

# ME/CFS Report

## June 2017

Report summarising Healthwatch Lancashire's findings to contribute to a national picture of ME/CFS patient experience, as well as highlighting local issues for residents of Lancashire. The report is in support of Healthwatch Trafford's national survey.

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## Introduction

Healthwatch Lancashire is committed to listening to patients and members of the public in Lancashire and making sure their views and experiences are heard by those who run, plan, commission and regulate health and social care services.

In March 2017, Healthwatch Trafford contacted Healthwatch Lancashire with the results of a national survey they had completed with patients living with Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome (CFS).

## What is ME/CFS?

### ME (Myalgic Encephalomyelitis) and CFS (Chronic Fatigue Syndrome)

“ME is a chronic illness that affects many body systems and their functions. The changes seem particularly to affect the nervous and immune system, but they also affect other parts of the body. The illness can cause profound exhaustion, muscle pain, problems with mental function, such as memory loss and poor concentration, malaise and other symptoms. Many people know the condition as ME but the formal term used currently by the medical profession is Chronic Fatigue Syndrome (CFS).”

### Who does it affect?

“ME can affect men, women and children of all ages and backgrounds. It is estimated that there are over 250,000 people in the UK with ME: nearly two thirds of them are women. A recent study in the USA showed that about 1 in 250 people in the community have symptoms of CFS. Most people develop the illness between their early twenties and mid-forties. However, ME does affect children and young people, generally those between the ages of 13 and 15 but sometimes children as young as five.”

*Information obtained March 2017 from:  
<http://clancsme.org.uk/what-is-me/>*

## Methodology

It is often those closest to the process who are best placed to give useful feedback on the way services work and how they can be improved. Patients and relatives are the ones who experience the process or service first hand, they have a unique, highly relevant perspective. Patient and relatives input into designing services can be invaluable as sometimes seeing services from their point of view opens up real opportunities for improvement.

### Project Timing

Healthwatch Trafford approached Healthwatch Lancashire in March 2017. Healthwatch Lancashire conducted their ME/CFS campaign between March and April 2017.

### Project Implementation

Healthwatch Lancashire utilised the survey completed by Healthwatch Trafford in an online campaign that was promoted via the Healthwatch Lancashire website/social media outlets and via local ME/CFS support groups. Some changes were made to the original survey due to time constraints.

## Project Need

Healthwatch Trafford received several responses to their national survey from people in Lancashire and wanted to share this information with us, as it highlighted ME/CFS services as an issue for residents of Lancashire and across the country. Healthwatch Lancashire has links with the local ME/CFS support group, Central Lancs ME/CFS Support Group, who have identified similar issues (particularly around the commissioning of treatment services) and are currently working to raise these issues with local Clinical Commissioning Groups, making this a very relevant topic for Lancashire.

## Project Aim

The aim of Healthwatch Trafford's original project was to gather and understand experiences of ME/CFS patients accessing health services, in order to identify where services are doing well and where they need to improve, with a view to working with services and commissioners to make them better. Healthwatch Lancashire's aim was to utilise the local intelligence and links we currently have with patients in Lancashire to contribute to the findings, in order to express their needs at a national level.

## Project Objective

The objective of this project was to ensure the findings will further contribute to a national picture of ME/CFS patient experience, as well as highlighting local issues for residents of Lancashire. This project will also support ongoing conversations between local support groups and the Clinical Commissioning Groups regarding the commissioning of treatment services in the area. Approximately 25 other local Healthwatch across the country have also been involved in contributing to Healthwatch Trafford's original project.

## Acknowledgements

Healthwatch Lancashire would like to thank everyone who took part in this survey, and the Central Lancs ME/CFS Group for distributing the survey and their involvement. We would also like to thank Healthwatch Trafford for passing on local insight and supporting Healthwatch Lancashire with this report.

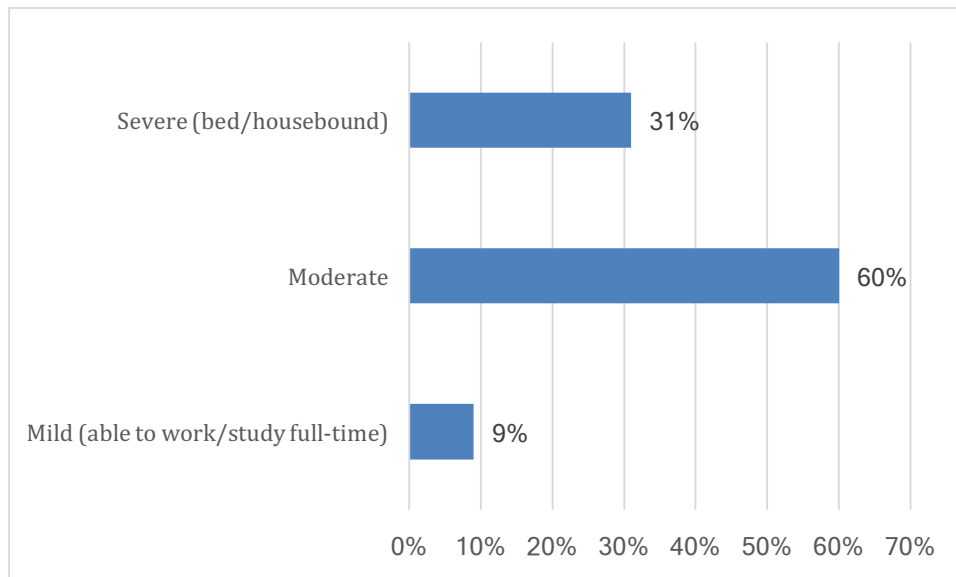
## Summary of findings

In total, 48 people shared their experiences (27 people from the original Healthwatch Trafford survey and a further 21 from the Healthwatch Lancashire campaign). Here are the key findings:

- The majority of people (60%) said they would describe their current level of ME/CFS as moderate. A further 31% of people said they would describe their current level of ME/CFS as severe. Half (50%) of people said they have had ME/CFS for 10 years or more.
- The large majority of people (98%) said they have had a formal diagnosis from a doctor. 51% of people said they received a diagnosis after a specialist referral to either an ME/CFS clinic or an alternative department. A further 28% received a diagnosis from their GP. 13% of people received a diagnosis from a private doctor or paid service.
- Just over half (53%) of people said they have received information on living with ME/CFS from the department where they received their diagnosis. A quarter of people said they had never received information from the NHS on how to live with their condition.
- 61% of people said they found the information they received helpful, however, 39% said they did not find this information helpful.
- 34% of people said it took between 6 and 12 months from first reporting symptoms to their GP to diagnosis. 13% of people said this process took more than five years.
- Over half (53%) of people said their GP is supportive but not knowledgeable about their condition. Nearly a quarter (24%) of people said their GP is neither knowledgeable nor supportive.
- Around a quarter of people (26%) said they would trust their GP to provide them with information on their condition. The large majority (74%) said they would not trust their GP or were unsure whether they would.
- Nearly half (47%) of people said they have been referred to an ME/CFS department in their local area. Nearly a quarter (24%) said they have not been referred to any services. 21% of people said they had been referred to an ME/CFS department out of area and the remaining 8% said they had been referred to other departments that were not specific to ME/CFS.
- 86% of people said they had never received or requested a GP home visit because they couldn't attend the surgery.
- The large majority of people (79%) said their GP always or mostly speaks with respect and fairness and listens. 3% of people said their GP rarely speaks to them this way.
- The large majority of people (82%) said they had not been unable to access or been refused any tests or treatments. 18% of people said they had been unable to access or refused these.
- 72% of people said they have accessed ME/CFS specialist care at a hospital. Over half of people (57%) said the hospital somewhat understood and accommodated their needs.

## Results:

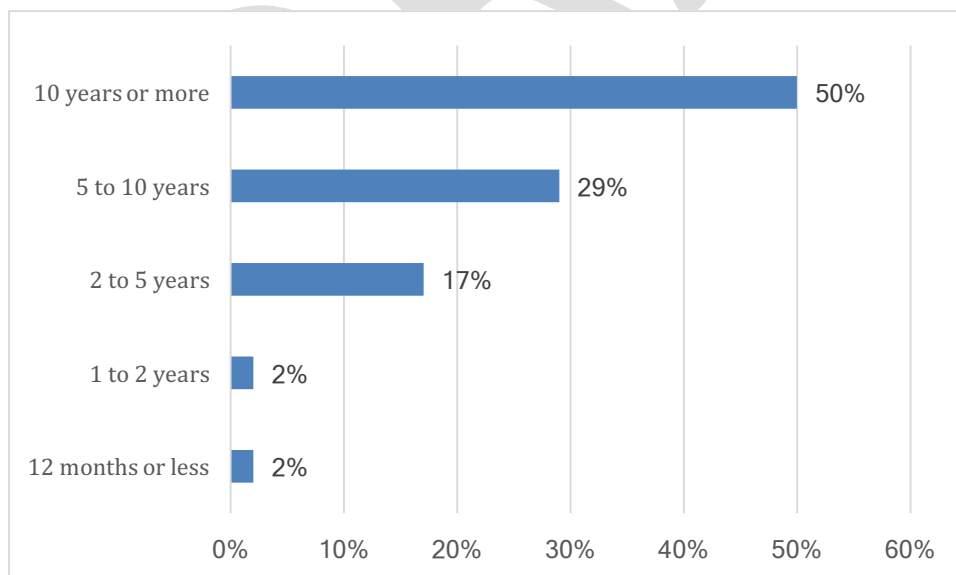
### 1. We asked: 'How would you describe your current level of ME/CFS?'



The majority of people (60%) said they would describe their current level of ME/CFS as moderate. A further 31% of people said they would describe their current level of ME/CFS as severe.

(48 out of 48 answered)

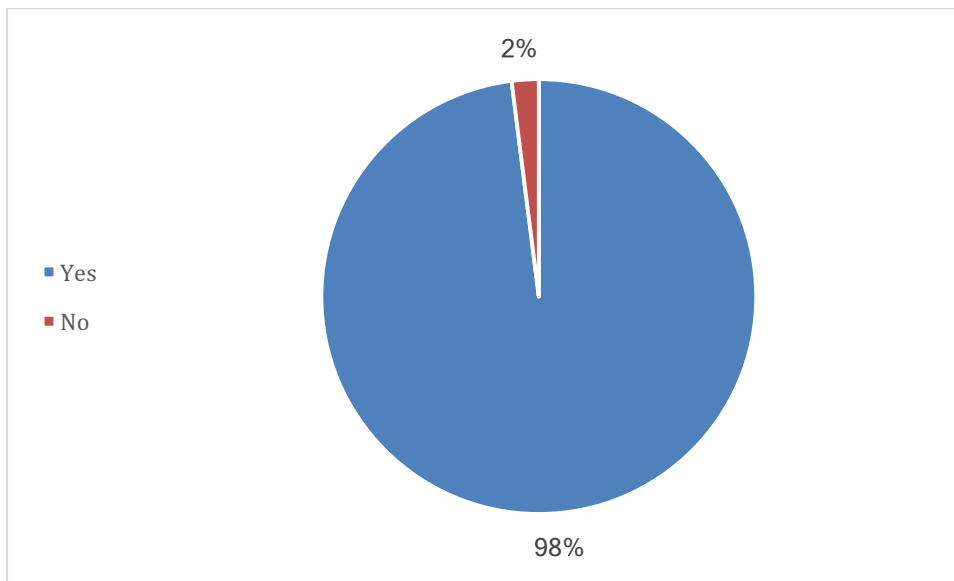
### 2. We asked: 'How long have you had ME/CFS?'



Half (50%) of people said they have had ME/CFS for 10 years or more.

(48 out of 48 answered)

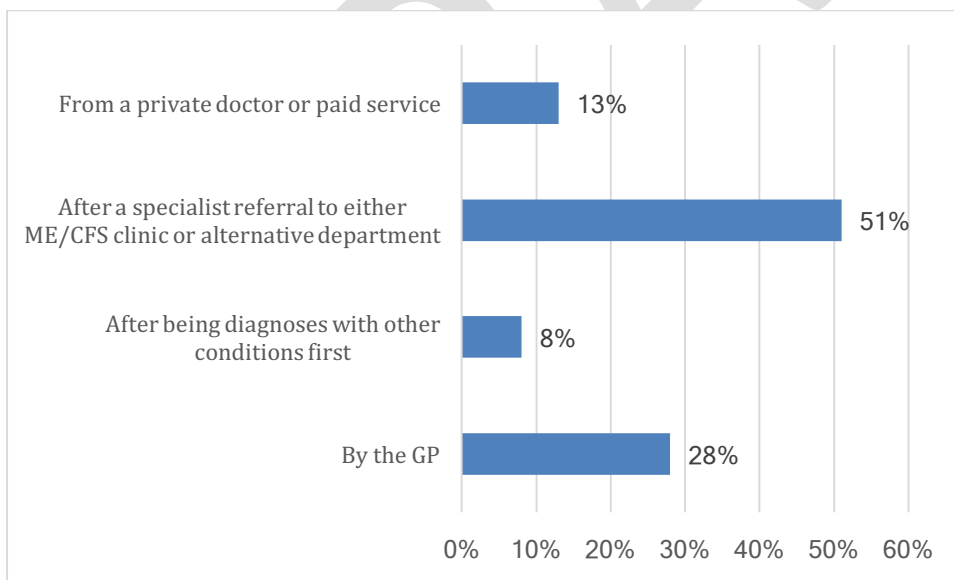
### 3. We asked: 'Have you had a formal diagnosis from a doctor?'



The large majority of people (98%) said they have had a formal diagnosis from a doctor.

(48 out of 48 answered)

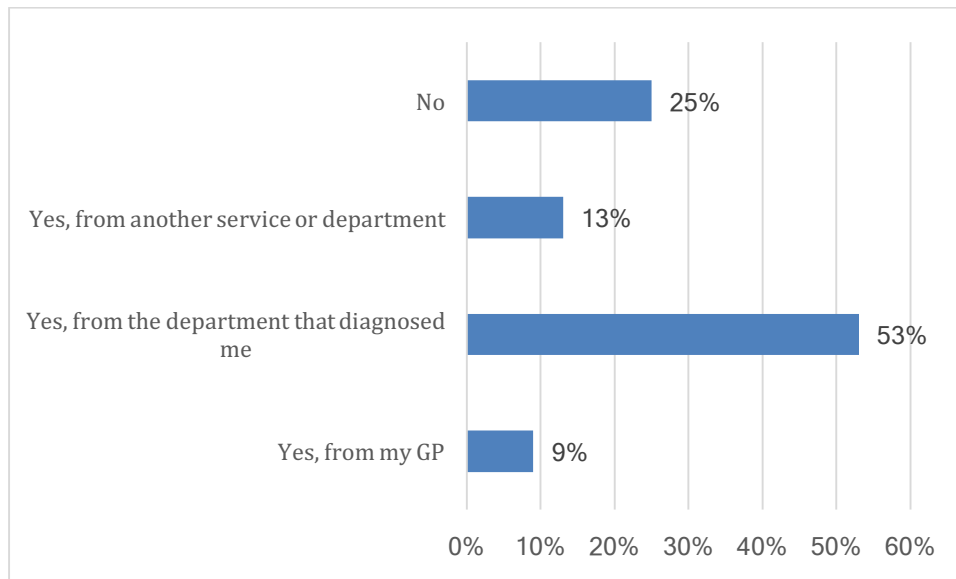
### 4. We asked: 'If yes, how were you diagnosed?'



51% of people said they received a diagnosis after a specialist referral to either an ME/CFS clinic or an alternative department. A further 28% received a diagnosis from their GP. 13% of people received a diagnosis from a private doctor or paid service.

(47 out of 48 answered)

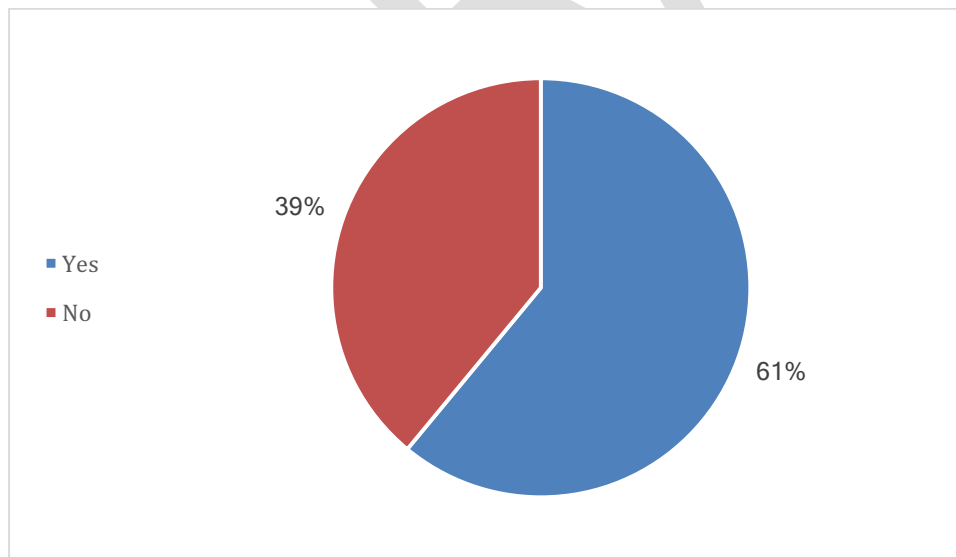
**5. We asked: 'Have you been offered any information from the NHS on living with the condition?'**



Just over half (53%) of people said they have received information on living with ME/CFS from the department where they received their diagnosis. Around a quarter of people said they had never received information from the NHS on how to live with their condition.

(40 out of 48 answered)

**6. We asked: 'If yes, was that information helpful?'**

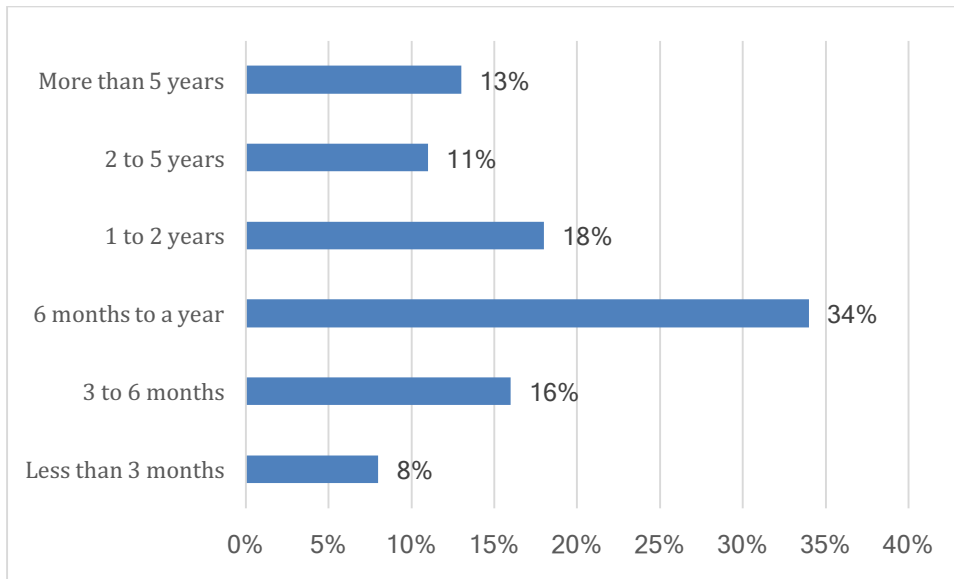


61% of people said they found the information they received helpful, however, 39% said they did not find this information helpful.

(33 out of 38 answered)



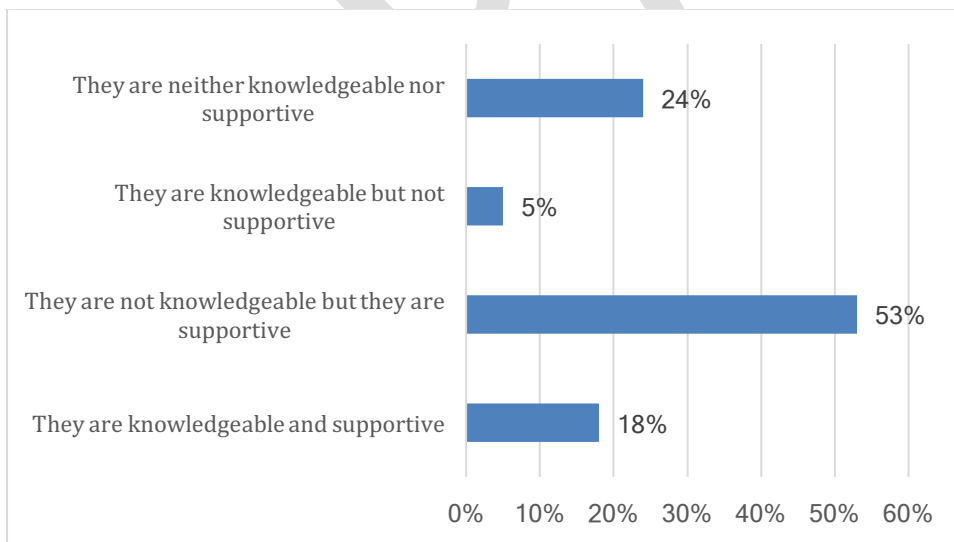
**7. We asked: 'How long did it take to be diagnosed after first reporting symptoms to your GP?'**



34% of people said it took between 6 and 12 months from first reporting symptoms to their GP to diagnosis. 13% of people said this process took more than five years.

(38 out of 48 answered)

**8. We asked: 'How does your GP talk about your condition?'**

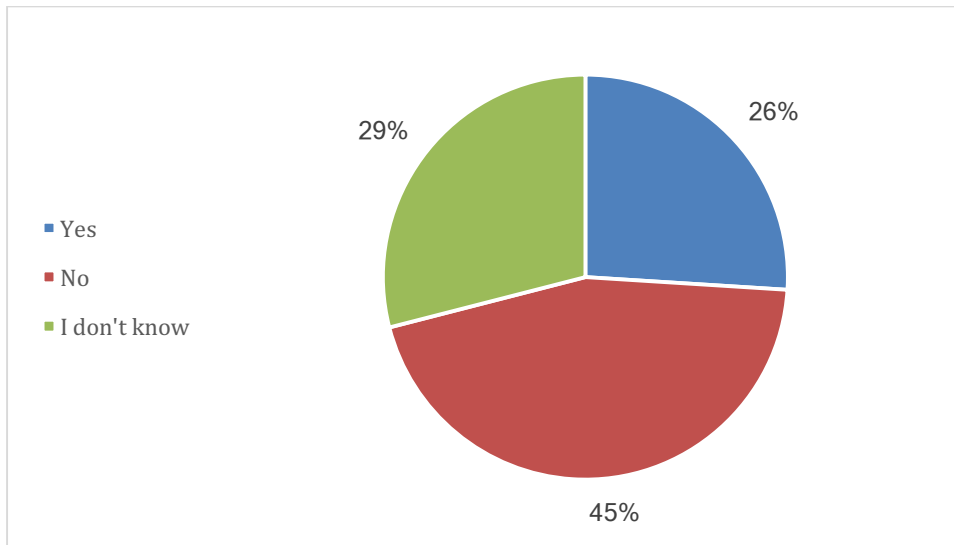


Over half (53%) of people said their GP is supportive but not knowledgeable about their condition. Nearly a quarter (24%) of people said their GP is neither knowledgeable nor supportive.

(38 out of 48 answered)



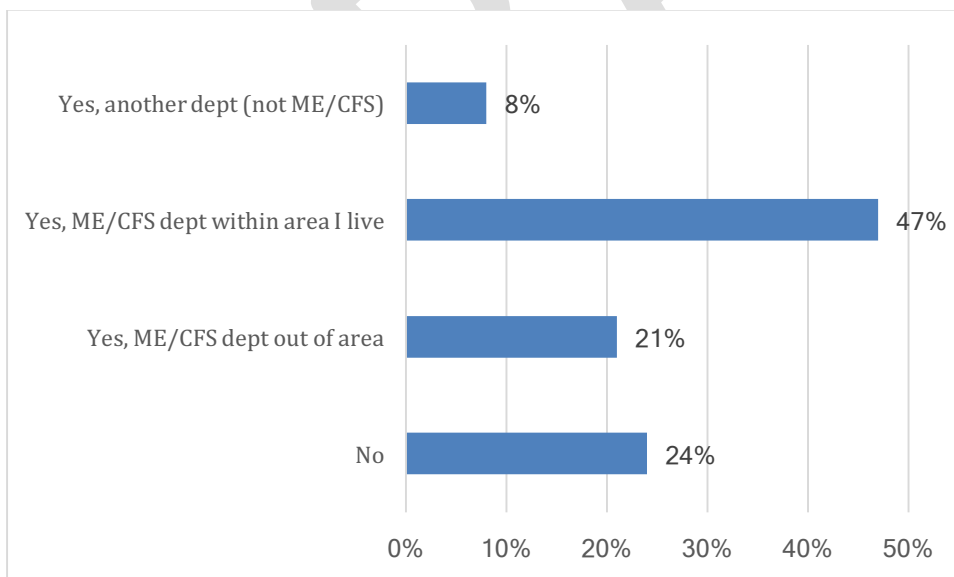
**9. We asked: 'Would you trust your GP to provide you with information about ME/CFS?'**



Around a quarter of people (26%) said they would trust their GP to provide them with information on their condition. The large majority (74%) said they would not trust their GP or were unsure whether they would.

(38 out of 48 answered)

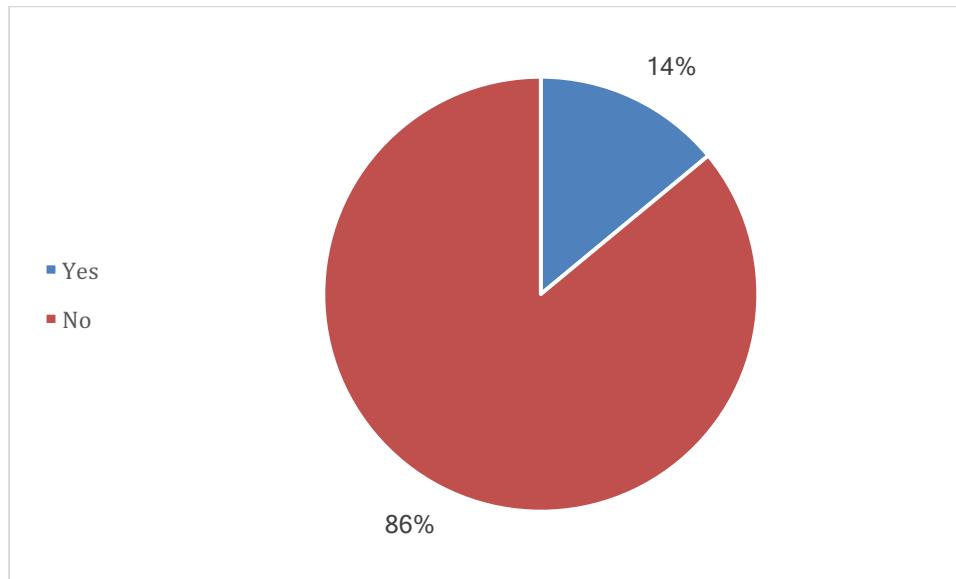
**10. We asked: 'Has your GP referred you to ME/CFS services?'**



Nearly half (47%) of people said they have been referred to an ME/CFS department in their local area. Nearly a quarter (24%) said they have not been referred to any services.

(38 out of 48 answered)

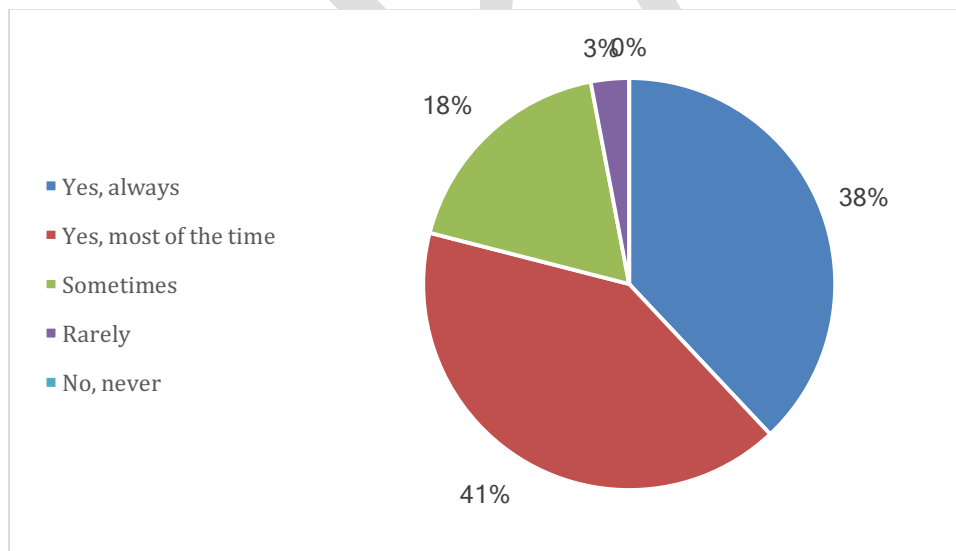
**11. We asked: 'Has a GP ever come out to you because you couldn't attend the surgery?'**



86% of people said the GP has not come out to them because they couldn't attend the surgery.

(37 out of 48 answered)

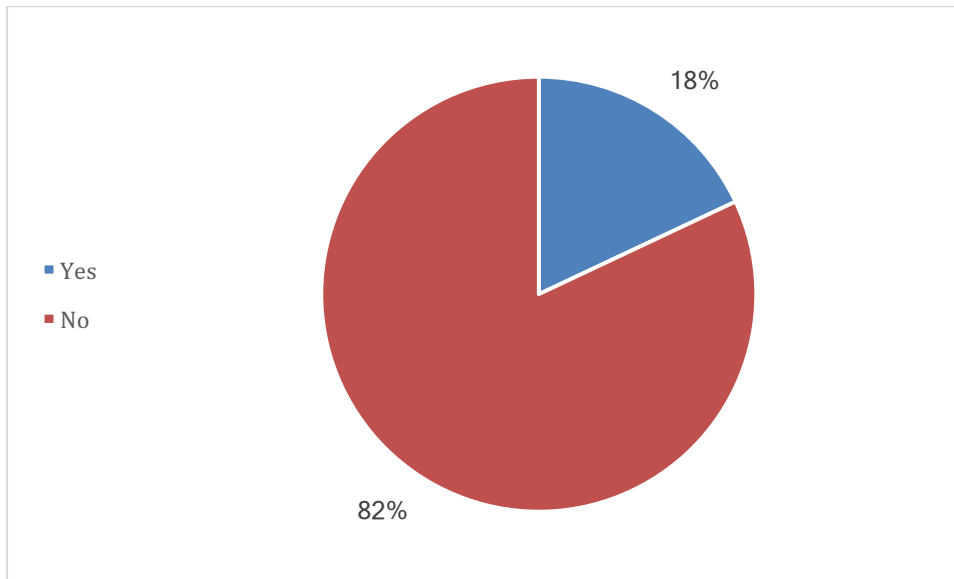
**12. We asked: 'Would you say your GP(s) speak to you with respect and fairness, listening to you?'**



The large majority of people (79%) said their GP always or mostly speaks with respect and fairness and listens. 3% of people said their GP rarely speaks to them this way.

(39 out of 48 answered)

**13. We asked: 'Have you ever been unable to access or been refused tests or treatment?'**



The large majority of people (82%) said they had not been unable to access or been refused any tests or treatments. 18% of people said they had.

(28 of 48 answered)

**Comments shared from those who said they had been unable to access or had been refused tests or treatment:**

*"I have been refused B12!"*

*"It took me four years of pushing to get a 'PoTS' [Postural tachycardia syndrome] diagnosis, and I have been refused to see an endocrinologist, despite showing thyroid and hormone symptoms."*

*"Rare Mitochondrial Disease Service referral/ testing. Immune screening. A second Vitamin D test during winter."*

*"Immunology. I was denied full immune and viral screening by the local authority. My GP was happy to refer me, but couldn't justify it."*

*"I was referred by my neurologist in Barrow to an inpatient clinic in Leeds, however, my local council refused the funding - we appealed and had the local MP backing us, however, they still declined the application saying that they couldn't warrant the funding on a treatment that was not 100% effective in all cases."*

*"The GP wouldn't test me for everything I have asked, nor will they find tests to save me doing them privately, as they don't see the need given I have already had a diagnosis."*

*"I have been accused of 'not wanting to get well' because I was too ill to attend an appointment."*

*"I have been with previous surgeries during my illness which refused me tests and treatment I requested saying there was no grounds for it, without examining my reasons for request."*

*"I am mostly housebound, I am unable to access tests because of that."*

**Healthwatch Trafford asked: 'Is there anything about GP services you would like to mention?'**

**Suggestions for improvements:**

*"I would like to have been referred to a neurologist earlier because of my worsening cognitive problems."*

*"They should refer you to a consultant."*

*"It would be nice to have at least one GP at the surgery who is kept up to date with the ME research and treatment options so we have a contact for appointments where we will be understood and get the advice we often so desperately need."*

*"I just wish GPs were trained in dealing with ME."*

*"They need to be trained and educated in dealing with ME sufferers in particular, so as not to prescribe medicines or treatments that can be harmful to us (vaccinations, anaesthetic, medications we can be sensitive to). In lieu of current services offering training, charity group 'Invest in ME' offer information packs that can accessed by doctors."*

**Positive comments shared:**

*"I have just moved to this doctor in Leyland and more has been done for me in 6 months than a whole four years at my last doctors."*

*"Their ignorance is not their fault."*

**Negative comments shared:**

*"My own GP is great, but it's hard to see them. Seeing different GPs is not useful with ME, as the history is too complicated. Also, having to come into the surgery is a dreadful ordeal for me and always leaves me ill for days, I usually get very ill and distressed and faint in the waiting room, as I am noise and sensory intolerant and I have 'PoTS' [Postural tachycardia syndrome] so can't sit up for long."*

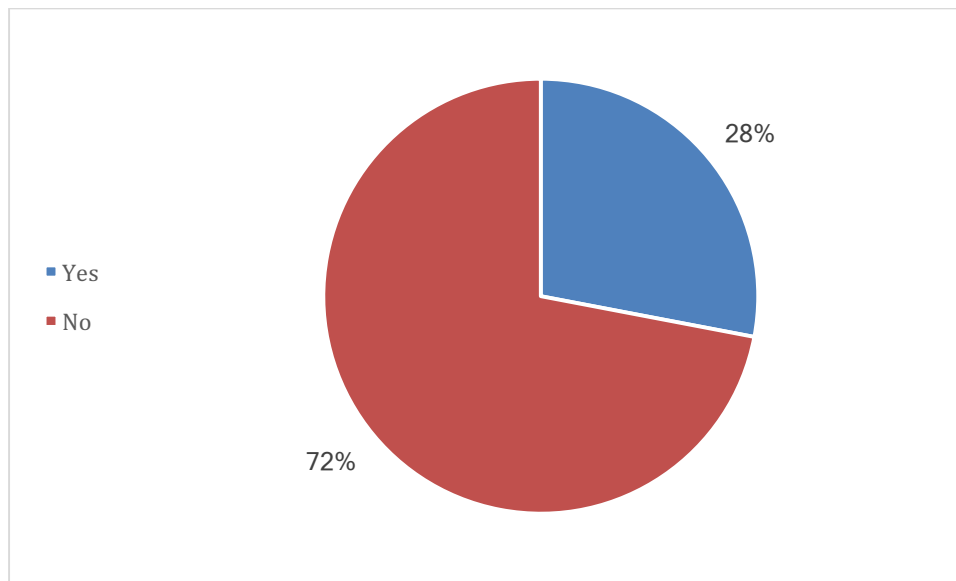
*"There is not enough knowledge or awareness. Given there is no set cure I often feel as though they almost shrug it off."*

*"After initial diagnosis (nearly 18 years ago) there has been very little, if any, monitoring or reviewing of my condition over the years."*

*"They have utterly no clue about latest developments in ME research, that it is a physical illness not a mental one, and they do not know how to treat it and have no interest in finding out. I am generally treated with open scepticism and contempt."*

*"My GP is very supportive with regard to benefit applications etc. and accepts ME as serious illness but has little specific knowledge of it, using the name Chronic Fatigue. Much of the advice is very general and not reflecting more recent research (e.g. they are unaware of the controversy over graded exercise therapy). I only see the GP every 18 months to two years for a courtesy appointment, for the purpose of giving up to date information in support of benefit applications. I get an annual phone call to confirm my medication list for repeat prescriptions. Routine bloods were taken in early years of my illness but no longer. Although the GP will do home visits if requested, reception staff in past have told me issues such as eczema, minor scalds/injuries etc. are not sufficient to warrant home visit so unless I'm very severely ill (e.g. needing antibiotics) most ordinary ailments people would be advised to see doctor or go untreated."*

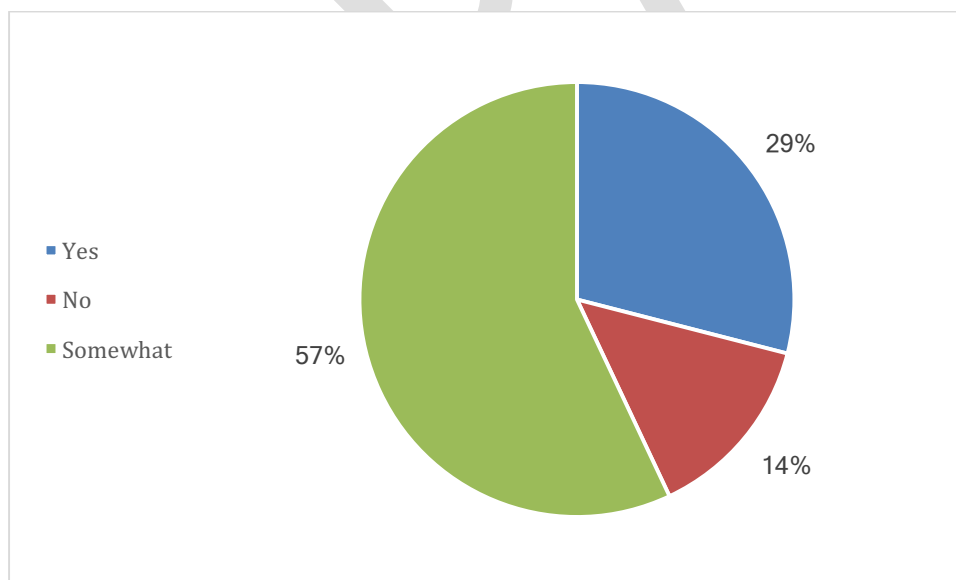
**14. We asked: 'Have you ever accessed any ME/CFS specialist care at a hospital?'**



72% of people said they have accessed ME/CFS specialist care at a hospital.

(39 out of 28 answered)

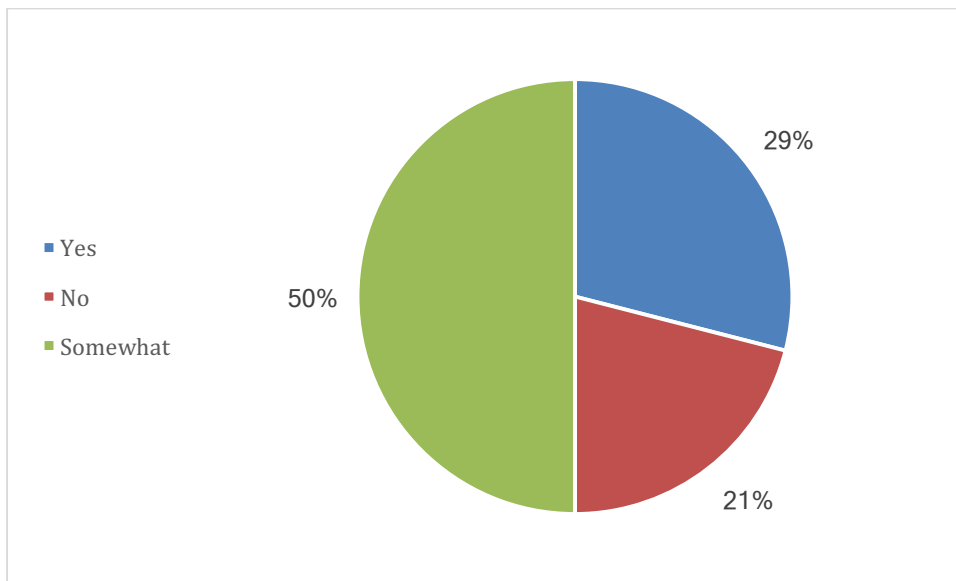
**15. We asked: 'If yes, did they understand your ME/CFS and accommodate you?'**



Over half of people (57%) said the hospital somewhat understood and accommodated their needs.

(14 out of 48 answered)

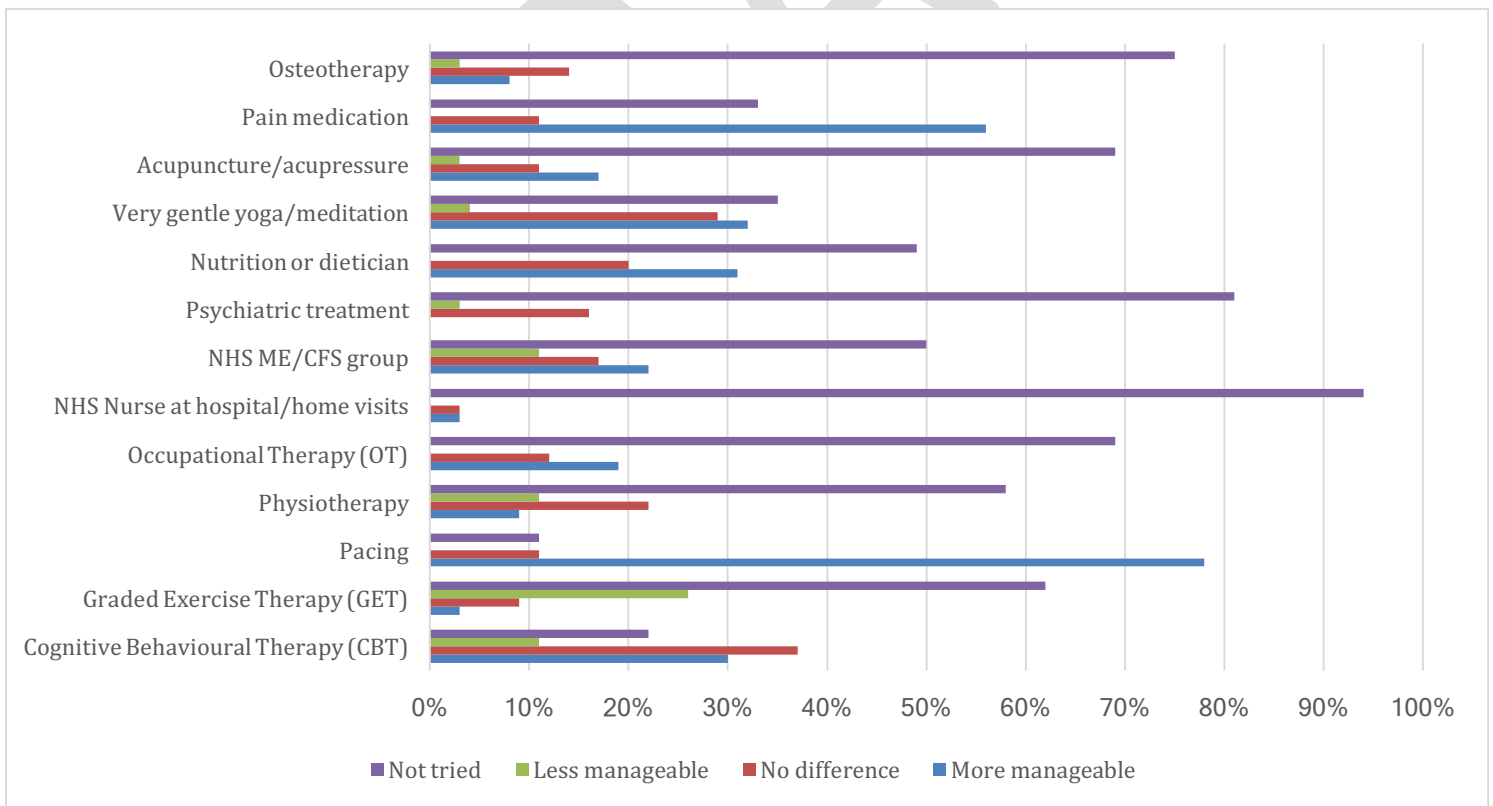
**16. We asked: 'Were the environment and services suitable?'**



Half of people (50%) said the environment and services in hospital were somewhat suitable for their needs.

(14 out of 48 answered)

**17. We asked: 'If you have used any of the following, did you find it made your ME/CFS more or less manageable?'**



### Pacing:

“Pacing’ is about balancing activity and rest to help manage M.E. and work towards recovery. The word ‘activity’ is used in a broad sense, to include mental and emotional activity, as well as the more obvious physical sort. To understand pacing it can help to think of your available energy as being like a mobile phone battery. If you completely drain the battery you have to wait to recharge it before you can use the phone again. If you use *some* of the battery and make regular top ups, then your phone will always be ready for use. The four key elements of pacing are: activity, rest and relaxation, establishing a sustainable baseline and increasing your activity as you are able. The principles behind pacing are not set in stone and there are different interpretations of how they can be applied.”

Information obtained May 2017 from:

<https://www.actionforme.org.uk/uploads/pdfs/pacing-for-people-with-me-booklet.pdf>

### Graded Exercise Therapy (GET):

“Graded exercise therapy (GET) is a structured exercise programme that aims to gradually increase how long you can carry out a physical activity. It usually involves exercise that raises your heart rate, such as swimming or walking. Your exercise programme will be adapted to your physical capabilities. GET should only be carried out with the help of a trained specialist with experience of treating CFS/ME and, if possible, it should be offered on a one-to-one basis. After finding out what you can already do comfortably, the length of time you exercise and the intensity will gradually be increased.”

Information obtained May 2017 from:

<http://www.nhs.uk/Conditions/Chronic-fatigue-syndrome/Pages/Treatment.aspx>

### Responses to Question 17:

- The treatment or therapy with the highest number of responses saying it made people’s conditions *more manageable* is pacing (78%), followed by pain medication (56%) and very gentle yoga/meditation (32%).
- The treatment or therapy with the highest number of responses saying it made *no difference* to people’s conditions is cognitive behavioural therapy (37%), followed by very gentle yoga/meditation (29%) and physiotherapy (22%).
- The treatment or therapy with the highest number of responses saying it made people’s conditions *less manageable* is graded exercise therapy (26%), followed by cognitive behavioural therapy, physiotherapy, and NHS ME/CFS support group (11%).
- The treatment or therapy with the highest number of responses saying people had *not tried* them is NHS Nurse at hospital/home visits (94%), followed by psychiatric treatment (81%) and osteotherapy (75%).

### Summary:

- People said that pacing is the treatment/therapy that makes their condition *more manageable*.
- People said that cognitive behaviour is the treatment/therapy that made the *least difference* to their condition.
- People said that graded exercise therapy is the treatment/therapy that makes their condition *less manageable*.
- People said that NHS Nurse at hospital/home visits is the treatment/therapy that has been *tried the least*.



## Central Lancs ME/CFS Group:

Healthwatch Lancashire spoke to representatives from the Central Lancashire ME/CFS Support Group about:

- Their experiences supporting patients
- Local issues pertaining to treatment options and
- Other support services

*“Central Lancashire ME/CFS Support Group is a self-help group offering support, guidance and friendship to other sufferers. As the group is run mostly by fellow sufferers we understand the difficulties of dealing and living with ME/CFS.*

*We run regular meetings (both social and informative), organise speakers and produce quarterly newsletters. Members have access to our support workers, Helen and Lynn, and there is a library of magazines, books and CDs.*

*Scores of people have decided to join Central Lancashire ME/CFS Support Group because membership gives them:*

- *Clear, unbiased information on many aspects of ME*
- *Our newsletter, which keeps them up to date on ME news and members’ experiences*
- *Telephone help-lines*
- *Access to a library of books and relaxation tapes*
- *The opportunity to add their voice and be a force for change”*

*Information obtained in March 2017 from: <http://clancsme.org.uk/wp/>*

The Central Lancs ME/CFS support group were informed that in November 2016 the provision of treatment services for ME/CFS conditions were to be terminated. This has since prompted conversations between the support group and the local Clinical Commissioning Groups (CCGs).

In January 2017, Greater Preston and Chorley & South Ribble CCG’s met with the Central Lancs ME/CFS support group for a ‘Focus Group Meeting’ to discuss options for the future. During this, the CCGs explained the background for the integrated musculoskeletal services procurement and said that there would be specific provision for patients with ME/CFS within the service. The purpose of the meeting was to understand how patients experienced and evaluated the previous service and what they would want from the service in the future.

It was emphasised that the CCGs would listen to, and take on board all comments however they could not guarantee that the new service would include all features that the patients expressed a desire to have. It was also highlighted that the CCG had plans in place to provide an interim service before the new service went live.

The new service was expected to commence from November 2017 but is now expected in the spring of 2018.

Following this meeting, the CCGs made further contact with the support group to enquire about the scope of the support worker's role. The support group responded by sharing the job specification for their Lottery funded posts as well as sharing additional responsibilities that have arisen since the group has evolved. The support group now has a thriving closed Facebook group and communicate with their members more via social media and text (which is not mentioned in the job specification). The groups host more events than was originally envisaged and in more locations.

They also help members with appeals and tribunals, taking them to Disability Equality for their input and advice in the early stages, and accompanying members as reliable witnesses, as opposed to just transporting them, as their claims and distress increase. One support worker noted that they had personally spent several hours in the days leading up to one appeal going through the copious amounts of confusing paperwork with a member, and ensuring they understood everything whilst supporting them emotionally. The individual won their appeal and is now independent and confident, however, prior to this there was a definite need for counselling, emotional support, lots of procedural knowledge and understanding. It was noted that the cost is mileage, time and emotion between all parties is immeasurable.

Further to this, the CCGs have added that the process for procuring services differs slightly in that it is a competitive dialogue approach, where the specification will be developed in conjunction with the successful bidders in a co-design fashion. The impact of this is as it is a lengthier process the new service will not be mobilised until early 2018. The CCGs noted that all notes from the Engagement Meeting would be fed into the design of the service but because the specification will be co-designed it could potentially change and so no information would be shared with the support group yet. The CCG feel that taking the time to go through this process will result in a better and higher quality service in the end.

The CCG also stated that they were in conversations with Lancashire Care Foundation Trust regarding an interim service arrangement and that the support group would be updated about this.

The support group feel that the CCGs have been honest but the responses from other organisations have left them in the dark. The support group have been contacted by Virgin Care, who currently deliver the service, asking about what the services would involve and whether sub-contracting of the support group could be a potential route. The support group have responded to Virgin Care stating that they wish to engage in further discussion, however have had no further contact.

Similarly, the support group have been contacted by Lancashire Care Foundation Trust who wanted to know what the support group did. As the support group know

of no provision of NHS ME/CFS services across the rest of Lancashire they would be interested in speaking with Lancashire Care Foundation Trust and as their Lottery grant runs out in the next 13 months they are anxious to ensure their own survival as well as to ascertain information to address the questions they are often asked but can't answer. Again, the contact ceased once the support group responded.

The support group feel that the CCGs have been honest in their approach, however, there are still many issues that require addressing. The biggest of these issues is that the Central Lancs ME/CFS Support Group still remains the only support of its kind, and there are no services outside of this area.

The support workers gave an example whereby they were contacted by a parent with a child who suffers from ME who was being seen by a paediatrician outside of the support group area. When asked how they came across the Central Lancs ME/CFS Support Group, the parent said they had been told that the only treatment option available was to join the support group.

There are also concerns that if the new service is not in place and well established by March 2018, when the Big Lottery funding that enables the Central Lancs support group to employ their support workers may potentially run out, then there will not only be a loss of the support group itself, but also a wealth of expertise and resources that the group currently provides.

A support worker from the Central Lancs Support Group has been invited to join the evaluation panel to review the potential bids in the tender process.

## Conclusion

### What have we found out?

Around half of people said they received a diagnosis after a specialist referral. 13% went private or paid for a diagnosis. Over a quarter of people said the process from experiencing symptoms to receiving diagnosis took between 6 months and a year. 13% said this process took over five years.

A quarter of people said they had never received information from the NHS on how to live with their condition. The large majority of people said they would not trust their GP to provide them with information on their condition or were unsure whether they would. Nearly a quarter of people said their GP is neither knowledgeable nor supportive, however, the large majority of people said their GP always or mostly speaks with respect and fairness and listens.

Nearly a quarter of people said they have not been referred to any services following their diagnosis. The large majority of people said they had not been unable to access or refused any tests or treatments, although 18% said they had had difficulty accessing or been refused tests or treatments.

Most people said they have accessed ME/CFS specialist care at a hospital. Over half said the hospital 'somewhat' understood and accommodated their needs.

### What have we learnt?

*"Through our existing links with local ME/CFS support groups, we were already aware of some of the issues that are prevalent for this community of patients. Upon receiving intelligence from Healthwatch Trafford we were able to further contribute to the picture of Lancashire's experiences of these services. This project has allowed Healthwatch Lancashire to ensure our local communities had the opportunity to have their say, as well as supporting Healthwatch Trafford to have their findings recognised on a national level."*

Beth Tildesley (Project Officer, Healthwatch Lancashire)

### How will we use this?

- This report will be shared with local Clinical Commissioning Groups and NHS England.
- Healthwatch Lancashire will maintain its links with the Central Lancs ME/CFS Group and ensure we are present to monitor and changes or improvements that are made to services.
- Healthwatch Lancashire will share this report with Healthwatch England, noting that this is a direct contribution to Healthwatch Trafford's original project.
- Healthwatch Lancashire remains open to collaborative pieces of work with other local Healthwatch should the opportunity arise in the future.