

Patient Experience Report:

healthwatch
Trafford

Tired of explaining:

**Experiences of services for ME/CFS patients
in Trafford and Greater Manchester**

Summary report

April 2015– March 2016

Published March 2017



Acknowledgements

Healthwatch Trafford would like to give thanks to those that have contributed to the considerable amount of work that has gone in to producing this report.

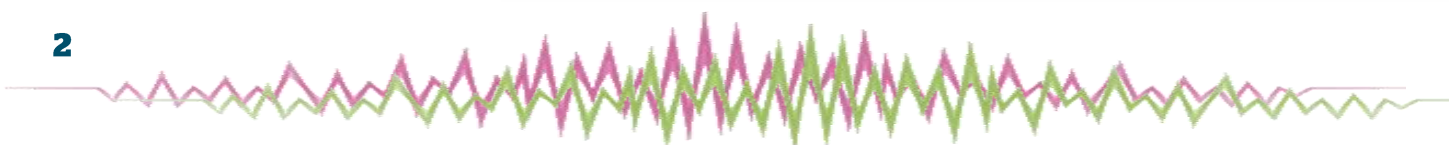
Joanna Melville, for her assistance for providing her insight into the report and on the report that she produced on Fibromyalgia using learning from this report whilst working on an internship with us from Manchester University.

Manchester Metropolitan University, specifically Stephen Walsh and Kevin Rowley, for the analysis and assistance in understanding the data we had collected.

Karen Morris, for the collaboration in design, inspiration, knowledge and experience, as well as considerable efforts in publicising the survey, without which we could not have constructed such a thorough piece of work with such a large number of responses.

All the support groups and organisations that have helped spread the word and shown interest in our work.

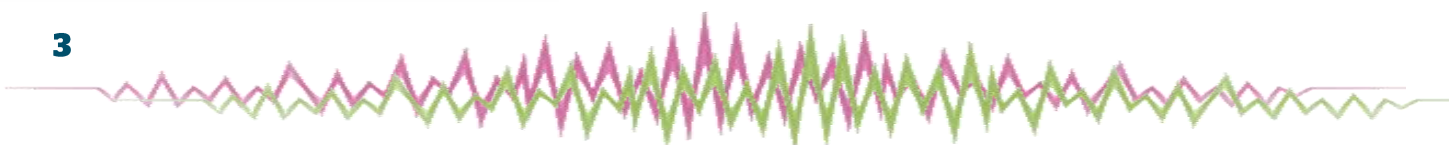
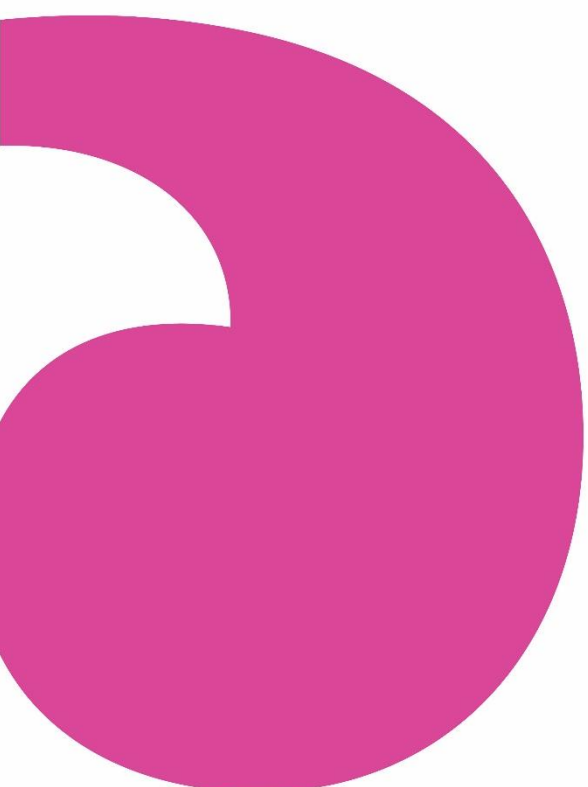
All those that have ME/CFS that took the time to complete the survey, without which this report would not exist.





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Introduction

This report concerns the experiences of people with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (known from this point onwards in the report as ME/CFS, ME or CFS) in Trafford and Greater Manchester. However, included within it for comparison, reference or background are the results we gathered from the rest of the United Kingdom.

In December 2014 Healthwatch Trafford was contacted by a Trafford resident who wanted to make a complaint about the way they had been treated by their GP. Part of the complaint was that they were treated badly because they said they suffered from ME/CFS, and that they felt this was not unusual amongst health care services.

Upon further discussion, we were told that these complaints were very common amongst those that had ME/CFS in the area and that there were plenty of people who would appreciate the opportunity to share their experiences of services in Trafford.

With this in mind we decided to set up a survey, giving people with ME/CFS the opportunity to share their experiences of local services in a systematic manner, hopefully giving us information that can provide us with the insight to see where the problems lie. The survey was created and put online at the end of April 2015.

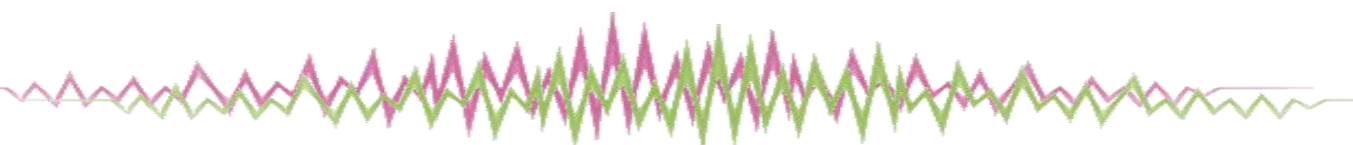
It was shared via the Healthwatch Trafford website, social media and via local ME/CFS networks. Not only did we hear from people in Trafford, but also Greater Manchester and across England.

The survey proved to be very popular and was circulated widely. To date, it has had more than 1000 responses. Whilst it remains open for people to continue to let us know their experiences, this report only uses responses collected from the survey being launched in April 2015 to March 2016.

The survey can be found on our website at

<http://healthwatchtrafford.co.uk/get-involved/surveys/>

Find the complete set of results and our findings in the full report 'Tired of explaining : Experiences of services for ME/CFS patients in Trafford and Greater Manchester' which can be found on our website at Healthwatchtrafford.co.uk/about-us/our-reports.





Executive Summary

ME/CFS is a condition that has a number of problems that make its effective treatment very difficult. Chief amongst these is the fact that it isn't really understood, and so many medical professionals and professional bodies cannot agree on what it is, its cause and what to do about it. Because of this, many people with the condition observe they are experiencing poor treatment, often making their condition worse. With some medical professionals treating it purely as a psychological problem, the physical aspects are not. From the point of view of Healthwatch Trafford, the cause and nature of the condition is unimportant, whereas the treatment, experience, dignity and respect that all patients are due under the NHS Constitution is paramount.

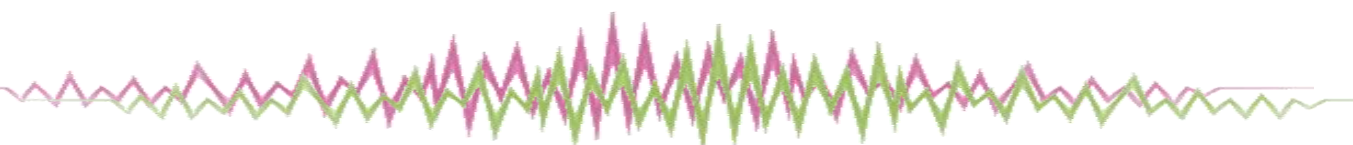
There is not national recognition of the condition's seriousness for those with it, with the nickname that appeared in the 1980's 'yuppie flu' trivialising it, yet living in memory. The reality is that 94% of our survey respondents had moderate to severe symptoms, meaning they were unable to work or study full-time. 74% had it for 5 years or more, with a quarter having had it for more than 20 years. So it is a condition that is significant for the NHS, the economy, for family and carers but most importantly for those suffering.

The survey responses pointed to problems with General Practice. The perception of service users is that levels of knowledge of the condition amongst GPs across the board appears unacceptably low. The clear majority feel that their GP was not knowledgeable about ME/CFS and a large portion of people felt that their GP was not supportive. Trust and confidence in a GP is hugely important, and not having that causes a number of knock-on effects - people don't trust advice, warnings, treatment plans and often diagnosis. Specific training of GPs in the subject would improve this and rebuild the confidence and trust of those that need it most, and remove the variability in the standard of treatment that seems to come with differing beliefs GPs have about the condition. The fact that there are those that said their GP was supportive (or even 'amazing') shows that excellent care is possible and indeed is being delivered already by some.

There is a significant variation in the availability and quality of information that people are being given about ME/CFS. Many receive nothing at all, and the standard of what those that are lucky enough to receive anything get, seems to fluctuate. The dangers of this are that people are forced to find their own information, the sources of which are often unknown and are of dubious quality or credibility. There is a real need for a standardisation across the board of the information available, which needs to be easily accessible and understandable, with an emphasis on quality. This will help people to understand necessary lifestyle changes, treatments and expectations.

It is also apparent from service user's experiences that there is a shortage of specialists, specialist clinics and treatments leading to long waiting times for those that need them. This delays diagnosis, and therefore treatment, of many. Addressing this will have significant benefits for those that are left suffering waiting for treatment or diagnosis. There are also a number of other barriers to treatment and diagnosis, including the distances that people are expected to travel for appointments, lack of 'remote appointments' and inappropriate appointment timings that can be the difference between seeing a specialist and getting treatment or being left to cope without it, often making things much worse.

Hospitals are seen to be unsuitable for those with ME/CFS. Service users feel staff in hospitals have particularly low understanding or knowledge of the condition and often





misunderstandings can cause problems. The environments are often not suitable either, with lighting, noise, visits among other things making rest incredibly difficult, especially important with a condition that is typified by non-restorative sleep at the best of times. This can exacerbate symptoms, both of the ME/CFS itself as well as any co-occurring conditions.

Many don't know how to access their medical records and are not supported to do so, meaning it can be difficult for them to keep track of their treatment or progress. Cognitive difficulty (e.g. 'brain fog'), which is often a significant part of ME/CFS, can make it hard for people to understand and remember what they are told in appointments, so assisting them to access their records could be a major help in keeping themselves on track.

Responses also suggested the 'pushing' of certain treatments from medical professionals meant that people often felt ignored or abandoned if these approaches were deemed unsuccessful. As with any other condition, approaches need to be suitable for the individual and must be reassessed once they have been tried for effectiveness. This will again improve the trust these patients have in those treating them and likely lead to better results.

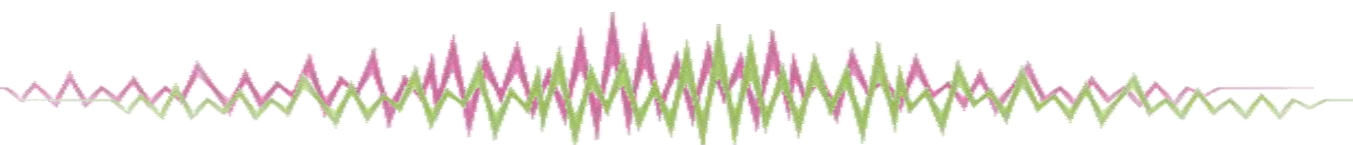
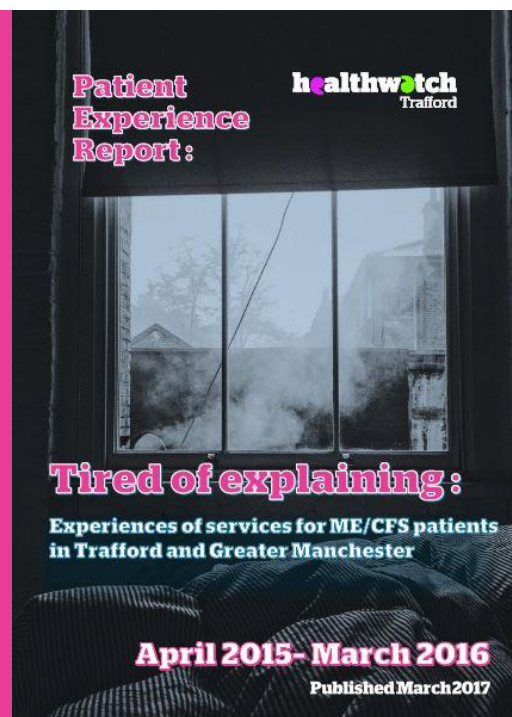
In summary, it seems that some simple changes and improvements could potentially make a huge difference in the experience of treatment for those with ME/CFS. It is reasonable to suggest that this would also improve the quality of treatment and adherence to it, improving outcomes. This in turn could reduce the financial burden of the condition on the health and welfare services, benefitting everyone.

As a final point, many of the recommendations made in this report could equally apply to other neurological conditions, such as Fibromyalgia and are not just specific to ME/CFS.

Find the complete set of results and our findings in the full report

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Recommendations

After thoroughly studying the findings of this report, it has become clear that many of the issues faced by those with ME/CFS in Trafford are the same as those in Greater Manchester, England and the rest of the UK. Improvements are needed nationwide on the way the condition is handled, so the recommendations made below are applicable to the NHS well beyond Trafford and GM.

1. General Practitioners require thorough training on ME/CFS

GPs need better training on the condition:- what it is, how to identify it, how to treat it. They need to be made aware of the specialists and services that are available and when to refer to them. They need to have a more standardised and compassionate way of treating these patients that is not dependent on their personal beliefs about ME/CFS and if they think it is a biological or a psychosocial issue.

By being more compassionate and less judgemental, they can help improve the trust people with ME/CFS have in their GP and improve their treatment experience. This in turn can help with the mental wellbeing of the patient (with them feeling they have been listened to and believed), as well as making it more likely that they will follow instructions and treatments given.

Across the UK

76%

of respondents
felt their GP **was not knowledgeable**
about ME/CFS

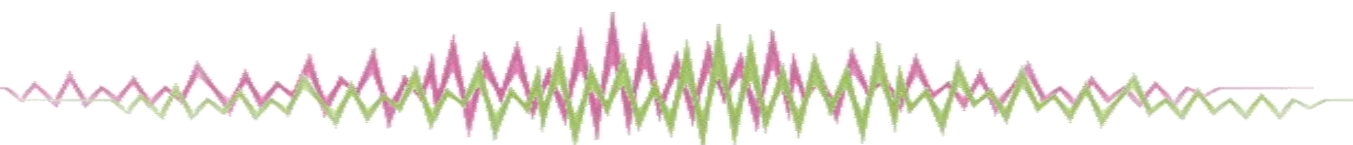
2. Diagnosis times to be improved

In Greater Manchester

68% took **longer than a year** to get a diagnosis.

A quarter waited **more than 5 years**

As most people are diagnosed by a specialist, referrals to specialists need to be made sooner. This may also require an increase in the availability of specialist clinics and appointments. As we have seen links with the amount of time it took to get a diagnosis and the number of GP appointments required per year, we can see a benefit to the system of diagnosing the condition faster, as well as a huge benefit to those diagnosed, who can then get information and start treatments to manage it.





3. Information on ME/CFS to be improved and standardised

It is so important that people get quality information about the condition and its management as soon as is possible as this has a huge impact on a number of things: It builds confidence and trust in GPs, gives people help knowing what to expect and how to manage themselves and stops people looking for information elsewhere of questionable value and origin.

If a standard of information could be agreed upon it would stop variation across the region (and country) and make it much easier for GPs to find and trust themselves.

Across the UK,
more than a third
of people diagnosed
with ME/CFD get
no information
from the NHS.

In Trafford,
it's more than half.

4. Clear mapping of services

A clear mapping of ME/CFS services, clinics, specialists and pathways in the region would help both GPs and patients understand what is available. In the course of producing this report we found that even those within Clinical Commissioning Groups and NHS Foundation Trusts that provided or funded ME/CFS treatments were not easily able to find out what services they provided. Improving this will help GPs in their jobs which in turn would help increase confidence and trust in them, as well as giving patients a realistic idea of what they can expect.

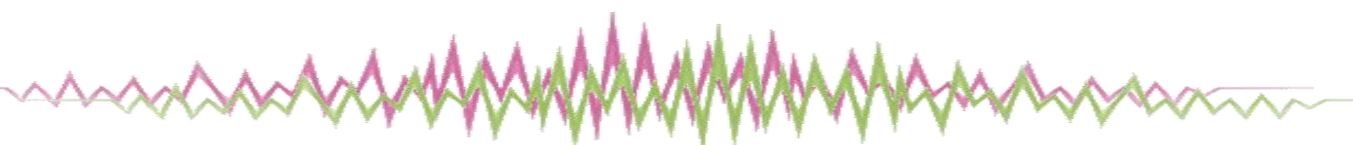
5. Improvements in the appointments offered

Appointments with GPs and specialists could be improved to make them more effective and more accessible for those with ME/CFS in the following ways:

More consistency across appointments - effective handling of medical records so that the patient doesn't have to explain their situation from scratch on every visit. This helps to increase the effective 'treatment time' within the appointment. Also meaning more of a consistent approach from different GPs, so that when seeing a different one, treatment isn't entirely different. This relates directly to recommendation 1.

"I tend to see the GP on good days, otherwise I am not well enough to see the GP"

Increased availability of 'remote' appointments - A part of the condition is chronic fatigue and low energy levels, as well as cognitive impairment. This often means travelling to an appointment can be difficult, if not impossible. Being able to offer 'remote appointments'





where appropriate could be an effective way of ensuring that those that are too unwell to travel (and are often most in need) do not miss out on important consultations.

Longer appointment times or double appointments - ME/CFS is a complex condition and can often complicate and exacerbate other conditions considerably. This, along with the cognitive impairment that is often a symptom ('brain fog'), can make it difficult to understand or be fully understood in an ordinary, relatively short GP appointment. By giving more time, the likelihood of being understood and taking information in, or being able to write it down increases, further improving confidence and trust in the GP and the patient experience.

6. Help patients understand how to access their medical records

Lots of people didn't know how to access their medical records, so helping them understand would have many benefits.

If patients were able to access their records, it would help them to keep track of their treatment, as well as the results of tests they have had. It would also give them the opportunity to check their diagnosis and give them the ability to challenge anything they think is inaccurate (which seems to happen more with people with ME/CFS). This could be equally applicable to those with other conditions, or even across the board for all NHS patients.

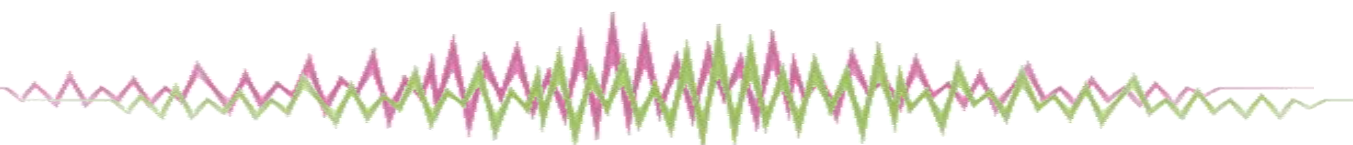
41.8%
don't know how
to access their
medical records
in Greater Manchester

7. Improved training and facilities in hospitals for in-patient stays

40.6%
said the hospital environment **was not suitable** for them in Greater Manchester, citing **poor facilities, noise and lack of knowledge** of the condition amongst staff as the **main concerns**

Better training and awareness of the condition amongst staff will greatly help the treatment, care and experience of those with ME/CFS when staying as an inpatient. As with GPs, this would increase confidence and trust, as well as helping to ensure that they are treated with dignity and respect - nobody should be called "lazy" by staff.

For a condition where quality of rest is essential, problems with light, noise, food and other factors can really hamper recovery. Improving this for patients with ME/CFS would greatly help their experience, as well as likely improving recuperation. This could involve reducing noise around the patients where possible, less bright or flashing lighting or timing visits to disturb rest as little as possible.





Background

Myalgic Encephalomyelitis/Myalgic Encephalopathy (ME) is an illness of unknown cause that causes tiredness and fatigue that doesn't go away with sleep or rest. The condition is known by many other names, including Chronic Fatigue Syndrome (CFS) as it is known by the NHS, Post-Viral Fatigue Syndrome (PVFS) and more recently Systemic Exertion Intolerance Disease or SEID, which is more common in the USA (popularised following rejection by many patients of the term Chronic Fatigue Syndrome/CFS). For the purposes of this report and the survey contained within it, the designation ME/CFS is used.¹

There are also several symptoms associated with the condition which some people may or may not suffer with, including;²

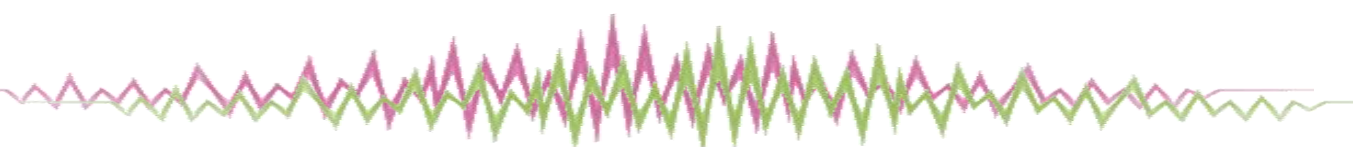
- muscular pain, joint pain and severe headaches
- poor short-term memory and concentration, and difficulty organising thoughts and finding the right words ("brain fog")
- painful lymph nodes (small glands of the immune system)
- stomach pain and other problems similar to irritable bowel syndrome, such as bloating, constipation, diarrhoea and nausea
- sore throat
- sleeping problems, such as insomnia and feeling that sleep isn't refreshing
- sensitivity or intolerance to light, loud noise, alcohol and certain foods
- other possible symptoms, such as dizziness, excess sweating, balance problems and difficulty controlling body temperature
- psychological difficulties, such as depression, irritability and panic attacks

It is a well-known but little understood condition, with no general consensus around its cause and nature. There is a lot of debate over this, with most of it falling outside the remit of this report, but what is important is that there are many people suffering with the condition (an estimated quarter of a million people in the UK according to NHS Choices) and yet the quality of care these people are receiving, and the knowledge of the condition - that the health professionals dealing with these people have - is being called into question.

In the course of carrying out this survey and creating this report, we have become aware of what a politically charged condition ME/CFS is. It is one which people feel very strongly about and that splits professional opinion. There are regular contradictions associated with it, such as health insurance companies classing it as a psychological illness (and therefore not covering it) yet anyone with ME/CFS is not allowed to give blood. Healthwatch Trafford is not making any kind of a judgement on this debate, but is focussing on the fact that, regardless of the cause and nature of the condition, those with it should be able to access good quality services and treatment within the NHS.

¹ There is much debate over what name is most suitable, as many feel CFS or PVFS are not representative of what they have. This is not a debate that Healthwatch Trafford is qualified to enter into and for the purposes of the report we have used ME/CFS as they are simply the most commonly used designations amongst those we have spoken to.

² List of symptoms taken from the NHS Choices webpage on CFS symptoms <http://www.nhs.uk/Conditions/Chronic-fatigue-syndrome/Pages/Symptoms.aspx>





Methodology

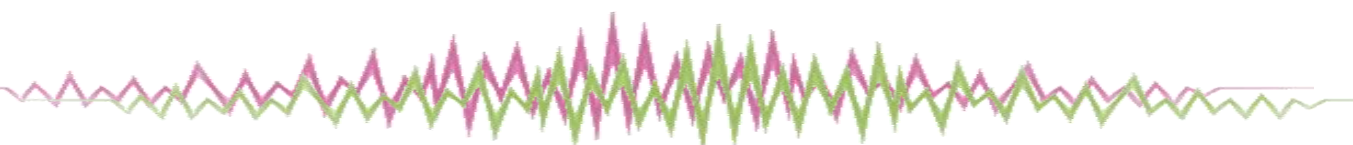
The Survey was designed with input from a number of sources, to all of whom we are very grateful. The questions were designed to gather a mix of qualitative and quantitative information on services in the Trafford location. With the focus on Trafford, the questions were picked to highlight the specific local services (GPs & Local Hospitals). These experiences were to enable evaluation of these services in order to provide specific recommendations. The survey's purpose was specifically an experience gathering exercise and not clinical or medical research.

To reach as many people as we could in the borough within our available resource, we decided the medium of an online survey would be most appropriate. This would give us the opportunity to spread it quickly via our social media accounts, as well as allowing us to email links to those local networks that might be interested in the survey.

We also printed a number of copies to allow people to fill out the survey by hand if that would be more appropriate for them or if they didn't have access to an online computer or internet connected device, and a number of these were sent out to people that requested them.

The survey was constructed using SurveyMonkey and the link to it and to the page on our website where the survey was embedded were shared.

The results were then collated and analysed. You can find the question specific findings following the results section.





Points to note

The survey was primarily aimed at Trafford as at Healthwatch Trafford, our remit only extends to the services that people who live and work in Trafford use. We felt it would be beneficial to allow others to fill in the survey to provide regional and national context to what is happening, allowing us to potentially see where things are being done well and where areas need to improve. Also it is difficult to separate areas entirely as many services overlap (for example people from Trafford being referred to Salford Royal NHS Foundation Trust or other areas for treatment or from other areas to Trafford. However as soon as it was made public, it became quickly apparent that there were a lot of people outside the borough who feel passionately about the subject and wished to share their experiences.

Any surveys filled in by people in other Local Healthwatch areas will have their results passed on to the relevant Healthwatch so they can decide if they wish to take any action. The report will also be passed on to Healthwatch England so they can decide what they wish to do with the findings.

It must be made clear that we at Healthwatch Trafford are not researchers. The links, patterns and trends we have found in the data and suggested explanations we have made are speculative, made with the knowledge and experience we have available. However, these are merely our interpretations of the information and should be recognised as such.

The survey proved to be much more popular than we could have imagined, and this has increased the time it has taken to go through it.

In the data that follows, the focus is on that of Trafford, with results of Greater Manchester included for its relevance to services in the area and the amount of cross-boundary treatments. Results from Greater Manchester (henceforth referred to as GM) include Trafford results.

Results from the rest of the country are included for comparison and to provide a national context. They include results from the whole of the United Kingdom of Great Britain and Northern Ireland, but does not include the Isle of Man or other Crown Dependencies. It is referred to in the results as UK or 'Rest of UK' (excluding Greater Manchester). Some of the results compared are more locally targeted with comparison to the rest of England.

This report acknowledges there is variation around the country with the type of medical professionals seen by respondents, which could include psychologists and physiotherapists and other medical professionals as referenced in the NICE guidance³ but it is beyond the scope of this report to compare the incidence, effectiveness or appropriateness of these approaches.

There is scope for deeper analysis and investigation of the results in this report, particularly with comparison to existing statistics and information on the condition, however limited resources available mean that we are currently unable to invest further time into it.

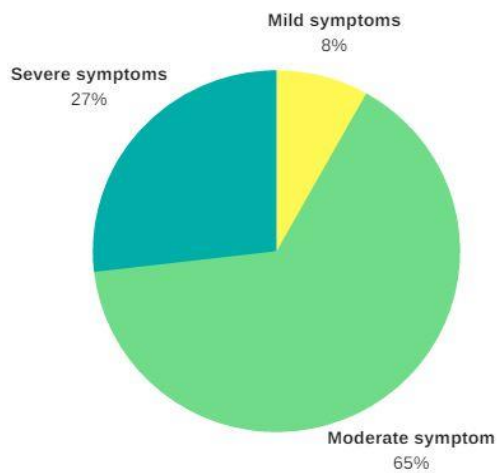
It must also be noted that due to the nature of the condition - symptoms such as 'brain fog' and fatigue will have affected the completion rate of this large survey, meaning the rate of people answering questions drops off as the survey progresses, which is to be expected.

³ National Institute for Health and Care Excellence (NICE) clinical guideline [CG53]
<https://www.nice.org.uk/guidance/cg53/ifp/chapter/Specialist-CFSME-care>



Key results

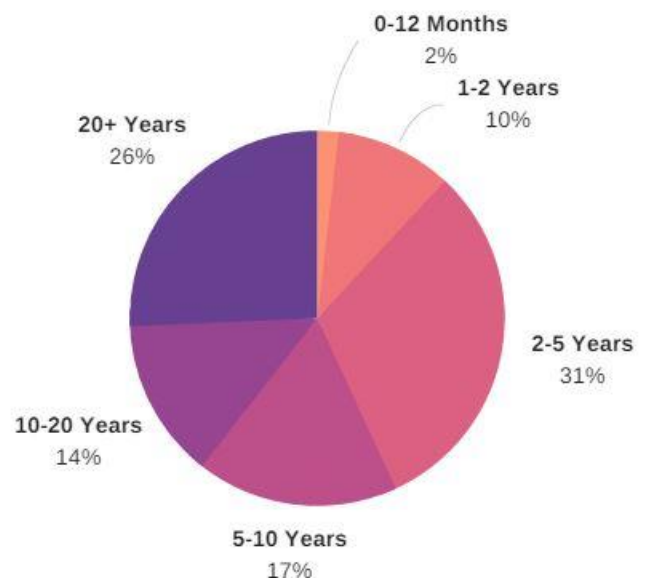
The full range of results are available in the full report, available at Healthwatchtrafford.co.uk/about-us/our-reports



In **Greater Manchester** **91.9%** of people with ME/CFS are unable to work or study because of their condition

77% have had ME/CFS for **5 years or more.**

34.7% for **more than 15 years**



In Greater Manchester

52% of those with ME/CFS are

disabled

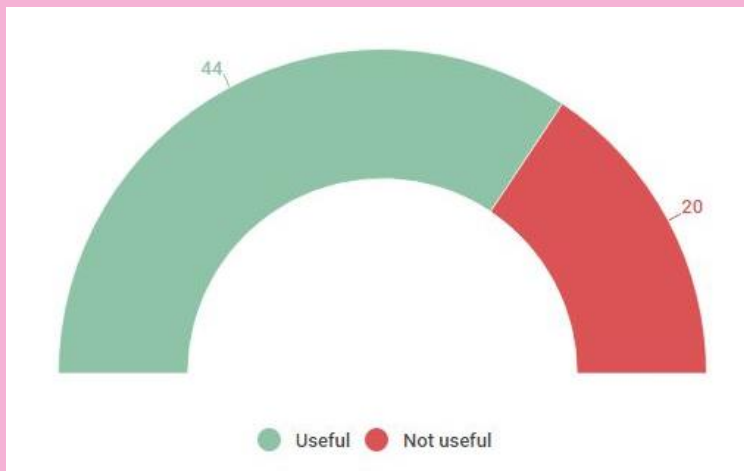
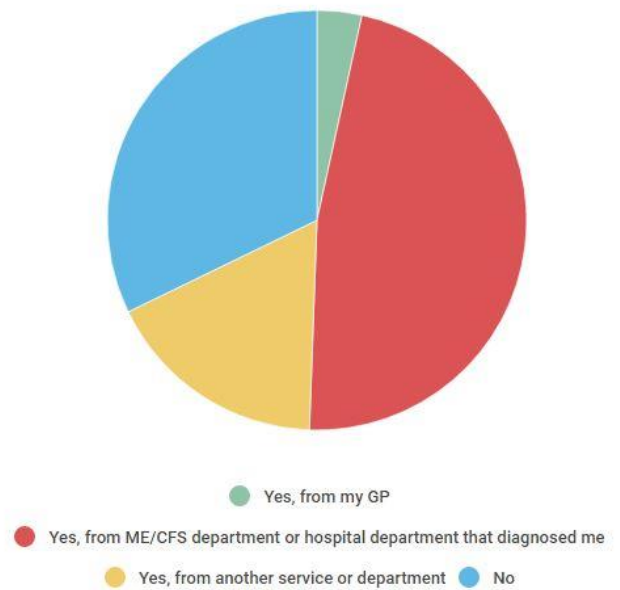
and not able to work





Across the UK,
more than a third
of people diagnosed
with ME/CFD get
no information
from the NHS.

In Trafford,
it's more than half.

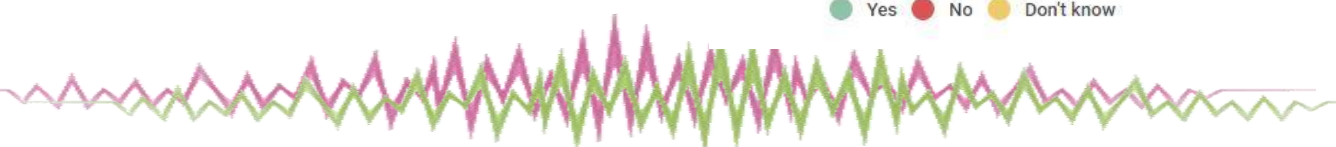
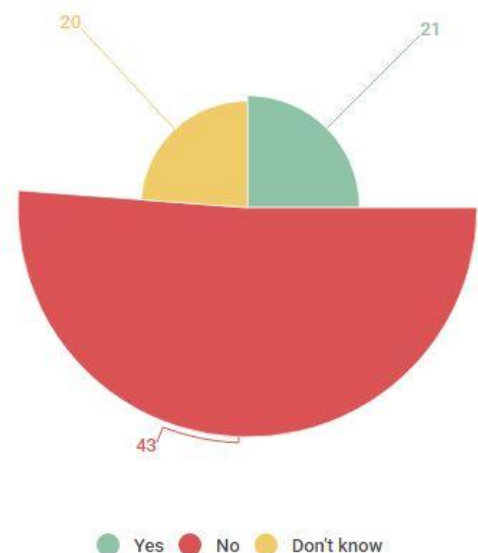


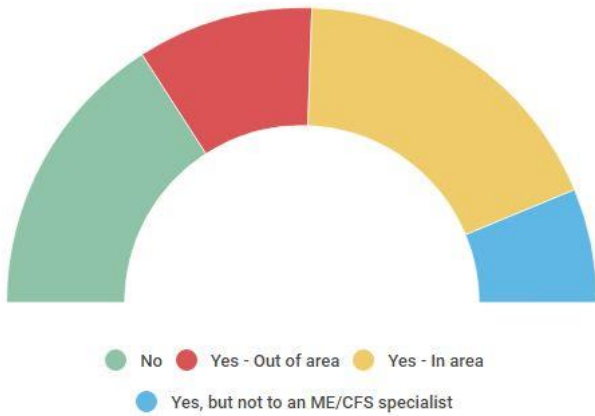
40% that
did get info
said it **wasn't**
useful

In Greater Manchester

51%

said they **wouldn't trust**
their GP to provide them with
information about ME/CFS



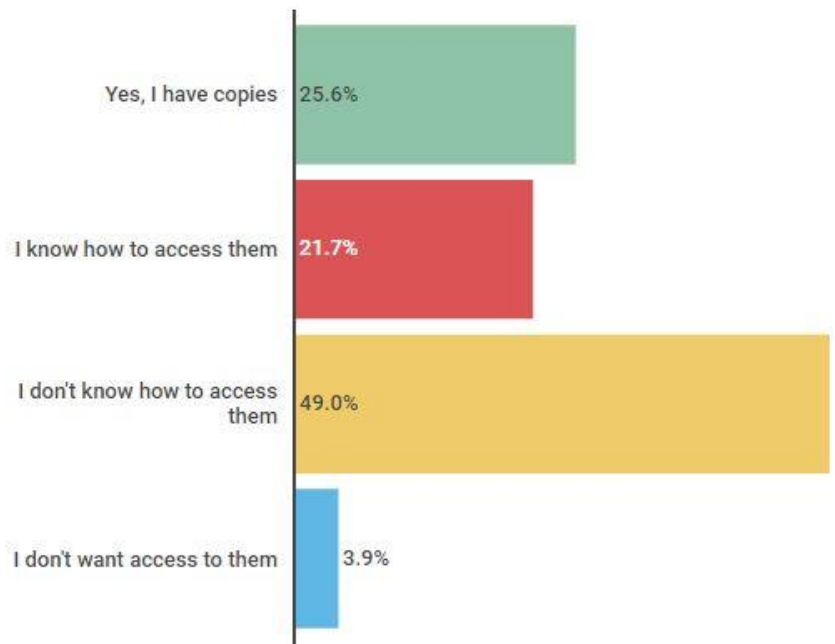


31.8% of respondents in **GM** have never been referred to an **ME/CFS specialist**.

In **Trafford** its **36%**

49%

did not know how to access their medical records across the UK



Only 9.4% of respondents in **GM** said that In-patient facilities were **suitable** for them.

40%

said they were **unsuitable**.

"I do not say I have ME - people just don't understand it."

"...it all worries me how I would cope if ever I needed to go into hospital"

"They didn't understand ME."

"Wasnt allowed my meds and treated like I was making it up!"

"ME patients are exhausted and not just tired. When a senior nurse says you must get out of bed it is not always appropriate."



Find the complete set of results and our findings in the full report 'Tired of explaining : Experiences of services for ME/CFS patients in Trafford and Greater Manchester' which can be found on our website at Healthwatchtrafford.co.uk/about-us/our-reports.



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