learn how it affects you. There is no one treatment or medication that works for all; what suits one person will not necessarily suit another.
- 05 New Symptoms -** Do not ignore new symptoms; it is not always fibromyalgia. If you are not sure, see your GP.
- 06 Complementary Therapies -** Try complementary therapies such as Acupuncture, Reflexology or Aromatherapy. Hyperbaric Oxygen Chamber Treatment, available at MS therapy centres, has shown promise in helping people with pain and insomnia. A hot bath or shower can help to ease aches and pains.
- 07 Relaxation -** Stress often increases symptoms, therefore it is important to relax as much as you can. Learn how to relax by joining a relaxation or mindfulness class; do whatever it takes for you to switch off, reading, painting, knitting, music, visiting family or friends.
- 08 Exercise -** It is better to keep moving if you can. Take gentle exercise such as walking or swimming, or join an exercise class such as Yoga, Tai Chi, Pilates etc.
- 09 Information -** Fibromyalgia Action UK is the registered charity for Fibromyalgia where you can get a variety of information. Seek support online, there are many sites supporting Fibromyalgia. Our Facebook group is Fibromyalgia Friends Together Leicestershire. Use the internet as a tool but recognise not all information is correct.
- 10 Benefits -** Apply for any relevant benefits as these can make your life much easier. Keeping a diary of symptoms will help you complete the forms. Help is available at your local CAB office. If you have difficulty walking apply for a Blue badge

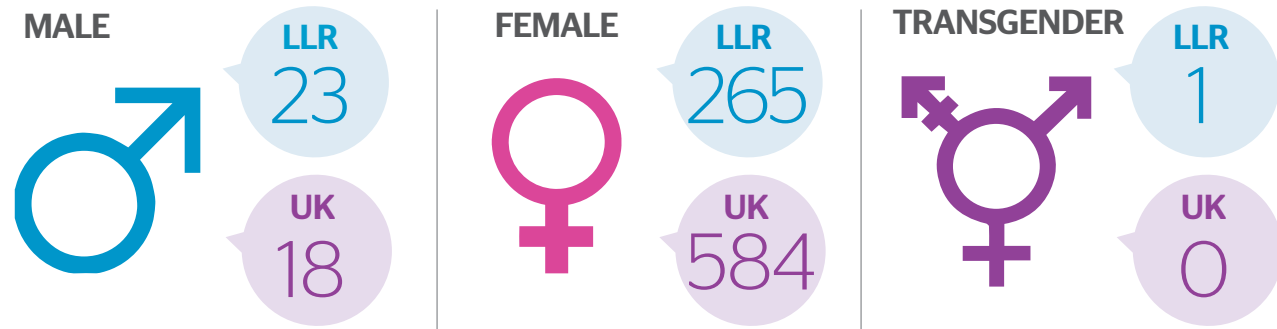
Contact:
 ✉ kathleen@shuttlewood-clarke.org
 ☎ 07860 639693 or 01530 244914
Shuttlewood Clarke Foundation
 Ulverscroft Grange, Whitwick Road, Ulverscroft, Leicestershire. LE67 9QB
Fibromyalgia Friends Together meet on the third Thursday of the month at Ulverscroft Manor, Priory Lane, Ulverscroft, Leicestershire. LE67 9PH



Demographics

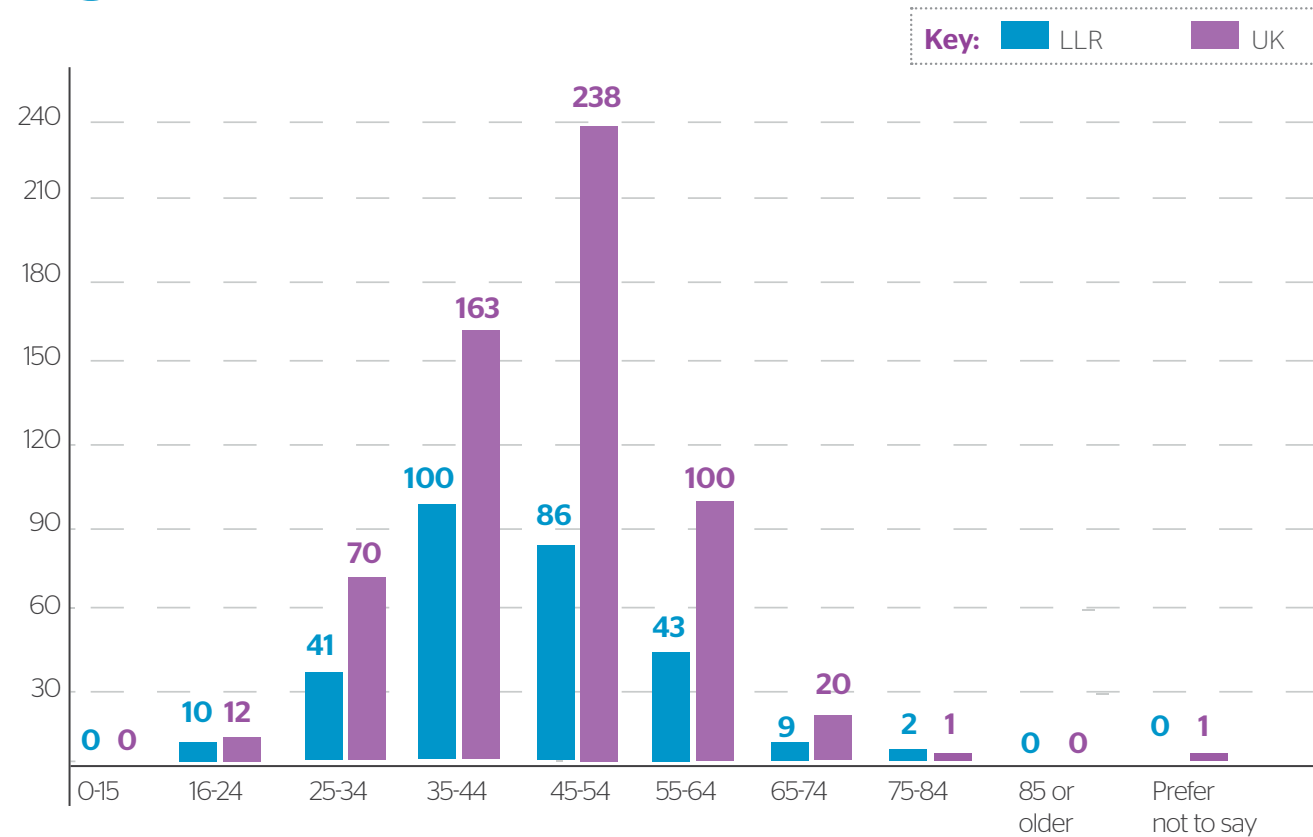
As part of the survey we asked respondents for their gender, age, ethnicity and which district or borough they lived. The responses that we were given are as follows:

Gender



LLR & UK: 4 - PREFER NOT TO SAY

Age of respondent



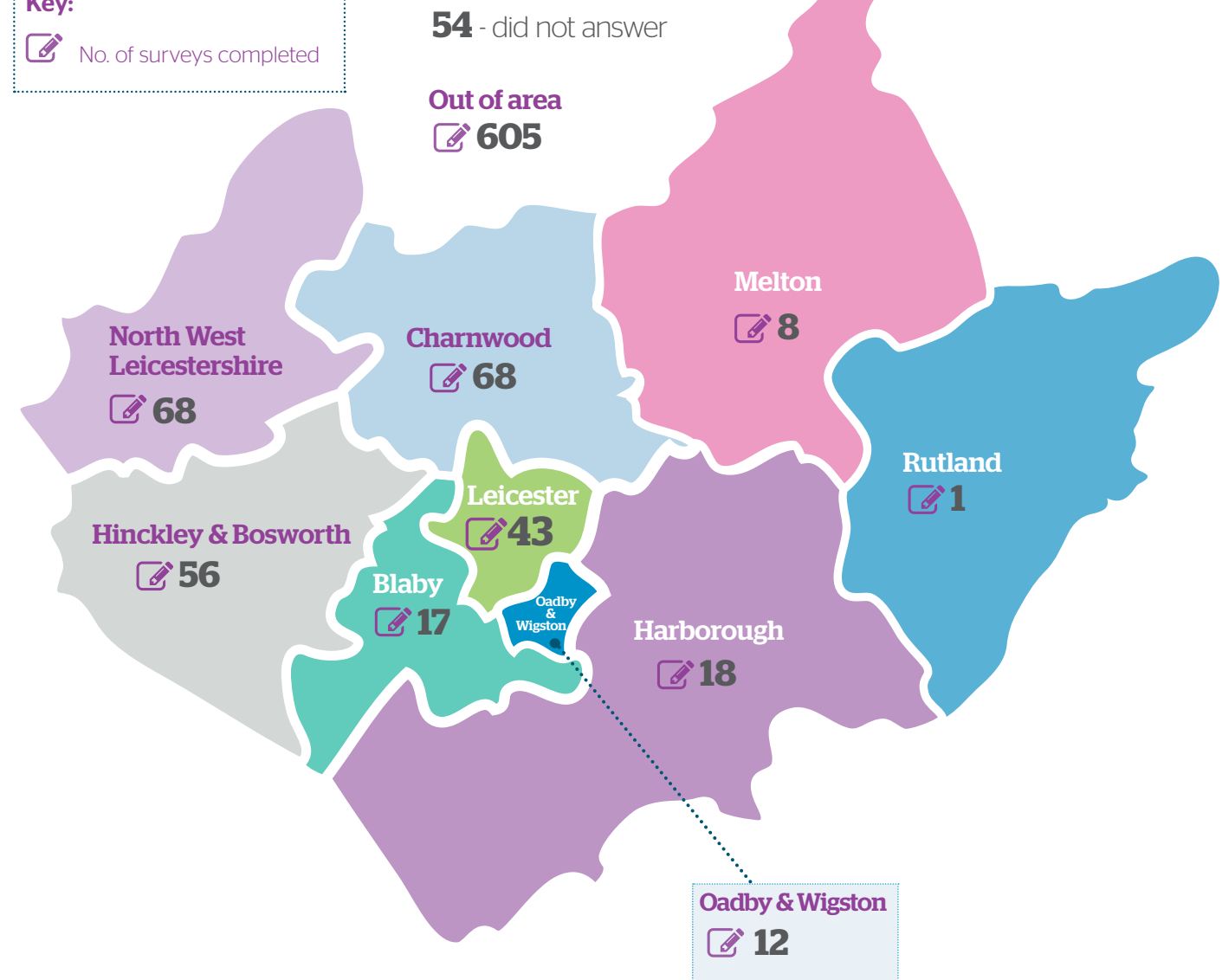
Ethnicity

We asked respondents what their ethnic group was the majority of respondents from both LLR and the UK were English/Welsh/Scottish/Nrthern Ireland/British.



Where do you live?

Key:
 No. of surveys completed



Useful Contacts

LOCAL SUPPORT GROUPS & ORGANISATIONS:

Fibromyalgia Friends Together Group

- ✉ Ulverscroft Manor, Priory Lane, Markfield, Leicestershire
- ☎ 01530 244914
- @ hello@shuttlewood-clarke.org
- 🌐 www.shuttlewood-clarke.org/about-us/

Leicestershire Fibromyalgia and ME/CFS Meet up group

- ✉ Heathley Park, Groby Road, Leicester, LE3 9QH
- ☎ 07795 661 061
- @ Leicestershire.fibro.meet.ups@gmail.com
- 🌐 www.leicestershirefibromeeetups.weebly.com

Market Harborough ME/CFS and Fibromyalgia Support Group

- @ harboromefm@gmail.com

Ashby Fibromyalgia and ME Group

- ✉ Sally Cordy
- @ ashbymegroup@googlemail.com

NATIONAL SUPPORT GROUPS & ORGANISATIONS:

Fibromyalgia Action UK

- ✉ Unit S1, Troon Way Business Centre, Humberstone Lane, Leicester, LE4 9HA
- ☎ National general helpline: 0300 999 333
UK Welfare benefits helpline: 0300 999 0055
- 🌐 www.fmauk.org/

Fibromyalgia Online Support Group - MD Action

- 🌐 www.mdjunction.com

Campaign to recognize Fibromyalgia as a disability in the UK

www.change.org/p/uk-parliament-make-fibromyalgia-a-disability #MAKETHEMHEAR @FibroPetition

“After a course in Pain Management, I feel alone again with my pain, fatigue and lack of mobility. I feel my doctor doesn’t understand the impact it has on my life or how I don’t cope. Neither is my medication assessed or reappraised to find better alternatives. I’ve essentially been on the same pain meds for over 20 years, but pain/mobility is worsened gradually. It feels like no one cares.”

Female, 35-44, Leicester City

'It's not in my head!'

Healthwatch Leicestershire

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info@healthwatchleics.co.uk

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