Patient Experience Report:

healthwatch
Trafford

Tired of explaining:

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

April 2015- March 2016

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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.

Contents

Introduction

This report concerns the experiences of people with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (know 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/

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.

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.

2. Diagnosis times to be improved

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.

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.

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.

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

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 impatient. 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.

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[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 quantitive 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 guidance[3] 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.

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

Results

The survey results can be found in this section. National and regional information is provided alongside Trafford data in most cases where appropriate to add context or ‘weight’ to the validity of the answers.

Some answers are not included as they are not relevant to the report (specifically, the questions regarding the survey itself and how to improve future surveys). Qualitative answers only cover the area stated on each set of answers. Due to the labour intensive nature of coding the responses, it was not possible to go through all of the answers we received from across the entire country.

Location

1. What is your local authority (local council)?
2. UK Region (Where applicable)

ME as a condition

3. How would you describe your current level of ME/CFS
4. How long have you had ME/CFS?
5. What has been the main factor/s or trigger/s for your ME/CFS?
6. Have you had a formal diagnosis from a doctor?
7. If yes - How were you diagnosed?
8. Have you been offered any information from the NHS on living with the condition?
9. If yes, was that information helpful?
10. If you have used any of the following, did you find it made your ME/CFS more or less manageable?
11. Is there anything else you would like to tell us about managing your condition?

GPs

12. What is the name and address of your GP Surgery?
13. How long did it take to be diagnosed after first reporting symptoms to your GP?
14. How does your GP talk about your condition?
15. Would you trust your GP to provide you with information about ME/CFS?
16. Has your GP referred you to ME/CFS services?
17. Has a GP ever come out to you because you couldn’t attend the surgery?
18. How often do you see your GP on average each year?
19. Would you say your GP/s speak to you with respect and fairness, listening to you?
20. Have you ever been unable to access or been refused tests or treatment?
21. Is there anything about GP services you would like to mention?

Hospitals

22. What hospitals do you regularly use?
23. What was the hospital you used MOST RECENTLY
24. Have you accessed any ME/CFS specialist care at a hospital?
25. Do you find most (non specialist) hospital staff have knowledge of or understand your condition?
26. Would you say hospital staff speak to you with respect and fairness, listening to you?
27. Where appropriate, have you been able to access phone, email, online or home visits? E.g. test results, making appointments, etc.
28. Is there anything about hospital services that you would like to mention?
29. Have you ever been an in-patient whilst having ME/CFS?

30. If yes, did they understand your ME/CFS and accommodate you?
31. Were the environment and services suitable?
32. Is there anything else about in-patient services you would like to mention?

Complaints

33. Have you ever complained to PALS (the Patient Advice Liaison Service) or a Practice Manager?
34. If yes, what was the response you received?
35. Have you ever complained to NHS England, the Local Government Ombudsman (LGO), or the Parliamentary and Health Service Ombudsman (PHSO)?
36. If yes, what was the response you received?

Medical Records

37. Do you have copies of your medical letters/records or know how to access them?

Demographics

38. Do you identify as;
39. What is your age?
40. Which of the following best describes your current relationship status?
41. Which of the following categories best describes your employment status?
42. How would you describe your ethnicity?
43. Sexual orientation

Survey specifics

44. How did you find out about this survey?
45. How easy was it to complete?
46. How could our surveys be improved in the future?

Results Data

In total, there were 147 responses from Greater Manchester, of which 47 were from Trafford.

Location

1. What is your local authority (local council)? (Within GM)

LOCAL AUTHORITY	% OF RESPONDENTS	NO. OF RESPONDENTS
TRAFFORD	32.0%	47
MANCHESTER	11.6%	17
SALFORD	20.4%	30
BOLTON	8.2%	12
STOCKPORT	6.1%	9
ROCHDALE	5.4%	8
WIGAN	11.6%	17
BURY	2.7%	4
TAMESIDE	0.7%	1
OLDHAM	1.4%	2

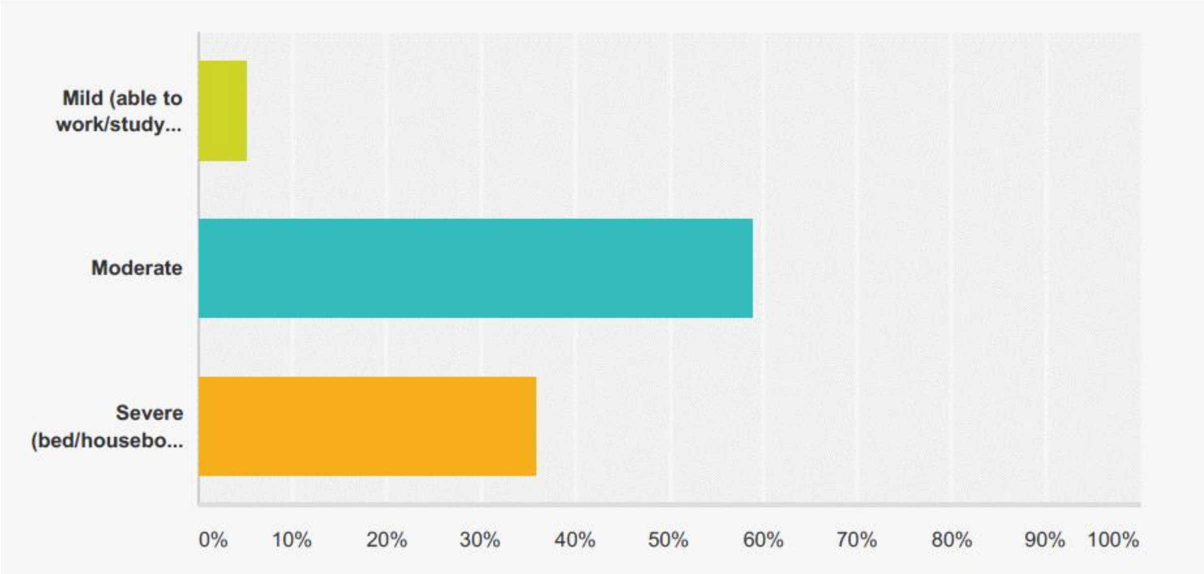
2. UK Region (Where applicable)

From a total of 915 overall, the 147 from Greater Manchester.

ME as a condition

3. How would you describe your current level of ME/CFS?

Trafford		
Answer Options	Response Percent	Response Count
Mild (able to work/study full-time)	5.1%	2
Moderate	59.0%	23
Severe (bed/housebound)	35.9%	14
answered question		39
skipped question		8



GM		
Answer Options	**Response Percent**	**Response Count**
Mild (able to work/study full-time)	8.1%	10
Moderate	65.0%	80
Severe (bed/housebound)	26.8%	33
answered question		**123**
skipped question		**24**

UK		
Answer Options	**Response Percent**	**Response Count**
Mild (able to work/study full-time)	10.6%	78
Moderate	58.2%	427
Severe (bed/housebound)	31.2%	229
answered question		**734**
skipped question		**104**

4. How long have you had ME/CFS?

Trafford		
Answer Options	Response Percent	Response Count
12 months or less	0.0%	0
1 to 2 years	17.9%	7
2 to 5 years	7.7%	3
5 to 10 years	20.5%	8
10 to 15 years	23.1%	9
15 to 20 years	10.3%	4
20 years or more	20.5%	8
answered question		39
skipped question		8

GM		
Answer Options	Response Percent	Response Count
12 months or less	1.6%	2
1 to 2 years	8.9%	11
2 to 5 years	12.1%	15
5 to 10 years	27.4%	34
10 to 15 years	15.3%	19
15 to 20 years	12.1%	15
20 years or more	22.6%	28
answered question		124
skipped question		23

UK		
Answer Options	Response Percent	Response Count
12 months or less	1.9%	14
1 to 2 years	6.6%	49
2 to 5 years	16.0%	119
5 to 10 years	23.4%	174
10 to 15 years	17.9%	133
15 to 20 years	13.6%	101
20 years or more	20.7%	154
answered question		744
skipped question		94

5. What has been the main factor/s or trigger/s for your ME/CFS?

Multiple responses were allowed(% is number of people that gave each answer)

Trafford		
Answer Options	Response Percent	Response Count
Virus or infection e.g. (Glandular Fever etc.)	74.4%	29
Traumatic event, operation or accident	12.8%	5
Vaccination/Inoculation or drug treatment (e.g. Hepatitis B vaccination etc.)	12.8%	5
Physical / Environmental substances (e.g. toxins, elements or fumes etc.)	12.8%	5
Hormonal problems	15.4%	6
Another illness e.g. cancer	15.4%	6
Parasite(s)	0.0%	0
Stress, Depression or other mental health issue	35.9%	14
Lifestyle (E.g. Eating habits, extreme exercise, recreational drugs, sleeping patterns etc.)	7.7%	3
Other (please specify)	15.4%	6
answered question		**39**
skipped question		**8**

Answers specified as 'Other'

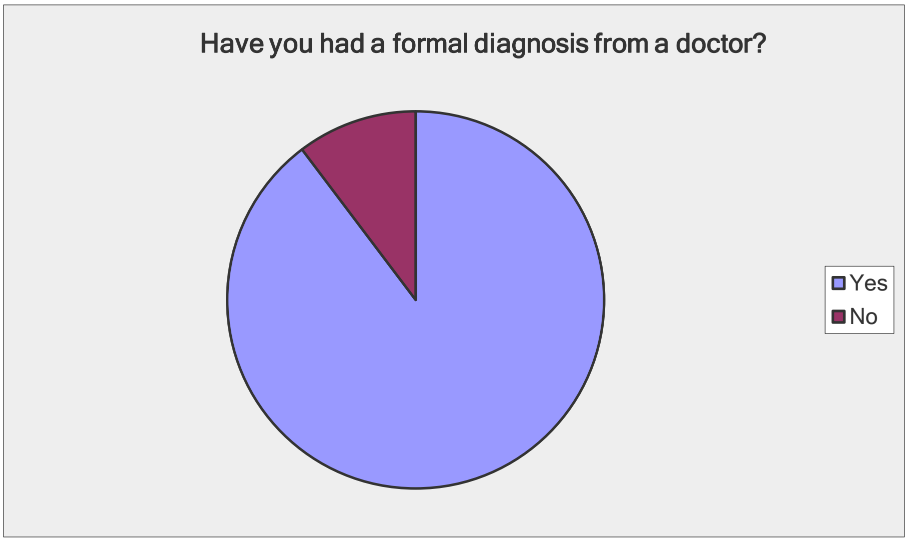
Bitten when on a visit to USA.
Burnout from work - having unrelenting standards.
Pregnancy
No evidence-based trigger, only suspicions.
Stressful lifetime events death, divorce, Ill child over a period of years.
Significant life events, divorce bereavement chronic illness in the family over a number of years whilst holding down high pressured job.

GM		
Answer Options	Response Percent	Response Count
Virus or infection e.g. (Glandular Fever etc.)	71.8%	89
Traumatic event, operation or accident	19.4%	24
Vaccination/Inoculation or drug treatment (e.g. Hepatitis B vaccination etc.)	8.9%	11
Physical / Environmental substances (e.g. toxins, elements or fumes etc.)	10.5%	13
Hormonal problems	12.1%	15
Another illness e.g. cancer	8.1%	10
Parasite(s)	0.0%	0
Stress, Depression or other mental health issue	26.6%	33
Lifestyle (E.g. Eating habits, extreme excercise, recreational drugs, sleeping patterns etc)	6.5%	8
Other (please specify)	21.0%	26
answered question		**124**
skipped question		**23**

UK		
Answer Options	Response Percent	Response Count
Virus or infection e.g. (Glandular Fever etc.)	72.9%	549
Traumatic event, operation or accident	20.1%	151
Vaccination/Inoculation or drug treatment (e.g. Hepatitis B vaccination etc.)	8.2%	62
Physical / Environmental substances (e.g. toxins, elements or fumes etc.)	5.7%	43
Hormonal problems	8.6%	65
Another illness e.g. cancer	3.6%	27
Parasite(s)	0.8%	6
Stress, Depression or other mental health issue	23.6%	178
Lifestyle (E.g. Eating habits, extreme excercise, recreational drugs, sleeping patterns etc)	6.4%	48
Other (please specify)	17.7%	133
answered question		753
skipped question		85

6. Have you had a formal diagnosis from a doctor?

Trafford		
Answer Options	Response Percent	Response Count
Yes	89.7%	35
No	10.3%	4
answered question		39
skipped question		8

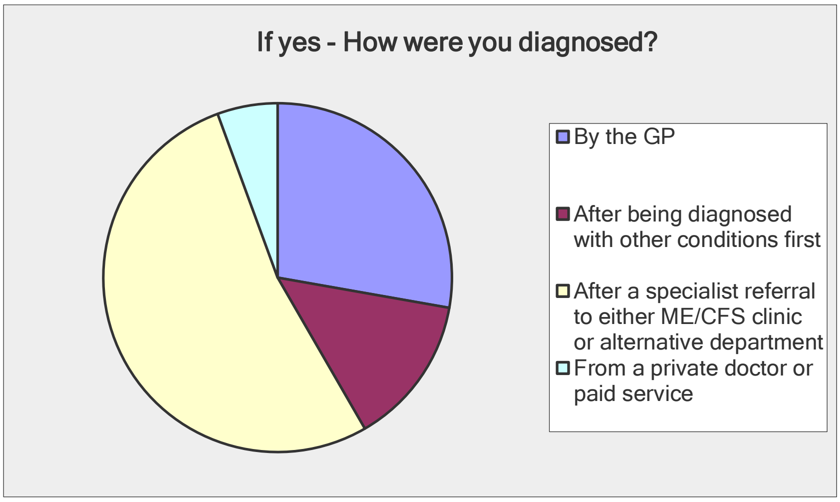


GM		
Answer Options	Response Percent	Response Count
Yes	94.4%	117
No	5.6%	7
answered question		124
skipped question		23

UK		
Answer Options	Response Percent	Response Count
Yes	94.4%	713
No	5.6%	42
answered question		755
skipped question		83

7. If yes - How were you diagnosed?

Trafford		
Answer Options	Response Percent	Response Count
By the GP	27.8%	10
After being diagnosed with other conditions first	13.9%	5
After a specialist referral to either ME/CFS clinic or alternative department	52.8%	19
From a private doctor or paid service	5.6%	2
answered question		36
skipped question		11



GM		
Answer Options	**Response Percent**	**Response Count**
By the GP	21.2%	25
After being diagnosed with other conditions first	12.7%	15
After a specialist referral to either ME/CFS clinic or alternative department	51.7%	61
From a private doctor or paid service	14.4%	17
answered question		**118**
skipped question		**29**

UK		
Answer Options	**Response Percent**	**Response Count**
By the GP	25.5%	183
After being diagnosed with other conditions first	10.0%	72
After a specialist referral to either ME/CFS clinic or alternative department	56.2%	403
From a private doctor or paid service	8.2%	59
answered question		**717**
skipped question		**121**

8. Have you been offered any information from the NHS on living with the condition?

Trafford		
Answer Options	Response Percent	Response Count
Yes, from my GP	4.0%	1
Yes, from ME/CFS department or hospital department that diagnosed me	28.0%	7
Yes, from another service or department	16.0%	4
No	52.0%	13
answered question		**25**
skipped question		**22**

GM		
Answer Options	Response Percent	Response Count
Yes, from my GP	3.4%	3
Yes, from ME/CFS department or hospital department that diagnosed me	47.2%	42
Yes, from another service or department	16.9%	15
No	32.6%	29
answered question		**89**
skipped question		**58**

UK		
Answer Options	Response Percent	Response Count
Yes, from my GP	6.7%	39
Yes, from ME/CFS department or hospital department that diagnosed me	44.8%	261
Yes, from another service or department	13.7%	80
No	34.7%	202
answered question		**582**
skipped question		**256**

9. If yes, was that information helpful?

Trafford		
Answer Options	Response Percent	Response Count
Yes	46.7%	7
No	53.3%	8
answered question		15
skipped question		32

GM		
Answer Options	Response Percent	Response Count
Yes	67.7%	44
No	32.3%	21
answered question		65
skipped question		82

UK		
Answer Options	Response Percent	Response Count
Yes	59.5%	244
No	40.5%	166
answered question		410
skipped question		428

10. If you have used any of the following, did you find it made your ME/CFS more or less manageable?

Trafford

Answer Options	More manageable	No difference	Less manageable	Not tried	Response Count
Cognitive Behaviour Therapy (CBT)	3	7	0	8	18
Graded Exercise Therapy (GET)	1	1	7	8	17
Pacing	13	1	1	4	19
Physiotherapy	1	2	1	13	17
Occupational Therapy (OT)	1	1	0	14	16
NHS Nurse at hospital or home visits	1	0	0	15	16
NHS ME/CFS group	2	3	1	10	16
Psychiatric treatment	1	3	0	12	16
Nutrition or dietician	3	2	0	12	17
Very gentle yoga/meditation	6	2	0	8	16
Acupuncture/acupressure	4	2	0	11	17
Pain medication	6	5	0	5	16
Osteopathy	1	2	0	14	17
answered question					19
skipped question					28

GM

Answer Options	More manageable	No difference	Less manageable	Not tried	Response Count
Cognitive Behaviour Therapy (CBT)	16	29	2	25	72
Graded Exercise Therapy (GET)	8	8	36	19	71
Pacing	47	17	2	10	76
Physiotherapy	4	19	13	34	70
Occupational Therapy (OT)	4	6	4	53	67
NHS Nurse at hospital or home visits	3	8	1	55	67
NHS ME/CFS group	12	12	3	42	69
Psychiatric treatment	5	10	2	49	66
Nutrition or dietician	14	7	1	46	68
Very gentle yoga/meditation	29	8	6	25	68
Acupuncture/acupressure	14	9	0	44	67
Pain medication	29	20	3	16	68
Osteopathy	8	9	1	50	68
answered question					78
skipped question					69

IF you have used any of the following, did you find it made your ME/CFS more or less manageable?

Answer Options	More manageable	No difference	Less manageable	Not tried	Response Count
Cognitive Behaviour Therapy (CBT)	77	175	44	206	502
Graded Exercise Therapy (GET)	36	58	203	201	498
Pacing	340	92	27	55	514
Physiotherapy	64	92	81	242	479
Occupational Therapy (OT)	87	71	15	305	478
NHS Nurse at hospital or home visits	30	23	5	404	462
NHS ME/CFS group	68	92	30	288	478
Psychiatric treatment	27	76	41	326	470
Nutrition or dietician	115	91	12	260	478
Very gentle yoga/meditation	166	79	41	196	482
Acupuncture/acupressure	71	77	23	301	472
Pain medication	244	111	26	104	485
Osteopathy	64	42	11	349	466
answered question					531
skipped question					307

11. Is there anything else you would like to tell us about managing your condition?

Please see appendix (TO BE ADDED) for transcript of these answers.

GPs

12. What is the name and address of your GP Surgery?

Answers to this question are not being published to ensure full confidentiality for respondents. The information we have gathered relevant to Trafford has been recorded and will be used in the course of our work with GPs in the area, our local CCG and NHS England.

13. How long did it take to be diagnosed after first reporting symptoms to your GP?

Trafford		
Answer Options	Response Percent	Response Count
Less than 3 months	8.7%	2
3 to 6 months	21.7%	5
6 months to a year	8.7%	2
1 to 2 years	34.8%	8
2 to 5 years	13.0%	3
More than 5 years	13.0%	3
answered question		23
skipped question		24

GM		
Answer Options	Response Percent	Response Count
Less than 3 months	3.5%	3
3 to 6 months	17.6%	15
6 months to a year	10.6%	9
1 to 2 years	30.6%	26
2 to 5 years	11.8%	10
More than 5 years	25.9%	22
answered question		85
skipped question		62

UK		
Answer Options	Response Percent	Response Count
Less than 3 months	5.8%	33
3 to 6 months	15.6%	88
6 months to a year	24.6%	139
1 to 2 years	16.5%	93
2 to 5 years	16.6%	94
More than 5 years	20.9%	118
answered question		565
skipped question		273

14. How does your GP talk about your condition?

How does your GP talk about your condition?

Answer Options	Response Percent	Response Count
They are knowledgeable and supportive	16.7%	4
They are not knowledgeable but they are supportive	50.0%	12
They are knowledgeable but not supportive	4.2%	1
They are neither knowledgeable nor supportive	29.2%	7
answered question		24
skipped question		23

GM

Answer Options	Response Percent	Response Count
They are knowledgeable and supportive	25.0%	21
They are not knowledgeable but they are supportive	46.4%	39
They are knowledgeable but not supportive	2.4%	2
They are neither knowledgeable nor supportive	26.2%	22
answered question		84
skipped question		63

UK

Answer Options	Response Percent	Response Count
They are knowledgeable and supportive	20.0%	112
They are not knowledgeable but they are supportive	45.1%	252
They are knowledgeable but not supportive	3.8%	21
They are neither knowledgeable nor supportive	31.1%	174
answered question		559
skipped question		279

15. Would you trust your GP to provide you with information about ME/CFS?

Trafford		
Answer Options	Response Percent	Response Count
Yes	24.0%	6
No	60.0%	15
I don't know	16.0%	4
answered question		25
skipped question		22

GM		
Answer Options	Response Percent	Response Count
Yes	24.4%	21
No	51.2%	44
I don't know	24.4%	21
answered question		86
skipped question		61

UK		
Answer Options	Response Percent	Response Count
Yes	24.0%	136
No	48.9%	277
I don't know	27.0%	153
answered question		566
skipped question		272

16. Has your GP referred you to ME/CFS services?

Trafford		
Answer Options	Response Percent	Response Count
No	36.0%	9
Yes, ME/CFS dept. out of area	36.0%	9
Yes, ME/CFS dept. within the area/council that I live	12.0%	3
Yes, another dept. (no ME/CFS clinic available). - Please specify	16.0%	4
answered question		25
skipped question		22

GM		
Answer Options	Response Percent	Response Count
No	31.8%	28
Yes, ME/CFS dept. out of area	19.3%	17
Yes, ME/CFS dept. within the area/council that I live	36.4%	32
Yes, another dept. (no ME/CFS clinic available). - Please specify	12.5%	11
answered question		88
skipped question		59

UK		
Answer Options	Response Percent	Response Count
No	32.0%	182
Yes, ME/CFS dept. out of area	23.0%	131
Yes, ME/CFS dept. within the area/council that I live	34.8%	198
Yes, another dept. (no ME/CFS clinic available). - Please specify	10.2%	58
answered question		569
skipped question		269

17. Has a GP ever come out to you because you couldn't attend the surgery?

Trafford		
Answer Options	Response Percent	Response Count
Yes	29.2%	7
No	70.8%	17
answered question		24
skipped question		23

GM		
Answer Options	Response Percent	Response Count
Yes	20.2%	17
No	79.8%	67
answered question		84
skipped question		63

UK		
Answer Options	Response Percent	Response Count
Yes	20.4%	112
No	79.6%	436
answered question		548
skipped question		290

18. How often do you see your GP on average each year?

Trafford		
Answer Options	Response Percent	Response Count
1-2 times per year	12.5%	3
3-4 times (Once a quarter)	41.7%	10
5-6 times (every two months)	33.3%	8
Monthly	12.5%	3
Weekly	0.0%	0
answered question		24
skipped question		23

GM		
Answer Options	Response Percent	Response Count
1-2 times per year	18.8%	16
3-4 times (Once a quarter)	29.4%	25
5-6 times (every two months)	34.1%	29
Monthly	17.6%	15
Weekly	0.0%	0
answered question		85
skipped question		62

UK		
Answer Options	Response Percent	Response Count
1-2 times per year	27.6%	154
3-4 times (Once a quarter)	32.3%	180
5-6 times (every two months)	25.1%	140
Monthly	14.2%	79
Weekly	0.9%	5
answered question		558
skipped question		280

19. Would you say your GP/s speak to you with respect and fairness, listening to you?

Trafford		
Answer Options	**Response Percent**	**Response Count**
Yes, always	25.0%	6
Yes, most of the time	37.5%	9
Sometimes	25.0%	6
Rarely	8.3%	2
No, never	4.2%	1
answered question		**24**
skipped question		**23**

GM		
Answer Options	**Response Percent**	**Response Count**
Yes, always	33.3%	29
Yes, most of the time	31.0%	27
Sometimes	27.6%	24
Rarely	6.9%	6
No, never	1.1%	1
answered question		**87**
skipped question		**60**

UK		
Answer Options	**Response Percent**	**Response Count**
Yes, always	30.1%	171
Yes, most of the time	35.1%	200
Sometimes	24.6%	140
Rarely	8.4%	48
No, never	1.8%	10
answered question		**569**
skipped question		**269**

20.Have you ever been unable to access or been refused tests or treatment?

Have you ever been unable to access or been refused tests or treatment?		
Answer Options	Response Percent	Response Count
No	100.0%	16
Yes - please explain		8
answered question		**16**
skipped question		**31**

Have you ever been unable to access or been refused tests or treatment?		
Answer Options	Response Percent	Response Count
No	100.0%	51
Yes - please explain		34
answered question		**51**
skipped question		**96**

Have you ever been unable to access or been refused tests or treatment?		
Answer Options	Response Percent	Response Count
No	100.0%	319
Yes - please explain		216
answered question		**319**
skipped question		**519**

21. Is there anything about GP services you would like to mention?

We analysed the responses from only people from Trafford due to the amount of time it takes to analyse so much qualitative data. The remaining data is available for further analysis – if you wish to access it please contact Healthwatch Trafford (details at the end of this report).

The themes we found in Trafford were as follows:

Categorisation	*Count of appearances*
GP doesn't know enough about my illness	21
Inconsistency of care (different GP each time, GPs leaving, different levels of knowledge)	11
GP is supportive/sympathetic	6
Condition confused with depression / 'just tired'	6
GP doesn't have enough time	6
Disbelief about the condition	5
Poor medical records (inconsistent, not up to date, diagnosis not recorded because it could be prejudicial)	4
Treated as hypochondriac	4
Had to change GP to receive care / stay with GP in old area to receive care	4
Need to be proactive about treatment and care / request referral to services	4
Poor GP interpersonal care (GP doesn't listen, rude or insulting, treated as 'problem patient', laughed at, condescending)	3
Training on ME/CFS needed	3
Tend to see GP on 'good' days / not well enough to see GP	2
Cannot get GP appointment when necessary / difficult to get appointment	2
Failure to diagnose	2
Having to explain everything each time	2
GP is amazing	2
Feel a nuisance to the GP	2
GPs unaware of specialist services	2
GPs unable to refer to specific services for reasons of ME/CFS (under NICE guidelines)	2
Poor support from social services / local council	2
Lack of follow-up care from hospital / disjointed care	2
Need for specialist ME/CFS service, including for GPs to access for point of knowledge	1

Hospitals

22. What hospitals do you regularly use?

Responses from Trafford:	25
Trafford General Hospital	9
Salford Royal Hospital	8
Wythenshawe Hospital (UHSM)	3
Manchester Royal Infirmary	2
The Christie	1
Stepping Hill	1
None/Other	1

23. What was the hospital you used MOST RECENTLY?

TRAFFORD
What was the hospital you used MOST RECENTLY

Answer Options	Response Percent	Response Count
Trafford General Hospital	25.9%	7
Altrincham General Hospital	3.7%	1
Wythenshawe Hospital (University Hospital South Manchester)	11.1%	3
Manchester Royal Infirmary	11.1%	3
Salford Royal Hospital	40.7%	11
Manchester Royal Eye Hospital	0.0%	0
The Christie Hospital	0.0%	0
Other Hospital (please tell us which)	7.4%	2
	answered question	27
	skipped question	26

24. Have you accessed any ME/CFS specialist care at a hospital?

Trafford		
Answer Options	Response Percent	Response Count
Yes	62.5%	15
No	37.5%	9
answered question		24
skipped question		23

GM		
Answer Options	Response Percent	Response Count
Yes	53.5%	46
No	46.5%	40
answered question		86
skipped question		61

UK		
Answer Options	Response Percent	Response Count
Yes	47.8%	261
No	52.2%	285
answered question		546
skipped question		292

25. Do you find most (non specialist) hospital staff have knowledge of or understand your condition?

Trafford		
Answer Options	Response Percent	Response Count
Yes, most understand and treat me appropriately	0.0%	0
Yes, most have some knowledge of ME/CFS	10.5%	2
Most don't have much knowledge of ME/CFS	31.6%	6
No, most do not understand ME/CFS	57.9%	11
answered question		19
skipped question		28

Do you find most (non specialist) hospital staff have knowledge of or understand your condition?		
GM	Response Percent	Response Count
Yes, most understand and treat me appropriately	1.3%	1
Yes, most have some knowledge of ME/CFS	11.7%	9
Most don't have much knowledge of ME/CFS	41.6%	32
No, most do not understand ME/CFS	45.5%	35
answered question		77
skipped question		70

UK		
Answer Options	Response Percent	Response Count
Yes, most understand and treat me appropriately	3.8%	19
Yes, most have some knowledge of ME/CFS	14.3%	71
Most don't have much knowledge of ME/CFS	36.4%	181
No, most do not understand ME/CFS	45.5%	226
answered question		497
skipped question		341

26. Would you say hospital staff speak to you with respect and fairness, listening to you?

Trafford		
Answer Options	Response Percent	Response Count
Yes, always	10.5%	2
Yes, most of the time	52.6%	10
Sometimes	10.5%	2
Rarely	21.1%	4
No, never	5.3%	1
answered question		19
skipped question		28

GM		
Answer Options	Response Percent	Response Count
Yes, always	15.6%	12
Yes, most of the time	29.9%	23
Sometimes	36.4%	28
Rarely	15.6%	12
No, never	2.6%	2
answered question		77
skipped question		70

UK		
Answer Options	Response Percent	Response Count
Yes, always	12.0%	60
Yes, most of the time	34.5%	172
Sometimes	36.3%	181
Rarely	14.8%	74
No, never	2.4%	12
answered question		499
skipped question		339

27. Where appropriate, have you been able to access phone, email, online or home visits? E.g. test results, making appointments, etc.

Trafford		
Answer Options	Response Percent	Response Count
Yes	65.0%	13
No	10.0%	2
N/A (not applicable)	25.0%	5
answered question		20
skipped question		27

GM		
Answer Options	Response Percent	Response Count
Yes	54.4%	43
No	31.6%	25
N/A (not applicable)	13.9%	11
answered question		79
skipped question		68

UK		
Answer Options	Response Percent	Response Count
Yes	49.5%	258
No	28.0%	146
N/A (not applicable)	22.5%	117
answered question		521
skipped question		317

28. Is there anything about hospital services that you would like to mention?

We analysed the responses from only people from Trafford due to the amount of time it takes to analyse so much qualitative data. The remaining data is available for further analysis – if you wish to access it please contact Healthwatch Trafford (details at the end of this report).

The themes we found in Trafford were as follows:

Categorisation	*Count of appearances*
Poor knowledge of staff toward ME/CFS / Education needed	11
Keen on 'pushing' certain treatments (graded exercise, CBT)	9
Lack of consistency of quality of care between hospitals / departments should work together more	6
Consultant helpful	5
Waiting lists very long /waiting times in hospitals long	3
Abandoned' if not responsive to treatment	3
Unaware of specialist services in GM	3
Lack of flexibility (no option for remote appointments)	2
Poor attitude of staff toward ME/CFS (condescending, think it is 'laziness', lack of compassion toward symptoms)	2
Treatment made condition worse	2
Struggle to attend appointments (time of appointment / distance to hospital)	2
Only attended hospital for diagnosis	2
Transferred between hospitals to 'follow' specialist	2
Services 'good'	2
Accommodation in hospital not appropriate for ME/CFS (lack of high back chairs)	2
Problems with medical records / letters (not factually correct)	1
Hospital transport inadequate	1
Symptoms not always 'bad' when attending appointment	1
Treat individual symptoms separately rather than as a whole	1
Hospital allows flexibility of appointment times (e.g. change from am to pm)	1

29. Have you ever been an in-patient whilst having ME/CFS?

Trafford		
Answer Options	Response Percent	Response Count
Yes	37.5%	9
No	62.5%	15
answered question		24
skipped question		23

GM		
Answer Options	Response Percent	Response Count
Yes	34.5%	30
No	65.5%	57
answered question		87
skipped question		60

UK		
Answer Options	Response Percent	Response Count
Yes	36.6%	201
No	63.4%	348
answered question		549
skipped question		289

30. If yes, did they understand your ME/CFS and accommodate you?

Trafford		
Answer Options	Response Percent	Response Count
Yes	30.0%	3
Somewhat	10.0%	1
No	60.0%	6
answered question		10
skipped question		37

GM		
Answer Options	Response Percent	Response Count
Yes	12.5%	4
Somewhat	34.4%	11
No	53.1%	17
answered question		32
skipped question		115

UK		
Answer Options	Response Percent	Response Count
Yes	11.8%	25
Somewhat	34.4%	73
No	53.8%	114
answered question		212
skipped question		626

31. Were the environment and services suitable?

Trafford		
Answer Options	Response Percent	Response Count
Yes	20.0%	2
Somewhat	30.0%	3
No	50.0%	5
answered question		10
skipped question		37

GM		
Answer Options	Response Percent	Response Count
Yes	9.4%	3
Somewhat	50.0%	16
No	40.6%	13
answered question		32
skipped question		115

UK		
Answer Options	Response Percent	Response Count
Yes	17.6%	37
Somewhat	41.0%	86
No	41.4%	87
answered question		210
skipped question		628

32. Is there anything else about in-patient services you would like to mention?

We analysed the responses from only people from Trafford due to the amount of time it takes to analyse so much qualitative data. The remaining data is available for further analysis – if you wish to access it please contact Healthwatch Trafford (details at the end of this report).

The themes we found in Trafford were as follows:

Categorisation	*Count of appearances*
Poor facilities (food, bedding, lighting, noise)	8
Lack of knowledge of ME/CFS amongst staff / Education needed	6
Poor sleep and rest	5
Staff caring and professional	3
Good quality of care received	2
Lack of compassion from staff	2
Importance of medication and its application misunderstood / Not given at the right time	2
Inconsistent standard of care between hospitals	1
Need for a symptomatic clinic to assist with symptoms	1
Not appropriate to be told by staff to 'get out of bed'	1

Complaints

33. Have you ever complained to PALS (the Patient Advice Liaison Service) or a Practice Manager?

Trafford		
Answer Options	Response Percent	Response Count
Yes, to PALS	15.0%	3
Yes, to a practice manager	0.0%	0
Yes, to both	10.0%	2
No	75.0%	15
answered question		20
skipped question		27

GM		
Answer Options	Response Percent	Response Count
Yes, to PALS	11.1%	9
Yes, to a practice manager	2.5%	2
Yes, to both	7.4%	6
No	79.0%	64
answered question		81
skipped question		66

UK		
Answer Options	Response Percent	Response Count
Yes, to PALS	10.7%	57
Yes, to a practice manager	7.7%	41
Yes, to both	3.2%	17
No	78.5%	420
answered question		535
skipped question		303

34. If yes, what was the response you received?

Trafford		
Answer Options	Response Percent	Response Count
Positive, I was happy with their response	16.7%	1
Neutral, it was ok	16.7%	1
Negative, I was not satisfied by their response	66.7%	4
answered question		6
skipped question		41

GM		
Answer Options	Response Percent	Response Count
Positive, I was happy with their response	33.3%	6
Neutral, it was ok	22.2%	4
Negative, I was not satisfied by their response	44.4%	8
answered question		18
skipped question		129

UK		
Answer Options	Response Percent	Response Count
Positive, I was happy with their response	24.2%	29
Neutral, it was ok	30.0%	36
Negative, I was not satisfied by their response	45.8%	55
answered question		120
skipped question		718

35. Have you ever complained to NHS England, the Local Government Ombudsman (LGO), or the Parliamentary and Health Service Ombudsman (PHSO)? - tick all that apply

Trafford		
Answer Options	Response Percent	Response Count
Yes, to NHS England	14.3%	3
Yes, to the Local Government Ombudsman (LGO)	0.0%	0
Yes, to the Parliamentary and Health Service Ombudsman (PHSO)	14.3%	3
No	81.0%	17
answered question		21
skipped question		26

GM		
Answer Options	Response Percent	Response Count
Yes, to NHS England	3.8%	3
Yes, to the Local Government Ombudsman (LGO)	1.3%	1
Yes, to the Parliamentary and Health Service Ombudsman (PHSO)	7.6%	6
No	91.1%	72
answered question		79
skipped question		68

UK		
Answer Options	Response Percent	Response Count
Yes, to NHS England	2.4%	12
Yes, to the Local Government Ombudsman (LGO)	1.4%	7
Yes, to the Parliamentary and Health Service Ombudsman (PHSO)	2.4%	12
No	95.5%	487
answered question		510
skipped question		328

36. If yes, what was the response you received?

Trafford		
Answer Options	Response Percent	Response Count
Positive, I was happy with their response	0.0%	0
Neutral, it was ok	16.7%	1
Negative, I was not satisfied by their response	83.3%	5
answered question		6
skipped question		41

GM		
Answer Options	Response Percent	Response Count
Positive, I was happy with their response	0.0%	0
Neutral, it was ok	9.1%	1
Negative, I was not satisfied by their response	90.9%	10
answered question		11
skipped question		136

UK		
Answer Options	Response Percent	Response Count
Positive, I was happy with their response	7.7%	3
Neutral, it was ok	23.1%	9
Negative, I was not satisfied by their response	69.2%	27
answered question		39
skipped question		799

Medical Records

37. Do you have copies of your medical letters/records or know how to access them?

Trafford		
Answer Options	Response Percent	Response Count
Yes, I have copies	31.8%	7
I know how to access them	27.3%	6
I don't know how to access them	40.9%	9
I don't want access to them	0.0%	0
answered question		22
skipped question		25

GM		
Answer Options	Response Percent	Response Count
Yes, I have copies	35.4%	28
I know how to access them	19.0%	15
I don't know how to access them	41.8%	33
I don't want access to them	3.8%	3
answered question		79
skipped question		68

UK		
Answer Options	Response Percent	Response Count
Yes, I have copies	25.6%	132
I know how to access them	21.7%	112
I don't know how to access them	49.0%	253
I don't want access to them	3.9%	20
answered question		516
skipped question		322

Demographics

38. Do you identify as;

Trafford		
Answer Options	Response Percent	Response Count
Female	84.2%	16
Male	15.8%	3
Other	0.0%	0
answered question		19
skipped question		28

GM		
Answer Options	Response Percent	Response Count
Female	85.9%	67
Male	14.1%	11
Other	0.0%	0
answered question		78
skipped question		69

UK		
Answer Options	Response Percent	Response Count
Female	86.4%	458
Male	13.2%	70
Other	0.4%	2
answered question		530
skipped question		308

39. What is your age?

Trafford		
Answer Options	Response Percent	Response Count
17 or younger	0.0%	0
18-20	0.0%	0
21-29	21.1%	4
30-39	21.1%	4
40-49	5.3%	1
50-59	31.6%	6
60 or older	21.1%	4
answered question		19
skipped question		28

GM		
Answer Options	Response Percent	Response Count
17 or younger	0.0%	0
18-20	1.3%	1
21-29	6.4%	5
30-39	15.4%	12
40-49	34.6%	27
50-59	26.9%	21
60 or older	15.4%	12
answered question		78
skipped question		69

UK		
Answer Options	Response Percent	Response Count
17 or younger	4.3%	23
18-20	3.4%	18
21-29	9.0%	48
30-39	16.9%	90
40-49	30.5%	163
50-59	22.7%	121
60 or older	13.3%	71
answered question		534
skipped question		304

40. Which of the following best describes your current relationship status?

Trafford		
Answer Options	Response Percent	Response Count
Married	31.6%	6
Widowed	5.3%	1
Divorced	5.3%	1
Separated	0.0%	0
In a domestic partnership or civil union	0.0%	0
Single, but cohabiting with a significant other	10.5%	2
Single, never married	47.4%	9
answered question		19
skipped question		28

GM		
Answer Options	Response Percent	Response Count
Married	32.1%	25
Widowed	1.3%	1
Divorced	17.9%	14
Separated	3.8%	3
In a domestic partnership or civil union	0.0%	0
Single, but cohabiting with a significant other	7.7%	6
Single, never married	37.2%	29
answered question		78
skipped question		69

UK		
Answer Options	Response Percent	Response Count
Married	39.4%	205
Widowed	0.4%	2
Divorced	11.3%	59
Separated	2.3%	12
In a domestic partnership or civil union	4.6%	24
Single, but cohabiting with a significant other	9.2%	48
Single, never married	32.7%	170
answered question		520
skipped question		318

41. Which of the following categories best describes your employment status?

Trafford		
Answer Options	Response Percent	Response Count
Employed, working full-time	5.3%	1
Employed, working part-time	21.1%	4
Not employed, looking for work	5.3%	1
Not employed, NOT looking for work	5.3%	1
Retired	21.1%	4
Disabled, not able to work	42.1%	8
answered question		19
skipped question		28

GM		
Answer Options	Response Percent	Response Count
Employed, working full-time	7.7%	6
Employed, working part-time	16.7%	13
Not employed, looking for work	1.3%	1
Not employed, NOT looking for work	7.7%	6
Retired	12.8%	10
Disabled, not able to work	53.8%	42
answered question		78
skipped question		69

UK		
Answer Options	Response Percent	Response Count
Employed, working full-time	6.7%	35
Employed, working part-time	15.0%	79
Not employed, looking for work	1.5%	8
Not employed, NOT looking for work	8.9%	47
Retired	8.7%	46
Disabled, not able to work	59.1%	311
answered question		526
skipped question		312

42. How would you describe your ethnicity?

Trafford		
Answer Options	Response Percent	Response Count
White British	94.7%	18
Black British	0.0%	0
Asian British	0.0%	0
White	0.0%	0
Black African	0.0%	0
Black Caribbean	0.0%	0
Other Black	0.0%	0
Indian	0.0%	0
Pakistani	0.0%	0
Bangladeshi	0.0%	0
Chinese	0.0%	0
Other Asian	0.0%	0
Other (please specify)	5.3%	1
answered question		19
skipped question		28

GM		
Answer Options	Response Percent	Response Count
White British	94.9%	75
Black British	0.0%	0
Asian British	0.0%	0
White	1.3%	1
Black African	0.0%	0
Black Caribbean	0.0%	0
Other Black	0.0%	0
Indian	0.0%	0
Pakistani	0.0%	0
Bangladeshi	0.0%	0
Chinese	0.0%	0
Other Asian	0.0%	0
Other (please specify)	3.8%	3
answered question		79
skipped question		68

UK		
Answer Options	Response Percent	Response Count
White British	91.4%	480
Black British	0.0%	0
Asian British	1.0%	5
White	5.0%	26
Black African	0.0%	0

Black Caribbean	0.0%	0
Other Black	0.2%	1
Indian	0.0%	0
Pakistani	0.0%	0
Bangladeshi	0.0%	0
Chinese	0.2%	1
Other Asian	0.0%	0
Other (please specify)	2.3%	12
answered question		**525**
skipped question		**313**

43. Sexual orientation

Trafford		
Answer Options	Response Percent	Response Count
Straight / Heterosexual	94.7%	18
Gay / Lesbian / Homosexual	0.0%	0
Bisexual	0.0%	0
Other (please specify)	5.3%	1
answered question		**19**
skipped question		**28**

GM		
Answer Options	Response Percent	Response Count
Straight / Heterosexual	84.2%	64
Gay / Lesbian / Homosexual	6.6%	5
Bisexual	6.6%	5
Other (please specify)	2.6%	2
answered question		**76**
skipped question		**71**

UK		
Answer Options	Response Percent	Response Count
Straight / Heterosexual	89.7%	451
Gay / Lesbian / Homosexual	2.8%	14
Bisexual	4.4%	22
Other (please specify)	3.2%	16
answered question		**503**
skipped question		**335**

Survey specifics

These results are not published in this report as they are purely to assist us in our future work at Healthwatch Trafford. The question headings are included for completeness.

44. How did you find out about this survey?

45. How easy was it to complete?

46. How could our surveys be improved in the future?

Findings

Looking at the results, we have some question specific findings.

ME as a condition

1. How would you describe your current level of ME/CFS?

In Trafford, more than a third of respondents said they were housebound. That is higher than we see across GM and the UK as a whole, but is a relatively small sample size. It is within 10% of GM and UK and is likely to be a fair indication of the reality.

In total, just over 94% said they were moderate to severe in their symptoms, meaning they are unable to work or study full time. This, although slightly higher than the GM and UK results, is largely in line with them. This is a significant number of people and will have real consequences when it comes to personal liberty, employment, education and welfare.

2. How long have you had ME/CFS?

In Trafford, of the respondents 74% had ME/CFS for 5 years or more. This is almost identical to GM and National figures, as is a figure of just over 25% that have had the condition for over 20 years. This shows the condition needs to be looked at as a long-term issue, and given the duration of the condition combined with the figures in 1. It becomes clear there is a strong medical and financial impact over a long period of time, making it important to get diagnosis and treatment right as soon as possible.

3. What has been the main factor/s or trigger/s for your ME/CFS?

Although medical causes for ME/CFS are beyond the scope of this report, we felt it would be worth finding out if there was anything that people felt brought on the condition that could be attributed to local factors.

What we actually found was that the Trafford responses were again by-and-large similar to nationally and regionally identified triggers, with the two most popular replies being a virus or infection (74%) or stress, depression or other mental health issue (36%). However, the latter of these answers was around 10% higher than the national and regional statistic.

4. Have you had a formal diagnosis from a doctor?

Trafford reported a slightly lower formal diagnosis rate than GM and the UK, however in the context of this survey it might well be due to the local nature of the project and therefore more likely that people that don’t have a formal diagnosis in the area but are self-diagnosed will have heard about the survey than those in other areas.

5. If yes - How were you diagnosed?

Trafford residents largely fit the regional and national pattern here

The majority of Trafford participants responded that they were diagnosed through a specialist referral to either a ME/CFS clinic or an alternative department, with a response rate of 53% at a count of 19. The second largest response was a GP diagnosis, with a statistic of 28%. Additionally, some participants (14%) answered that they were diagnosed with ME after being diagnosed with other conditions previously. Few stated that a private service was a form of diagnosis- only 2 participants answered this. These responses correlated among those from Greater Manchester and the UK.

This indicates that specialist clinics are most suitable (or reliable) for diagnosis. The link between who diagnosed them, how long the diagnosis took and how long it took to get a referral would be a useful one to study more in depth.

6. Have you ever been offered any information from the NHS on living with the condition?

For this answer, the majority of respondents answered the question, at a rate of 53.1%, 60.4% and 69.45% of Trafford, Greater Manchester and the UK, respectively. In the broader areas of Greater Manchester and the UK, the majority of respondents answered that the ME/CFS department that diagnosed them had been a source of information on living with the condition, although this was the second largest result for Trafford, at a response of 28%. Trafford's highest response to the question was that they had not been offered any information, with a little over half stating this (52%). This means that the majority of people living with the condition have never been supplied with any information about it from the NHS, leading to people to look elsewhere to educate themselves. There is a good chance that if people are having to find their own information, the sources of information they use are likely to be varied and of unknown accuracy or quality.

This also raises the question of why the information is not being made available. Is it that GPs for example don't know there is any information on living with the condition available from the NHS, is it because they have limited knowledge of the condition themselves or where or how to get the information? This requires further investigation to understand the point of view of GPs and service providers.

This response was similar to those for the UK and Greater Manchester, as not having received any information was the second largest response. The lowest response from all three areas was having received information from the GP, none had any results higher than 10%.

7. If yes, was this information helpful?

None of the three areas had a response rate of over 50% for this question.

Greater Manchester and the UK had a majority response of 'Yes'. Trafford respondents- with a 31% response rate- typically answered 'No', although with a slim majority of 53%.

The narrow majority is similar to the response of the UK, where 59% chose the information to be helpful. Only Greater Manchester had the larger majority of 67% stating the information was helpful.

This would suggest that the standard of information provided in Trafford is not the same as that across the Greater Manchester area. The variation in the results also suggests a lack of consistency provided across the country and region.

8. If you have used any of the following, did you find it made your ME/CFS more or less manageable?

Trafford was the only area where the majority of participants did not answer this question, whilst GM and UK showed response rates over 50% and 60% respectively. This poses questions as to whether this selective responding suggests any differences within Trafford and the GM area, compared to the UK, in treatment provision or experience.

Of particular note is that unusually high numbers of Trafford residents had not tried physiotherapy, occupational therapy or nutrition to manage their conditions. It is possible that these options are less widely available within Trafford, or that GPs are not routinely suggesting these avenues. Given that just over 50% of patients nationally found Occupational Therapy improved their condition, with similar percentages for Nutrition, this may have significant effects upon patient experience in Trafford.

In terms of perceived effectiveness, reported levels of improvement or deterioration following particular treatments were similar in Trafford, Greater Manchester and the UK. This suggests that therapeutic interventions in Trafford are likely carried out in a similar way to those nationally.

9. How long did it take to be diagnosed after first reporting symptoms to your GP?

Whilst Greater Manchester and the UK had the majority of participants answer this question, just under half of respondents from Trafford answered. Of these respondents, over 60% of Trafford residents had waited over a year to be diagnosed with ME/CFS. This rate was slightly higher in Greater Manchester, at just over 68%, whilst nationally 54% of people waited more than a year for a diagnosis. This suggests that patients in Trafford and Greater Manchester may be taking longer to receive a diagnosis.

There are several possible reasons that this may occur. As ME/CFS is a diagnosis of exclusion, it may be that physicians in Greater Manchester are conducting more numerous tests before diagnosis. It may be that the same number of tests are being run, but that these are taking longer to conduct; either due to waiting times for such tests, or that symptoms are present for longer before tests are conducted. Alternatively, this may be due to an inability to detect the pattern of symptoms in order to connect aspects into an overall condition. This may occur if patients are seeing different GPs and not receiving continuity of care, or symptoms are not treated in context of overall health.

10. How does your GP talk about your condition?

For this question, Trafford showed a response rate of just over 50%, with the majority of respondents in Greater Manchester and the UK overall also answering. In Trafford, just over 79% of people reported that their GP was not knowledgeable about ME/CFs. This is part of a wider trend, with just over 72% and 76% reporting the same in Greater Manchester and the UK respectively. This suggests that lack of knowledge is a national problem, with implications regarding how patients are treated and whether patients are able to access the services that are in place.

In Trafford, 33.4% of GPs were reported to not be supportive about ME/CFS. Again, this is in line with reports from Greater Manchester and the UK, with 28.6% and 34.9% of GPs reports as unsupportive respectively. Rates of GPs who were felt to be neither supportive nor knowledgeable about ME/CFS hovered around 30% for all three areas. This large number of GPs perceived to be neither supportive or knowledgeable is likely to have a substantial impact upon patient experience.

11. Would you trust your GP to provide you with information about ME/CFS?

53% of Trafford respondents answered this question, whilst Greater Manchester and UK rates also showed a majority of participants responding. 60% of people in Trafford did not trust their GP to provide them with information about ME/CFS. This was higher than Greater Manchester (51.2%) and the UK (48.9%). However, rates of respondents stating they would trust their GP remained around 24% for all three areas, with the discrepancy between figures explained by lower numbers of participants who answered ‘I don’t know’ in Trafford. This may be due to strength of feeling in Trafford, with respondents being more sure that they did not trust their GP for this information.

If this is the case, two explanations are possible: either GPs were perceived as not being competent and unable to provide the information, or patients did not trust their GP because they did not believe their GP had accurate or supportive beliefs about ME/CFS. This ties in with findings that many participants reported disbelief and poor attitudes from GPs regarding ME/CFS as a condition. As over half of participants in Trafford had not been given any information by the NHS about ME/CFS, it is also possible that this result indicates their distrust that GPs would provide information of their own volition.

The consistently low results nationwide of participants who would trust their GP for this information reflects the low numbers of GPs who were seen to be both knowledgeable and supportive of the condition.

12. Has your GP referred you to ME/CFS services?

All three areas had response rates over 50%. In Trafford, 16% of patients responded that they had been referred to another department as no ME/CFS clinic was available. This contrasts with 48% of respondents who had been referred to specialist clinics for this condition; of these, 12% had been referred to a department within the Trafford area. As ME/CFS is characterised by fatigue, questions are raised regarding the impact of travelling out of area for the remaining 36%.

These findings are seemingly contradictory regarding the existence of services in Trafford, however it may depend upon time of referral as services may have become available or may no longer exist. Or the specialists that people are referring to are not ME/CFS specialists.

If participants were referred within the same time period, it seems reasonable to infer that GPs are unaware of existing services, including within Greater Manchester, or at least are not communicating this adequately to patients.

Nationally, rates of patients who had not been referred to ME/CFS clinics nor alternative departments ranged from 31.8%-36%. When considering those seeing other departments who were not ME/CFS specialists, this increased to 52% in Trafford, 44.3% in Greater Manchester and 42.4% UK-wide.

With this number of patients not seeing a specialist for their condition, it raises questions of who is overseeing their treatment. If this falls to GPs, this has worrying implications given the lack of knowledge that primary care physicians were felt to have (see findings of question 10).

13. Has a GP ever come out to you because you couldn’t attend the surgery?

All three areas had response rates of over 50%, with Trafford at 51.06%. Trafford had the highest percentage of reports that GPs had come out to them, at 29.2%. This compared to slightly lower rates in Greater Manchester and the UK, at 20.2% and 20.4% respectively. Although the question did not specify why the GP had come out, it is likely that in the context of the survey, this was taken to mean for ME/CFS related conditions. Furthermore, whether this was for another condition will still reflect flexibility when dealing with co-occurring illnesses, or the impact of a short-term illness upon someone already suffering with ME/CFS. It is therefore likely that these figures reflect willingness of doctors to treat patients outside of the surgery regardless of whether this is ME/CFS specific or not. As additional illnesses may impact a patient’s ME/CFS and exacerbate symptoms, home visits, regardless of cause, are likely to help patients with these symptoms.

14. How often do you see your GP on average each year?

Response rates remained above 50% for all three areas, with Trafford once again at 51.06%. Trafford and Greater Manchester had higher rates of patients visiting their GP three or more times a year than the UK (Trafford: 87.5%, GM: 81.2%, UK: 72.4%). This larger proportion of frequent visits may reflect severity or variability of symptoms, problems concerning treatment (such as side effects to medicines) or a number of other causes. This may include GPs continuing to try treatment, and offering support, making repeated visits feel worthwhile and of use to patients. However, when considered in light of findings that over 79% of patients in Trafford reported that their GP was not knowledgeable about ME/CFs, it seems unlikely that this is the case.

As people with ME/CFS in the Greater Manchester area appear to visit their GP more often, it is possible they are having more problems with their condition, or are not being given enough information to effectively their condition themselves (or have friends/family/carers treat them).

15. Would you say your GP/s speak to you with respect and fairness, listening to you?

Trafford response rates remained just above 50%, with the majority of respondents replying in all areas. In Trafford, 37.5% of patients felt that their GP/s sometimes, rarely or never spoke to them with respect and fairness. This number was fairly consistent in all areas, with 35.7% in Greater Manchester and 34.8% in the UK reporting the same. This is a large amount of people reportedly experiencing a poor manner from their GP.

In Trafford, only 25% of respondents felt their GP/s always treated them with respect and fairness, rising to 33.3% in Greater Manchester and 30.1% in the UK. This suggests that Trafford patients are experiencing higher than average rates of “poor manner” from their primary care physicians.

16. Have you ever been unable to access or been refused tests or treatment?

All areas once again returned responses above 50%, with Trafford at 51.06%. Trafford showed slightly lower percentages of people unable to access or refused tests or treatment (Trafford: 33.33%, GM: 40%, UK: 40.37%) than elsewhere in the UK. These numbers indicate a significant amount of patients unable to access these treatments or tests.

In Trafford, various reasons were given for being unable to access these. These ranged from waiting lists being too long (and thus not taking referrals) to being housebound from ME resulting in being unable to attend treatment in hospital, or missing other tests (such as cancer screening). If services are not flexible, it may result in those most severely affected being unable to access these treatments, and thus prejudicially meaning care is unavailable for those with more severe symptoms. As this extends beyond ME/CFS services, to appointments such as routine cancer screening, it is possible that those with severe ME/CFS may go on to have worse health outcomes, including from co-occurring illnesses.

17. Is there anything about GP services you would like to mention?

Trafford residents overwhelmingly responded that their GP didn’t know enough about ME/CFS. This lack of knowledge is likely to be the driving force behind many of the other themes, with ignorance of the condition affecting both interpersonal manner and clinical treatment. This manifested in GPs reportedly confusing ME/CFS with depression or being ‘just tired’, with obvious implications regarding correct treatment if the condition is being misdiagnosed. It is therefore likely that these patients are unable to access ME/CFS specific services without a provisional diagnosis, and may be given ineffective treatment. It is therefore not surprising that another theme was that training on ME/CFS was needed, or that there was a failure to diagnose the condition. This lack of awareness seemingly is tied to another theme, concerning patients needing to be proactive about treatment and care, including requesting referrals rather than relying on the GP to guide treatment.

Along with failure to correctly diagnose, another theme identified GPs being in disbelief about ME/CFS and not seeing it as a valid medical condition. Again, this is sure to hinder both treatment and will impact the way in which the patient is treatment, possibly leading to them feeling unsupported; another theme, being a hypochondriac, is likely to be related to this misunderstanding or disbelief about the condition. Poor interpersonal care was widely reported, with reports of GPs being rude or insulting, condescending or not listening. As GP services act as the primary point of contact for those with ME/CFS, this poor attitude towards patients is likely to be extremely discouraging and have negative effects upon patient experience of service use.

Issues regarding procedural complaints also formed the basis of themes, such as the GP not having enough time. This is likely compounded by another theme, that patients had to explain everything each time. As the ‘inconsistency of care’ theme encompasses seeing a different GP each time, this has implications for how patients’ symptoms are treated in context of their condition, and whether they have time to adequately explain in order to receive the correct treatment or recommendations. This inconsistency also covered GPs leaving and different levels of knowledge. Procedural problems were also evident in the theme concerning the difficulties surrounding securing an appointment, or GPs being unable to refer to specific services for reasons of ME/CFS. These all appear to collude to disrupt the ease in which patients may access treatment.

In contrast to these themes, there were also reports of GPs being supportive and sympathetic, or being ‘amazing’. It is therefore clear that despite widespread complaints, it is more than possible for GPs to provide excellent care for ME/CFS and to support patients with this condition.

18. Have you accessed any ME/CFS specialist care at a hospital?

The majority of respondents in all areas answered this question, with Trafford having a response rate of 51.06%. A larger proportion of people in Trafford had accessed ME/CFS specialist care at a hospital (62.5%) than those in Greater Manchester or the UK as a whole (53.5% and 47.8% respectively).

19. Do you find most (non-specialist) hospital staff have knowledge of or understand your condition?

Greater Manchester and the UK had response rates above 50% for this question, however Trafford dropped to 40.43%. In Trafford, 89.5% of people felt that most non-specialist hospital staff either did not have much knowledge of or did not understand ME/CFS. This was a similar finding to other areas, with 87.1% and 81.9% reporting the same in Greater Manchester and the UK in general. It is therefore clear that hospital staff are perceived to have either no or little knowledge of the condition. This has real implications for the way that patients are treated, whether medically or interpersonally.

20. Would you say hospital staff speak to you with respect and fairness, listening to you?

Trafford’s response rate remained at 40.43%, whilst other areas showed a majority response. 36.9% of patients from Trafford felt that hospital staff only sometimes, rarely or never spoke to them with respect and fairness. This rate was 54.6% in Greater Manchester and 53.5% in the UK. This suggests that people in Trafford report a higher percentage of hospital staff speaking to them with respect, fairness, and listening to them, that nationwide.

21. Where appropriate, have you been able to access phone, email, online or home visits? E.g. test results, making appointments, etc.

42.55% of participants in Trafford answered this question, whilst rates for Greater Manchester and the UK remained above 50%. Those able to access these types of services stood at 65% in Trafford, dropping to 54.4% and 49.5% in Greater Manchester and the UK respectively. This suggests that the Trafford area may be providing these services more often than respective services nationwide, however across GM and the UK as a whole, the number of respondents that say have not been able to access these services are still high (31.6% and 28% respectively).

22. Is there anything about hospital services that you would like to mention?

Similarly, to the question asking about GP services, the lack of poor knowledge of staff about ME/CFS and the need for education was a recurring theme. This poor knowledge is again likely to have implications regarding both clinical treatment and interpersonal care from medical professionals. This poor attitude of staff was once again highlighted, with condescension, lack of compassion and dismissive attitudes (thinking it is 'laziness') mentioned.

Regarding treatment, a theme became apparent regarding the preference of 'pushing' certain treatments such as graded exercise or CBT. This suggests that treatment is not a collaboration between patients and physicians, with the patient voice not being listened to. After this treatment, people mentioned being abandoned if they were not responsive, with some participants mentioning that such treatment actually made their condition worse.

Lack of consistency was once again a core aspect of a prominent theme, with a lack of consistency of quality of care across hospitals and departments mentioned. In addition, the waiting lists for these appointments seemed to be a recurring problem, as was the struggle to attend appointments due to the time of appointment or distance to the hospital. This was heightened by a lack of flexibility, with no option for remote appointments. This is likely to have a real impact upon those most severely affected with ME/CFS due to the debilitating fatigue those with the condition deal with. If a person is bedbound, a lack of remote appointments may be the difference between seeing a specialist and not receiving treatment or care.

There were also reports of consultants being helpful and services being good, so again it seems that some areas are excelling and are treating those with the condition in an appropriate manner, with one report of flexibility regarding appointment times (such as changing from am to pm).

23. Have you ever been an in-patient whilst having ME/CFS?

Response rates for all areas was above 50%. Rates of those having been an in-patient were similar across all three areas, with 37.5% in Trafford, 34.5% in Greater Manchester and 36.6% in the UK.

24. If yes, did they understand your ME/CFS and accommodate you?

Response rates did not exceed 50% for any of the three areas due to the prerequisite of having been an in-patient. 60% of participants in Trafford felt that their condition was not understood or accommodated. This was similar across areas with 53.1% and 53.8% in Greater Manchester and the UK respectively.

25. Were the environment and services suitable?

Again, none of the three areas had response rates above 50%, due to the prerequisite of experience of in-patient services. 50% of respondents from Trafford felt that the environment and services were not suitable, whilst this figure stood at 40.6% and 41.4% in Greater Manchester and the UK respectively. In-patient environments not being suitable for people with ME/CFS is clearly a national problem; the highest proportion of people saying they were suitable was 20% (Trafford). Many of these problems were elaborated upon in the follow up, qualitative question; these poor facilities included food, bedding, lighting and noise, as well as poor sleep and rest. Given the importance of rest in ME/CFS, conditions not being conducive to resting is likely to have a large impact upon patients' health and wellbeing. If patients are being seen for another condition, the exacerbation of ME/CFS symptoms is also likely to impair recovery following surgery or other in-patient services.

26. Is there anything else about in-patient services you would like to mention?

Again, the lack of knowledge of ME/CFS amongst staff and need for education was a predominant theme. This had similar impact in in-patient care as that reported in GP and hospital services, with both treatment and interpersonal implications. A lack of compassion from staff was highlighted (including a report of being told to 'get out of bed'), as was a misunderstanding of the importance of medication and its application.

Facilities were often perceived to not be appropriate for those with ME/CFS, for instance food, bedding, lighting and noise. This is likely to have contributed to another theme, that of poor sleep and rest. As ME/CFS patients often require large amounts of rest due to non-restorative sleep, the environment not being conducive to this can be reasonably assumed to have exacerbated symptoms.

Inconsistency of care between hospitals was highlighted, and backed up by contrasting reports of caring and professional staff, with good quality of care received. It is therefore clear that a disparity in care quality exists, with patient experiences differing hugely.

27. Have you ever complained to PALS (Patient Liaison Service) or a Practice Manager?

Trafford returned a 42.55% response rate, with Greater Manchester and the UK above 50%. Levels of complaints were similar across all areas; 25% of Trafford patients had filed a complaint, 21% of those in Greater Manchester had and 21.5% had in the UK.

28. If yes, what was the response you received?

Due to the prerequisite laid out in the previous question, response rates were similarly low across all areas; 12.77% in Trafford, 12.24% in Greater Manchester and 14.32% in the UK. Due to these response rates, Trafford and Greater Manchester both showed small sample sizes.

Trafford reported that 66.7% of people were not happy with the response they received, whilst this rate was 44.4% in Greater Manchester and 45.8% in the UK. In each area, those who were not happy with the response were the largest group, with those happy with the response ranging from 16.7% to 33.3%. This indicates that complainants are receiving a response they are not satisfied with in a large number of cases.

29. Have you ever complained to NHS England, the Local Government Ombudsman (LGO), or the Parliamentary and Health Service Ombudsman (PHSO)? – tick all that apply

The majority of respondents had not complained to any of these bodies; 81% had not in Trafford, 91.1% had not in Greater Manchester and 95.5% had not in the UK. Of those that had complained, the least accessed body was the LGO, with 0% complaining to them in

Trafford, 1.3% in Greater Manchester and 1.4% in the UK. This suggests that it may be worth more widely publicising this avenue.

Response rates were varied, with Trafford falling below 50% and greater Manchester and the UK having the majority of participants respond.

30. If yes, what was the response you received?

Due to the prerequisite imposed by the previous question, response rates were very low, reflecting numbers of those who had complained to the related bodies. 14.63% responded in Trafford, 7.48% in Greater Manchester and 4.65% in the UK. As with those who had complained to PALs or a practice manager, those who were happy with the response were the minority (0% in both Trafford and Greater Manchester, 7.7% in the UK) and those unhappy were the majority (83.3% in Trafford, 90.9% in Greater Manchester and 69.2% in the UK). This suggests that there is a nationwide lack of satisfaction in response to complaints to these services.

31. Do you have copies of your medical letters/records or know how to access them?

Response rates followed the same pattern as the past few answers, with Trafford at 46.8% and Greater Manchester and the UK both above 50%.

The largest response by percentage, across all groups, was that people did not know how to access their records (40.9% in Trafford, 41.8% in Greater Manchester and 49% in the UK). With large numbers of people being unaware how to access their medical records, it seems reasonable to assume that some participants may not have been aware that they could access these. As an alternative option was given for those that did not want to access records, it can also be assumed that these large percentages represent people who would like to see their medical records but were unaware of either their right to do so, or of the procedure to follow.

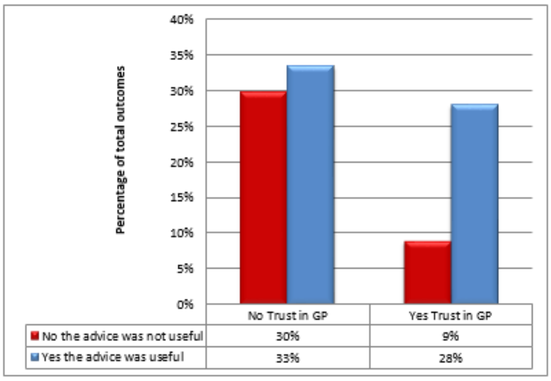
As ME/CFS often causes ‘brain fog’, or cognitive problems, it is likely that many people with the condition have memory problems or may otherwise struggle to remember what has been said in appointments/what tests have been run and the results of these. With this number of people wanting to access this information, but unaware of how to, it seems that little is being done to help patients with their condition-related cognitive difficulties.

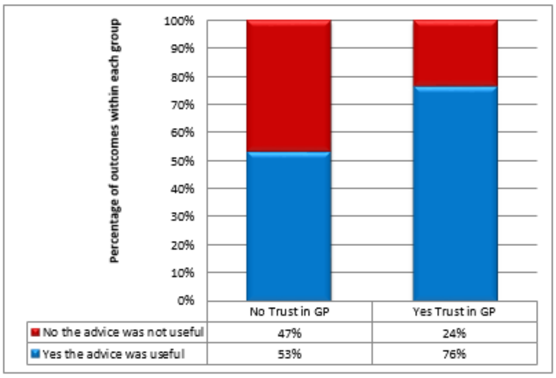
Further analysis

Links and comparisons

1. Trust in GP & Utility of advice

		NHS Advice useful?		
		No the advice was not useful	Yes the advice was useful	Row Totals
Trust in GP	No Trust in GP	94	106	200
	Yes Trust in GP	28	89	117
	Column Totals	122	195	317





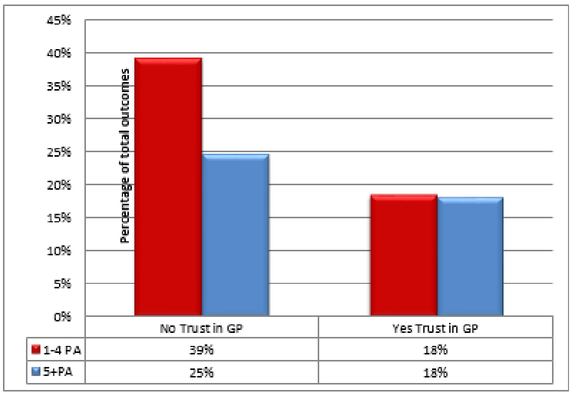
Here we looked at the correlation between how useful the information people had received about living with their condition was, and if they trusted their GP to provide them with information.

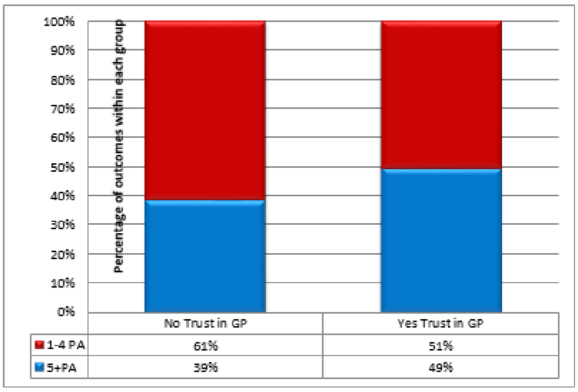
It is clear that amongst those in the group that said they did not trust their GP there was a much higher proportion of people that did not find the information they had been given useful. However most of the people that had received information said that it was useful.

This variance may be because it seems there is no standard information that is given out upon a diagnosis of ME/CFS in the NHS, meaning the information that is provided might be of varying quality and quantity. This could also indicate that these people are less likely to trust or value information if it comes from a GP that they do not have much trust in.

2. Trust in GP & Annual GP visits

		Annual GP Visits		
		1-4 PA	5+PA	Row Totals
Trust in GP	No Trust in GP	172	108	280
	Yes Trust in GP	81	79	160
	Column Totals	253	187	440





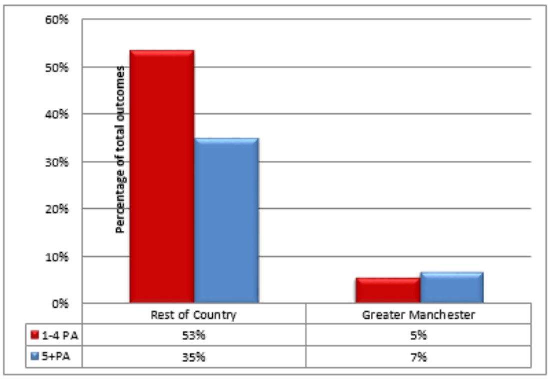
This comparison shows the number of GP visits per year that people who filled in the survey make, and if they have trust in their GP. It shows overall that the group that say they do not have trust in their GP tend to visit them much less often. Conversely this shows those visiting their GP more often are more likely to have trust in them.

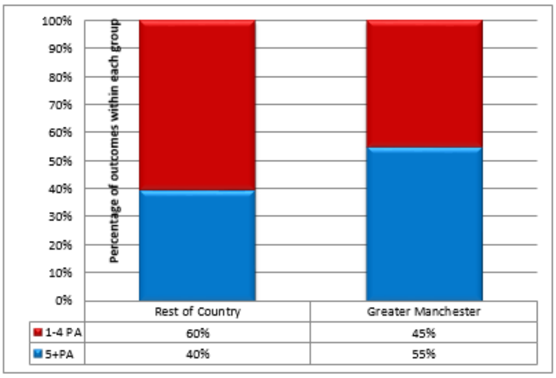
This could signify that people that do not have trust in their GP are more reluctant to see them, which could impact on their wellbeing. It could also suggest that trust in the GP increases when they are seen more often.

If we look at this table and the one above (1. Trust in GP & Utility of advice) it might be reasonable to suggest that the quality of information respondents were given that could be seen as affecting the trust respondents had in their GP, could also affect how often they visit their GP and possibly influence their potential welfare.

3. Greater Manchester & Rest of the UK : GP visits

		Annual GP Visits		
		1-4 PA	5+PA	Row Totals
Manchester or Rest of the Country	Rest of Country	327	214	541
	Greater Manchester	33	40	73
	Column Totals	360	254	614



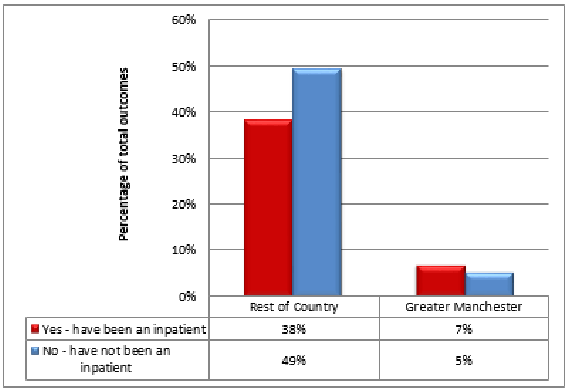


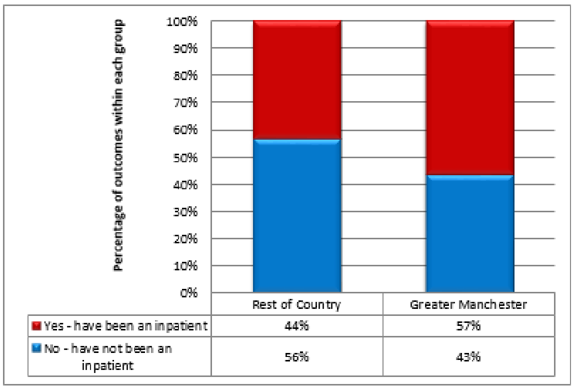
Here is a comparison of Greater Manchester and the rest of the UK respondents about how often they visit their GP.

It shows that those in the region are much more likely to visit their GP more often than in the rest of the UK. This is to the point where it is the reverse of the rest of the UK, where a strong majority visit 4 times per year or less, whereas in GM they are more likely to visit five times per year or more.

4. Greater Manchester & Rest of UK : Specialist Hospital Care

		Speciaist Hospital Care		
		Yes - have been an inpatient	**No - have not been an inpatient**	**Row Totals**
Greater Manchester & Rest of Country	**Rest of Country**	**233**	**299**	**532**
	Greater Manchester	**42**	**32**	**74**
	Column Totals	**275**	**331**	**606**



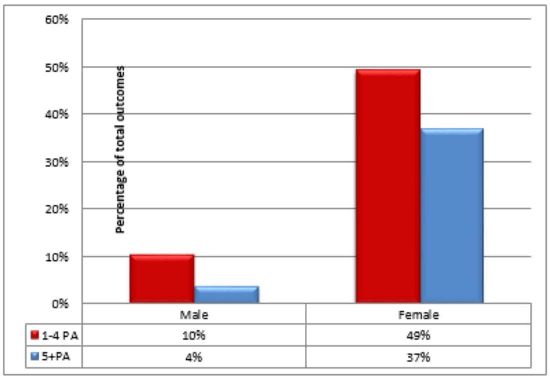


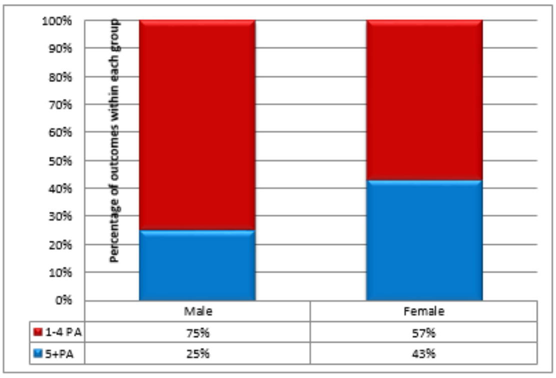
This question pulls together the responses of Greater Manchester and the rest of the UK to the question of whether they have been an in-patient with ME/CFS.

In Greater Manchester, the majority of respondents had been an in-patient, whereas in the rest of the UK, this figure was lower.

5. Gender & Annual GP visits

		Annual GP visits		
		1-4 PA	5+PA	Row Totals
Gender	**Male**	59	20	79
	Female	279	208	487
	Column Totals	338	228	566

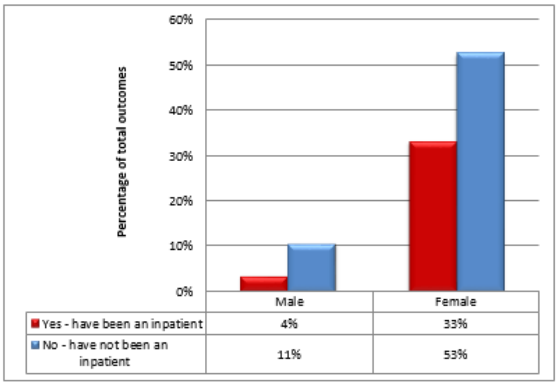


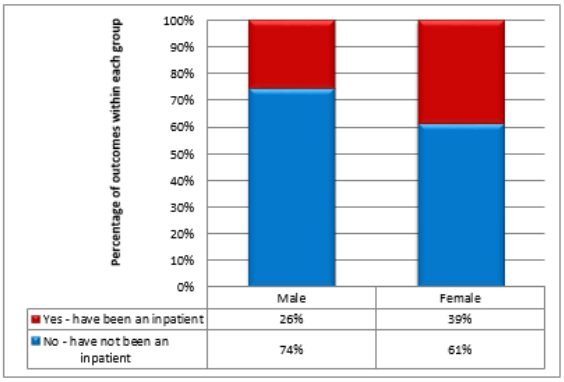


ME/CFS as a condition is widely known to occur in females significantly more often than in males. In GM amongst respondents 85.9% identifying as female and in the rest of the UK this figure was 86.4%. However, this table shows remarkably different behaviour between males and females, showing that males made significantly less visits to their GP in a year.

6. Gender & In-patient admission

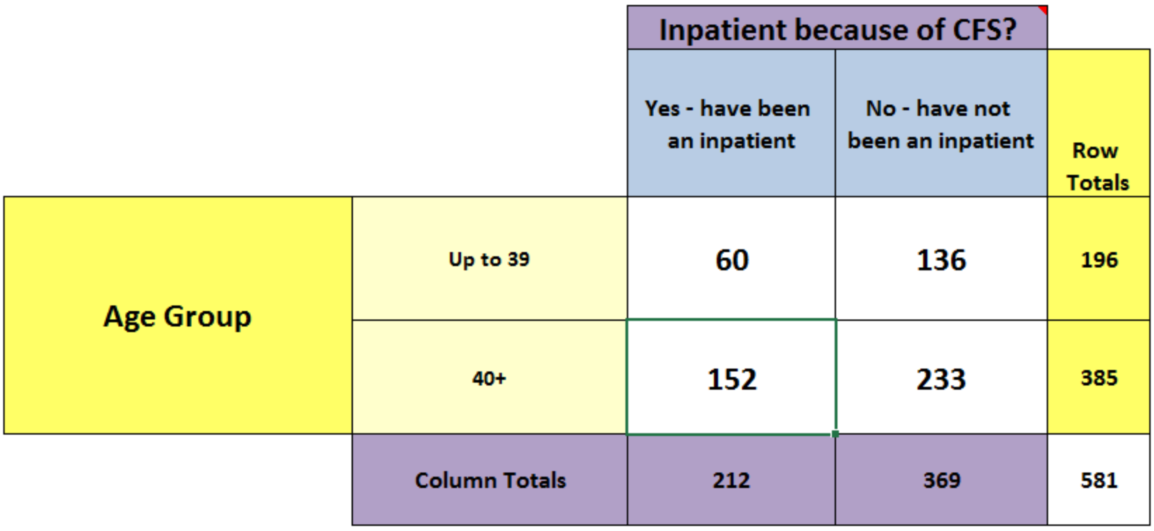
		Inpatient because of CFS?		
		Yes - have been an inpatient	No - have not been an inpatient	Row Totals
Gender	**Male**	21	61	82
	Female	191	303	494
	Column Totals	212	364	576



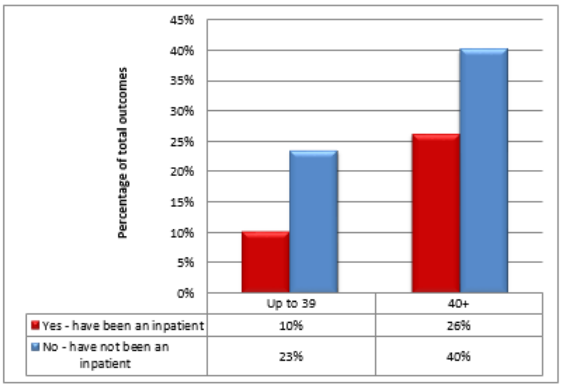


As with the previous table, the one above shows the difference between the male respondents and the female one. It shows that females are much more likely to have been an in-patient. It may be worth further exploration to see if this mimics the behaviour differences that exist in the likelihood of being an in-patient for any condition, although the data was not available at the time this report was published.

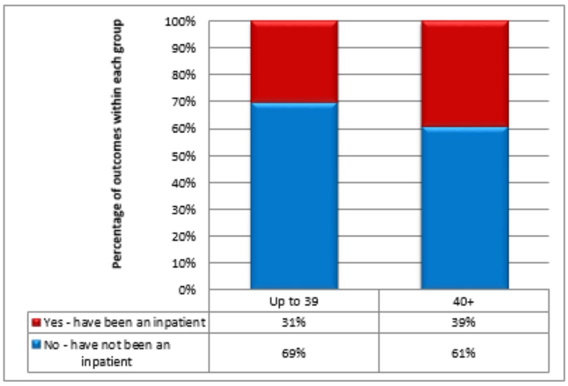
7. Age group & In-patient admission



		Inpatient because of CFS?		
		Yes - have been an inpatient	No - have not been an inpatient	Row Totals
Age Group	Up to 39	60	136	196
	40+	152	233	385
	Column Totals	212	369	581



	Up to 39	40+
🟥 Yes - have been an inpatient	10%	26%
🟦 No - have not been an inpatient	23%	40%

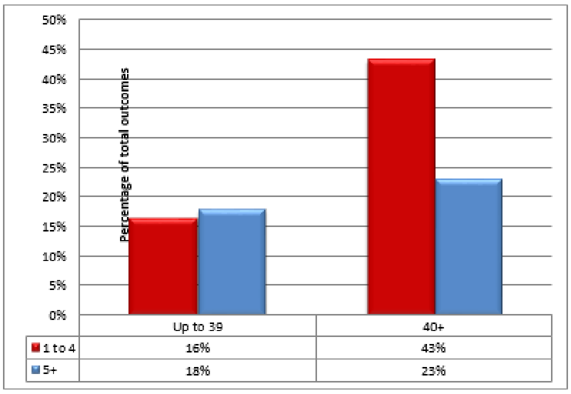


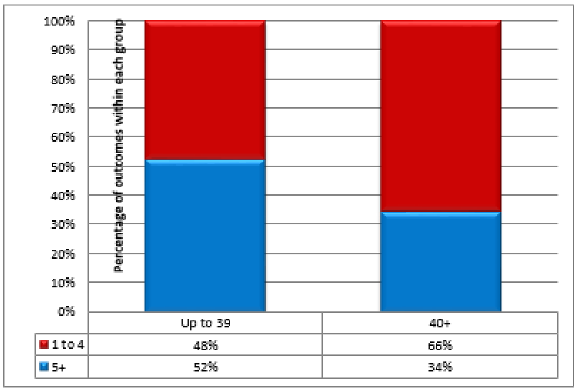
	Up to 39	40+
🟥 Yes - have been an inpatient	31%	39%
🟦 No - have not been an inpatient	69%	61%

Looking at this table show the likelihood of being an in-patient because of having ME/CFS is noticeably higher amongst those aged 40 or older. As with the previous graph, it may be worth further exploration to see if this mimics the behaviour differences that exist in the likelihood of being an in-patient for any condition, although the data was not available at the time this report was published.

8. Age group & GP visits

		GP Visits		
		1 to 4	**5+**	**Row Totals**
Age Group	**Up to 39**	**93**	**101**	**194**
	40+	**247**	**130**	**377**
	Column Totals	**340**	**231**	**571**

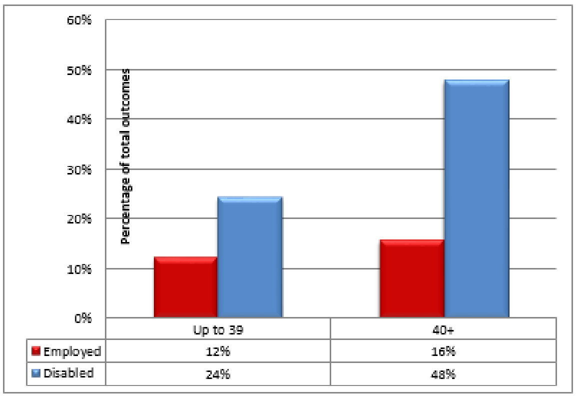


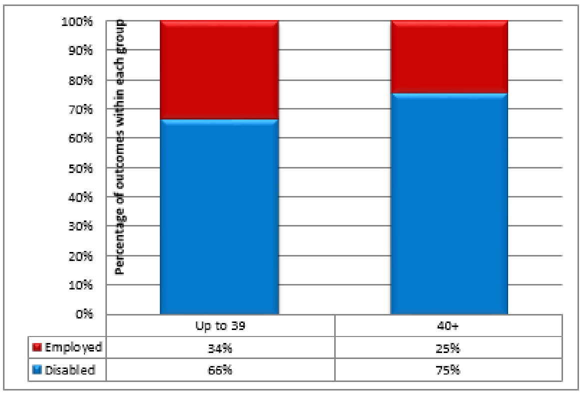


From previous data in the question that asks ‘How long have you had ME/CFS’ we know that 52% have had the condition for more than a decade, and 66% of the respondents were 40 years old or more. So we are aware that the condition seems to occur more in those 40 or over, but this table shows how much more likely this group is to need in-patient care. This might be age related rather than condition related, but is certainly likely to at least be complicated by ME/CFS.

9. Age group & Employed/Disabled

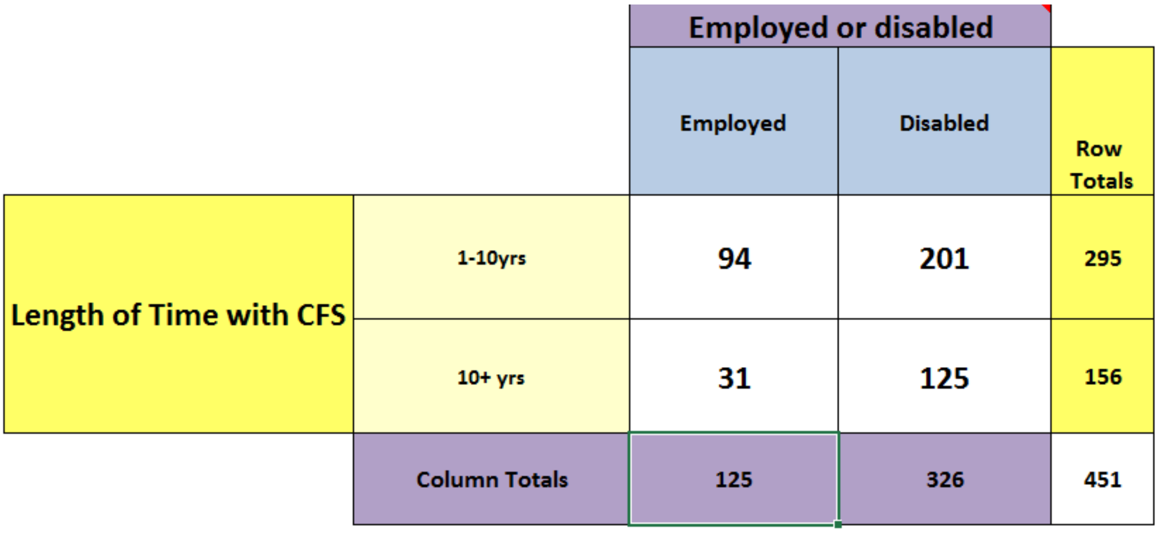
		Employed or disabled		
		Employed	**Disabled**	**Row Totals**
Age Group	**Up to 39**	56	111	167
	40+	72	220	292
	Column Totals	128	331	459



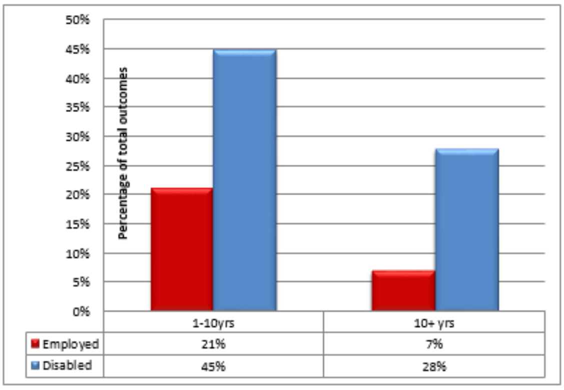


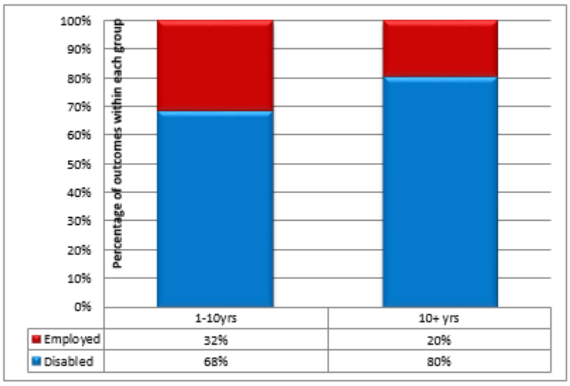
What is clear from the table above is that the majority of respondents with ME/CFS considered themselves disabled and not employed, regardless of age. However, this majority grew significantly in the 40+ age group.

10. Time with ME/CFS & Employed/Disabled



		Employed or disabled		
		Employed	Disabled	Row Totals
Length of Time with CFS	1-10yrs	94	201	295
	10+ yrs	31	125	156
	Column Totals	125	326	451

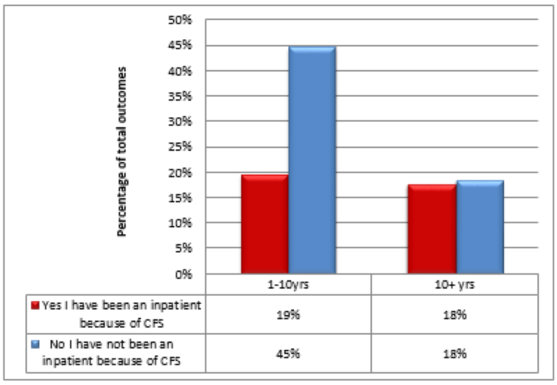


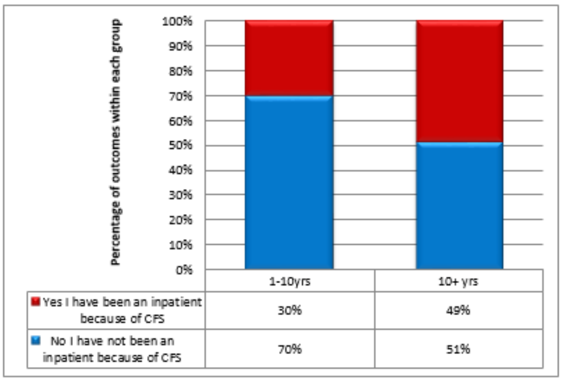


Here we can see that the likelihood of a respondent considering themselves do be disabled rather than employed increases from 68% from those that have had the condition less than 10 years, to 80% among those that have had it for 10 years or more.

11. Time with ME/CFS & In-patient visits

		Inpatient Yes or No		
		Yes I have been an inpatient because of CFS	**No I have not been an inpatient because of CFS**	**Row Totals**
Length of Time with CFS	**1-10yrs**	**115**	**263**	**378**
	10+ yrs	**104**	**109**	**213**
	Column Totals	**219**	**372**	**591**

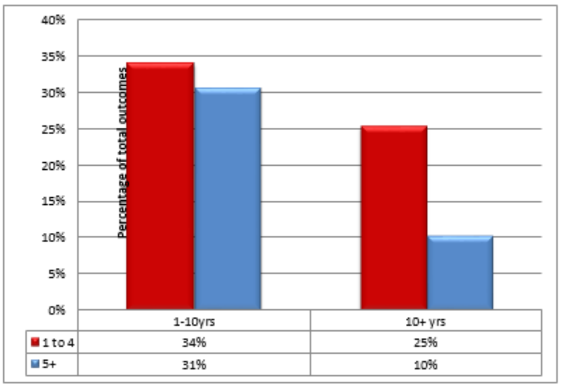


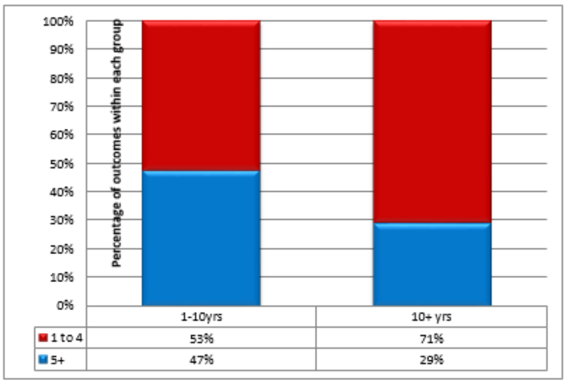


This table shows if a respondent has spent time as an in-patient because of ME/CFS compared to how long they have had the condition.

We can see that in-patient stays have occurred more in those that have had ME/CFS longer. This may be as the likelihood of needing an in-patient stay over a longer period of time grows. Of those that had the condition 10 years or more, almost half (49%) had needed in-patient care for their condition.

		Annual GP visits		
		1 to 4	5+	Row Totals
Length of Time with CFS	1-10yrs	202	182	384
	10+ yrs	150	61	211
	Column Totals	352	243	595



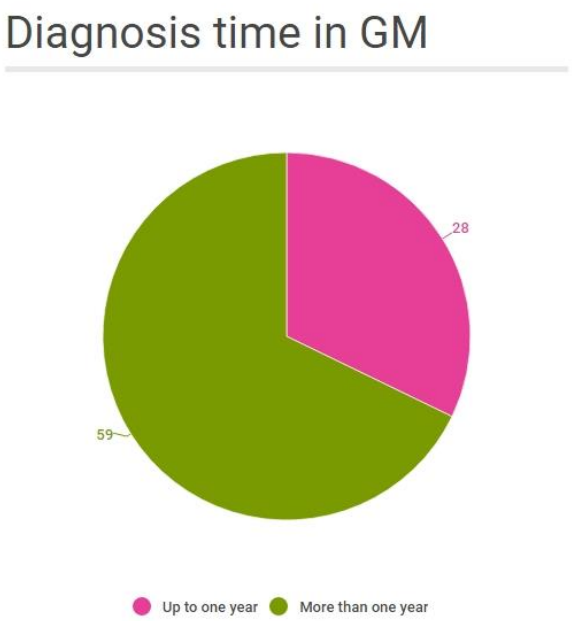


This table shows the number of GP visits by respondents was less for those that had the condition longer. Those that had the condition for less than 10 years were likely to see a GP more often per year.

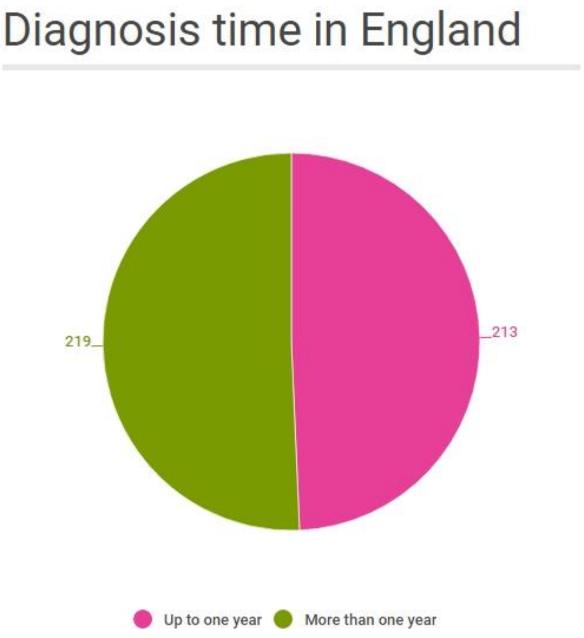
This could possibly be explained by those people newer to the diagnosis requiring more help with dealing with the condition, or not being as familiar with what the symptoms are and how they can be explained.

12. Up to one year vs Over one year – GM v England

		GM_v_England		Total
		Greater Manchester	England	
Diagnosis: Up to one vs over one year	yearless than 3 months and up to one year	28	213	241
	one year and up to more than 5 years	59	219	278
Total		87	432	519



Diagnosis time in GM

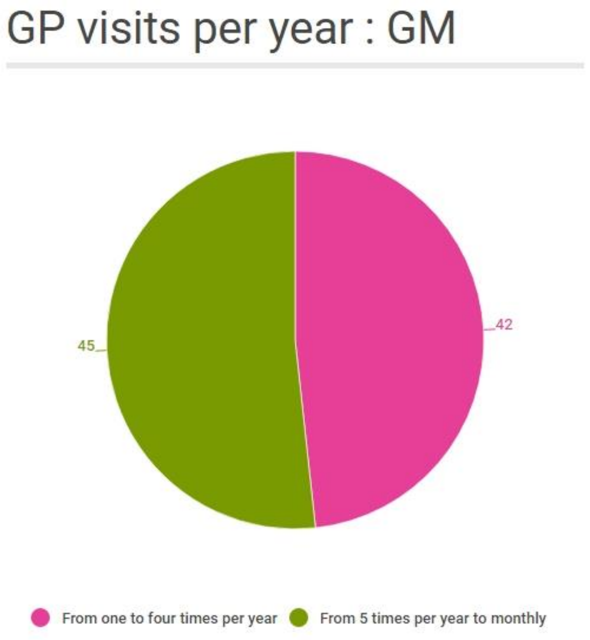


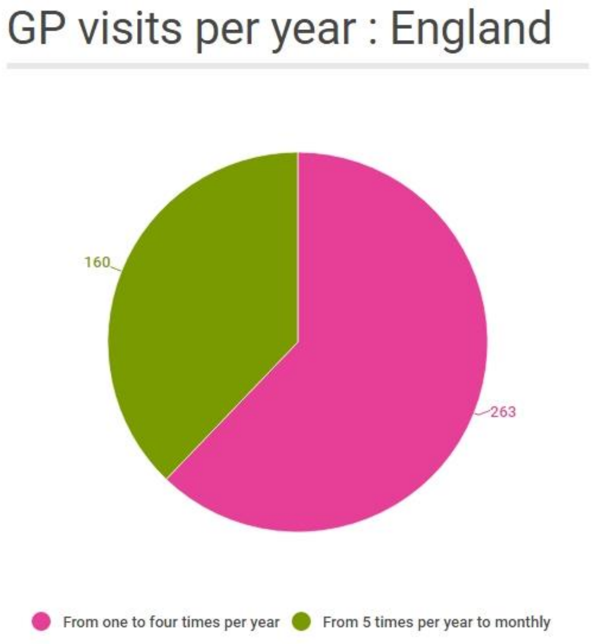
Diagnosis time in England

The information in this table shows that the amount of time that respondents said it took before they got a diagnosis in Greater Manchester compared to the rest of England. Interestingly it shows that the number of people that had to wait more than a year is significantly more in Greater Manchester.

13. Number of yearly GP visits – GM vs England

		GreatManc_v_England		
		Greater Manchester	England	Total
Annual GP Visits as Dichotomy	from 1 to 4 times/year	42	263	305
	from 5 per year to monthly	45	160	205
Total		87	423	510





In this table we see how often people visit their GP per year in Greater Manchester compared to the rest of England. We can see a significantly larger number of people visited their GP more often in GM. This is corroborated by table 3, which shows a similar comparison with the rest of the UK.

This could be related to the previous table (12) showing that diagnosis time is longer in GM, with people possibly more likely to visit their GP more often when in need of a diagnosis for their symptoms.

These tables could also relate to table 4, showing respondents from GM are more likely to have been an in-patient for ME/CFS. This appears to show that there is a possible link between the taking longer to get a diagnosis and likelihood of requiring in-patient care and more regular GP visits. This however could benefit from further study.

Response

Trafford Clinical Commissioning Group responded to the report with the following points:

- We note that the sample size of 47 Trafford patients who took part in the survey is relatively low and further work may be required to establish the extent of issues for Trafford patients. It should be noted that a member of our Patient Experience Matters team met with the Salford and Trafford ME Group early this year and this has provided us with further insight in the experiences faced by Trafford patients.
- It is clear that improved education, particularly for GPs would be beneficial.
- We recognise that not all issues can be addressed by Trafford CCG and we welcome the report being used to inform further discussion at a future Greater Manchester Commissioning Leads meeting.

NHS Trafford CCG has noted the report and has already started to discuss with colleagues ways that we can take forward some of the recommendations cited.

We would welcome further dialogue with Healthwatch Trafford to help us develop an action plan to help address the issues raised.

Next Steps

*This section is still being compiled, and will depend upon the responses of commissioners.

Appendix 1

The survey questions asked.

Introduction

The aim of this survey is to gather and understand experiences of ME/CFS patients accessing health services.

By gathering this information, we will be able to identify where services are doing well and where they need to improve. We can then work with services and commissioners to make them better.

If you are affected by ME/CFS we would really appreciate hearing your experiences, it should only take a few minutes. Please also be aware that your answers are COMPLETELY ANONYMOUS - you cannot be identified by your responses and we will not ask for your name at any point so please be honest. We will publish a report about our findings but individuals' answers will never be made public. Local Healthwatch are completely independent organisations and are not part of the NHS.

The survey is being carried out by Healthwatch Trafford, however if you are not a resident of Trafford please continue to fill out the survey and the results will be passed on to your local Healthwatch. If you would like to know more about your local Healthwatch, click here to find which covers your area.

You do not have to answer every question (although you do have to answer question 1) however the more information we can gather, the more accurate our report can be and the clearer the picture of how health services are serving the ME/CFS community we can build.

Please pass this on to anybody you think it might be relevant to.

So we can know which area's Healthwatch to send information to, please answer question 1 below.

* 1. What is your local authority (local council)?

[Pick from dropdown of all England Healthwatch areas, Scotland, Wales, Ireland, Isle of Man or other – please specify]

Your ME/CFS

Tell us a bit about your ME/CFS

2. How would you describe you current level of ME/CFS

☐ Mild (able to work/study full-time)
☐ Moderate
☐ Severe (bed/housebound)

3. How long have you had ME/CFS?

____

4. What has been the main factor/s or trigger/s for your ME/CFS?

☐ Virus or infection e.g. (Glandular Fever etc.) Traumatic event, operation or accident
☐ Vaccination/Innocultation or drug treatment (e.g. Hepatitis B vaccination etc.) Physical / Environmental substances (e.g. toxins, elements or fumes etc.) Hormonal problems
☐ Another illness e.g. cancer Parasite(s)
☐ Stress, Depression or other mental health issue
☐ Lifestyle (Eg. Eating habits, extreme excercise, recreational drugs, sleeping patterns etc) Other (please specify)

5. Have you had a formal diagnosis from a doctor?

☐ Yes
☐ No

6. If yes - How were you diagnosed?

____

Services you use

7. What is the name and address of your GP Surgery?

Surgery Name:

Address:

Address 2:

City/Town:

ZIP/Postal Code:

8. What hospitals do you regularly use?

Most used:

Other:

Other:

9. What was the hospital you used MOST RECENTLY

Accessing Services

10. Have you been offered any information from the NHS on living with the condition?

- ☐ Yes, from my GP
- ☐ Yes, from ME/CFS department or hospital department that diagnosed me
- ☐ Yes, from another service or department
- ☐ No

11. If yes, was that information helpful?

- ☐ Yes
- ☐ No

12. How long did it take to be diagnosed after first reporting symptoms to your GP?

- ☐ Less than 3 months 3 to 6 months
- ☐ 6 months to a year
- ☐ 1 to 2 years
- ☐ 2 to 5 years
- ☐ More than 5 years

GP services

How have you found GP's and appointments

13. How does your GP talk about your condition?

- ☐ They are knowledgeable and supportive
- ☐ They are not knowledgeable but they are supportive
- ☐ They are knowledgeable but not supportive
- ☐ They are neither knowledgeable nor supportive

14. Would you trust your GP to provide you with information about ME/CFS?

- ☐ Yes
- ☐ No
- ☐ I don't know

15. Has your GP referred you to ME/CFS services?

- ☐ No
- ☐ Yes ME/CFS dept out of area
- ☐ Yes ME/CFS dept within the area/council that I live
- ☐ Yes another dept (no ME/CFS clinic available). - Please specify

16. Has a GP ever come out to you because you couldn't attend the surgery?

- ☐ Yes
- ☐ No

17. How often do you see your GP on average each year?

- ☐ 1-2 times per year
- ☐ 3-4 times (Once a quarter)
- ☐ 5-6 times (every two months) Monthly
- ☐ Weekly

18. Would you say your GP/s speak to you with respect and fairness, listening to you?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Sometimes
- ☐ Rarely
- ☐ No, never

19. Have you ever been unable to access or been refused tests or treatment?

- ☐ No
- ☐ Yes - please explain

20. Is there anything about GP services you would like to mention?

____

Hospitals

How have you found your hospital treatment?

21. Have you accessed any ME/CFS specialist care at a hospital?

- ☐ Yes
- ☐ No

22. Do you find most (non specialist) hospital staff have knowledge of or understand your condition?

- ☐ Yes, most understand and treat me appropriately
- ☐ Yes, most have some knowledge of ME/CFS
- ☐ Most don't have much knowledge of ME/CFS
- ☐ No, most do not understand ME/CFS

23. Would you say hospital staff speak to you with respect and fairness, listening to you?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Sometimes
- ☐ Rarely
- ☐ No, never

24. Where appropriate, have you been able to access phone, email, online or home visits? E.g. test results, making appointments, etc.

- ☐ Yes
- ☐ No
- ☐ N/A (not applicable)

25. Is there anything about hospital services that you would like to mention?

____

In-patient treatment

26. Have you ever been an in-patient whilst having ME/CFS?

- ☐ Yes
- ☐ No

27. If yes, did they understand your ME/CFS and accommodate you?

- ☐ Yes
- ☐ Somewhat
- ☐ No

28. Were the environment and services suitable?

- ☐ Yes
- ☐ Somewhat
- ☐ No

29. Is there anything else about in-patient services you would like to mention?

____

Complaints

30. Have you ever complained to PALS (Patient Advice and Liaison Service) or a Practice Manager?

- ☐ Yes, to PALS
- ☐ Yes, to a practice manager
- ☐ Yes, to both
- ☐ No

31. If yes, what was the response you received?

- ☐ Positive, I was happy with their response
- ☐ Neutral, it was ok
- ☐ Negative, I was not satisfied by their response

32. Have you ever complained to NHS England, the Local Government Ombudsman (LGO), or the Parliamentary and Health Service Ombudsman (PHSO)? - tick all that apply

- ☐ Yes, to NHS England
- ☐ Yes, to the Local Government Ombudsman (LGO)

☐ Yes, to the Parliamentary and Health Service Ombudsman (PHSO)
☐ No

33. If yes, what was the response you received?

☐ Positive, I was happy with their response
☐ Neutral, it was ok
☐ Negative, I was not satisfied by their response

34. Do you have copies of your medical letters/records or know how to access them?

☐ Yes, I have copies
☐ I know how to access them
☐ I don't know how to access them
☐ I don't want access to them

Managing your condition

35. IF you have used any of the following, did you find it made your ME/CFS more or less managable?

	More manageable	No difference	Less manageable	Not tried
Cognitive Behaviour				
Therapy (CBT)				
Graded Exercise Therapy (GET)				
Pacing				
Physiotherapy				
Occupational Therapy (OT)				
NHS Nurse at hospital or home visits				
NHS ME/CFS group				
Psychiatric treatment				
Nutrition or dietician				
Very gentle yoga/meditation				
Acupuncture/acupressure				
Pain medication				
Osteopathy				

36. Is there anything else you would like to tell us about managing your condition?

____

Demographic information

We will use the information in this section to look for any patterns in treatment of any of the groups below. It is not used to identify you in any way. If you do not feel comfortable answering any of the questions then you can skip them, however the more we understand how various groups of people are treated the better we are able to improve their experiences so it would be very helpful to us if you did fill them in.

37. Do you identify as

☐ Female
☐ Male
☐ Other

38. What is your age?

☐ 17 or younger
☐ 18-20
☐ 21-29
☐ 30-39
☐ 40-49
☐ 50-59
☐ 60 or older

39. Which of the following best describes your current relationship status?

☐ Married
☐ Widowed
☐ Divorced
☐ Separated
☐ In a domestic partnership or civil union
☐ Single, but cohabiting with a significant other
☐ Single, never married

40. Which of the following categories best describes your employment status?

☐ Employed, working full-time
☐ Employed, working part-time
☐ Not employed, looking for work
☐ Not employed, NOT looking for work
☐ Retired
☐ Disabled, not able to work

41. How would you describe your ethnicity?

- ☐ White British
- ☐ Black British
- ☐ Asian British
- ☐ White
- ☐ Black African
- ☐ Black Caribbean
- ☐ Other Black
- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Other Asian
- ☐ Other (please specify)

42. Sexual orientation

- ☐ Straight / Heterosexual
- ☐ Gay / Lesbian / Homosexual
- ☐ Bisexual
- ☐ Other (please specify)

Last page!

Thanks for getting through this survey. Just before you submit it, could you please let us know how you found this survey, and how you think our surveys could be improved in the future?

43. How did you find out about this survey?

44. How easy was it to complete?

- ☐ Very easy
- ☐ Easy
- ☐ It was ok
- ☐ Quite difficult
- ☐ Very difficult

45. How could our surveys be improved in the future?

That’s it!

Appendix 2

Contained below are the comments that people made in the open-ended freetext sections of the survey. To protect the participants anonymity, the comments have been edited to ensure that anything that could identify a person has been removed. Other than edits for that reason, the comments are left verbatim.

Is there anything about GP services you would like to mention?

“Lots of different GP's now. non of them have known me for long.”

"I am unhappy [and have raised the issue] that I do not think the M.E. is flashed up on my digital records at the surgery”

“there is always an air of disbelief about the condition"

“Since moving to Trafford [edit] years ago I have seen my new GP on average less than once or twice a year but ticked that box as my answer because you did not offer me the option of ticking a box to indicate that. I can not comment on the quality of care from my GP as I am not well enough to see them. After being told that I had to come into surgery for appointments and not being well enough to do so now for almost three years, I managed to arrange a home visit for the first time this week. However, I was put under duress to attend the surgery when I asked for it and was told that as [edit] an adult I should be capable of getting to the surgery and that I would have to accept a less thorough examination at home to what I could expect from the surgery.I was even told that as "paraplegics" are capable of seeing them, so should I. As I am completely bed bound 95% of the time I said that I would rather have a home visit than not being seen at all and with much reluctance I was given a home visit by [edit] the surgery. The doctor who attended was very nice but I was alarmed that crucial information such as my allergies was missing from my medical notes. In addition to not being well enough to attend for my GP, I have also not been well enough to attend the hospital other than a few times. In fact I am suffering from possible [edit] cancer but have not been well enough to have that investigated. My GP arranged for me to see a nurse at the hospital to advise me on energy management and provide psychological support. However, as I have not been well enough to attend [edit] hospital, I have now been dismissed and not offered any alternatives. I have asked whether I could have treatment over the telephone or skype but have been told that this is not available. I am very dissapointed with this. Indeed, I feel that my last contact that i managed to have with my Consultant [edit] at the hospital was no better. After being told that I had to rush because [edit] they only had a 10 minute window after being delayed in seeing me, [edit] they told me that I was just repeating myself from what I told [edit] them last time and that [edit] they did not understand why I was seeing [edit] them as [edit] they could not see as to what [edit] they was supposed to do to help me. I feel completely abandoned with no help and often question my purpose in being here although I am desperate to live. I don't even have a carer at the moment as the council said I had to pay for one but I could not afford the contribution they were asking for. When the council came to make my financial assessment they did not ask me any questions about how much I need to spend on my disability nor in getting an understanding of my disability. Whilst my ex partner is in the process of writing an appeal he has not well enough to get it done so far as he suffers from [edit] a condition. He has been working on it for the past six months. I am really worried about whats going to happen with it. I feel that someone like me needs an advocate to support them in these circumstances. As it is, not only do I have to face my illness, I also have to face a general lack of understanding of it and no proper means of support. “

“I don't have a regular GP. There are several doctors and you see whichever one is free. This means its hard to build a relationship and you have to re-explain your circumstances and start from scratch each visit.”

“I had to ask for help before it was offered - which GP said [edit] themself! Should have been based on medical need surely? I personally pursued Trafford PCT to obtain legal entitlement to services under NICE Guidelines - eventually GP surgery supported my claim. Not pro-active at all. If I do not contact surgery, I would never hear from them.”

“Difficult to get appointments have to book weeks in advance if want to see a specific doctor”

“It's very difficult to see the same doctor regularly, I've seen 4 different doctors since diagnosis (including one locum), each with differing views on cfs and how to treat it so care and support has been varied.”

“For the past 16 years only seen 4 good GPs in Trafford, Salford, Manchester [Edit]. Others (7 big surgeries) treated like lazy hypochondriac, shouted at and aggressive gestures, laughed at inappropriate personal comments, refused treatment, spoken down to. Only after they realise ME/CFS”

"Most don't know where the specialists ME departments and refer you to the wrong place. They also don't know what ME is.”

“Over 16 years in Salford then Manchester now Trafford, I've been refused treatment, treated like a lazy benefit cheat hypochondriac, shouted at and aggressive personal comments and gestures, laughed at and spoken down to - by ever GP I've seen in 7 large GP surgeries except 4 gps [edit]"

"Seems to be general problem in old Trafford.”

“Overall in Trafford, Salford, Manchester been treated like lazy benefit cheat hypochondriac, refused treatments, shouted and laughed at, personal inappropriate comments."

“feel as though even though they listen they are dismissive and one feels like a hypochondriac. I have had the same symptoms for years which worsened after a cancer op. and feel let down even though hospital consultant is very nice and does all tests available. everything seems ok but why am i feeling so tired, lethargic, just wanting to lie down and sleep all the time.nothing getig done in the house or garden... so upsetting and not normal. las visit to doctor is as always ANTIDEPESSANTS.. i do not feel as though I need or want antidepressants as i think side effects outweigh anything else. I just want to function normally asnd not being in pain which is tiring in itself.   I feel a nuisance and feel a doctors visit is a waste of time”

“GP's are very unaware of ME. Many still charge for letters when ME sufferers have no income to afford charges. I have mainly needed letters to prove my situation and could not have achieved what I have, had my GP practice charged me for this element of support.”

“I moved to Trafford 6 months ago. I have remained registered with my GP where I used to live (with prior agreement of practice manager) as currently on waiting list for East Manchester CFS/ME service and have been for last 18 months. If I moved to a local Trafford GP I would not be able to access this service and I believe there is nothing similar offered in Trafford.”

“Only one dr worth seeing”

“My GP practice is incredibly supportive - they've referred me to UCL so I could take part in a clinical trial. There are no services locally beyond my GP that I'm aware of.”

“Where ME is concerned they have no training, no clear advice, or cure to offer. Once you have been passed to ME clinic that is all they are able to do.”

Is there anything about hospital services that you would like to mention?

“Skype for those who are bedbound. Also ambulance service to appointments is not an option for me. I have missed appointments due to them not showing up. But more importantly I have [edit] another condition and am exhausted by just sitting upright. I am told that I have to be ready at 8am even if appointment is not for hours. When an appointment is over it may take hours for me to get home. Travel takes everyone home first and you have to wait for enough people before they leave. This has made me very ill for over a month and I cant do it again. Also there is no where to lie down and I have allergies and there is nothing at the hospital I can eat. The way things are at the moment hospital appointment make me very ill and that is if i am well enough to attend and I haven't been for 3 years”

"I heard about the CFS department at Salford royal and my GP did support my referral to there.”

“anything I gained form the experience was actually negated by the huge distance from me that it was and I was nervous of driving there so had to go by tram and taxi”

“once there I had an ongoing 'battle' for them to distinguish between CFS and M.E. so I felt they did not truly understand the condition and were mainly dealing with people who could still work full time or study!"

“I was eventually given a choice of which specialist ME service to use. I opted for Salford as led by an endocrinologist. This has proved to be very pragmatic and supportive. I have gradually seen small improvements, which is what I was promised when I first went some five years ago.”

“Cannot fault Salford Royal been very impressed . MRI not as efficient long waits in clinic ,bloods and other services”

"Again education. Can be addressed with Invest In ME and ME Association booklets.”

“Nurses generally good. Drs generally bad.”

“GPS are the worse.”

“The only good ME/CFS clinic in Gtr Mcr I've accessed is former Dr [edit] at North Mcr.

“East Mcr waste of money - could give book e.g. Sue Pemberton Yorkshire ME clinic, of leaflets instead and use money instead for care and proper diagnosis and exclusion testing.”

“Groups, ME yoga (if optional), nutrition needed.”

“Biopsychosocial model with psychology and Graded Exercise used to much - which is dangerous and against medical research evidence."

“Main issue is education, not knowing what ME is. And those that claim to know or are specialists, have their own unproven 'theories' as well as focusing on psychology and graded exercise, which does not help. The only good ME clinic I've accessed is the former Dr [edit] in North Manchester. East Manchester service is waste of money, could use Sue Pemberton book or ME Association/Invest in ME info leaflet instead and spend money on care and diagnosis.”

“Education needed”

“ys.. i was left on a commode after a serious op lst time i was in and shoued for help as the door was closed.. i could not reach the buzzer.. my mobile was near me so i phoned a relative to get them to phone the hosp/ward for help. a nurse cme in beaming saying yOU RANG! no apology... I was in hosp for 0 days befoe i was granted help with a shower.....”

“ME rarely needs hospitalisation as life is not usually at risk. In fact, it is the absence of any real evidence of the illness that creates such poor understanding and recognition. My mother works with GPs and finds all three of them appear to not consider ME in their differential diagnosis and patients still go years without support or with the wrong diagnosis.”

“There are no services in Greater Manchester that I'm aware of.”

“There seems only partial cover of our symptoms. No referral to neurology or mitochondria departments to see if they can help.”

Is there anything else about in-patient services you would like to mention?

“I don not say I have ME - people just don't understand it.”

“Noise, food, dust allergy, bedding ie what the washing powder is as I'm allergic....it all worries me how I would cope if ever I needed to go into hospital”

"I have just had absolutely marvellous treatment following surgery at the Christie. the staff were much more respectful of the M.E. than my experience at Wythenshawe 12 years ago [who ignored it despite the then Stockport M.E. nurses providing an information pack for them]. the Christie staff were respectful and it always appeared on any written information about me some staff even asked about it. the worst element was the noise and light at night- a total onslaught to anyone woth sensory sensitivity. on refection I should have gone into much more detail about the M.E. when I attended my pre-op assessment. once in the Christie and experiencing these issues I asked for a side ward but whilst initially accepted for this unfortunately it became impossible as the patient already in there developed an infection However!! being on a ward was more 'sociable' for me and better for my mental health I think so having experienced a side room in Wythenshawe- and now both the Critical Care unit and then the ward at the Christie I couldn't say which was best”

“I'm sorry I can't be of more help on that score"

“Anæsthetist knew that ME sufferers need to have different amounts to most other folk of anæsthetic.”

"Again didn't understand ME - education. Not properly or at all as allergies or asleep.

“Too cold no blankets. Too loud and bright. Not allowed to sleep and rest. Too noisy overnight - nurses chatting loudly about personal non hospital stuff next to beds.”

“They didn't understand ME. Not fed due to allergies, too cold no extra blankets, too bright and noisy, not allowed to sleep and rest. No extra blankets, food allergies not catered fo, too light and noisy, not allowed to sleep. Not fed if asleep or allergy. Again education on ME”

“Mine was an attempted suicide and I was told to go to A&E should I feel the same way again. This is a totally unsuitable option and unrealistic, when feeling so low. Wasnt allowed my meds and treated like i was making it up!

“I was at MRIS, the staff were very, very supportive -I was in for gynae surgery, nothing to to with ME, and they were very accommodating.”

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

Is there anything else you would like to tell us about managing your condition?

“Do not mention my ME - try & get them to help with the sypmtoms”

“Diet and nutrition massively help. This is really one of the best things i have found to improve my condition. There is a person who has [edit] the same conditions like me and did not get better with medication but got completely well with the diet I am on. The nhs is going to do a medical study on her diet to learn from this. [edit]. However this diet and allergies cost a lot. I was told at financial assessment that allergies do not cost anything but that is very incorrect. Dairy and gluten free substitutes are at least twice the price. Wholefood diet is expensive. Vitamins that do help cost a lot. Nhs vitamins contain dairy and colourings so I can't have them. Fragrance free washing powders and cleaning products are expensive. High bills due to allergies, extra showers for [edit] other condition, vacuuming, heating for low blood pressure as I get very cold, washing machine and tumble dryer on all the time. Dehumidifier etc. I have to buy things to make doing things easier like electric can opener, tablet so I can get online, steamer to kill house dust, and my washing machine breaks more often as it gets clogged up with [edit] treatment cream from towels and clothes.

“I have not had any life experience since I was [edit] a child it is as if my life has been on hold. So as i get betrer there will be a lot of catching up for me to do which seems a bit daunting. would really love some help with getting better. I feel it is too easy for people to get forgotten about and fall through the net. How do you fight for help when you are too ill to talk on the phone or write letters. I missed a lot of school and so am not confident writing letters and my mind gets foggy.”

“There is a consultation with the nhs about m.e. in salford that my friend wants me to go to but as I am housebound it is highly unlikely I will be able to go. If skype were to be available I could join in. I am very very grateful for this questionnaire. Thank you very much for listening to me :) I focus on the positive everyday but for this I have had a rant and told you of all the things that I would like to be improved. I would like to say that the social worker I saw over a year ago was very lovely, helpful and understanding, so there is good stuff but I have fallen through the net because i cant afford the help, and im trying not to drown at the moment.”

Getting well has been really impeeded by [edit] where I have been living in which is very noisy. I have had crazy neighbours keeping me up at night and slamming doors breaking windows during the day. A place where people with m.e. could go to rest, a quiet place for rehabilitation would have gotten me better by now I think. I know this might be pie in the sky but I'm just mentioning it incase it's possible in the future. It would save money by helping people get better quicker, for those that need a quiet place. Why are people with m.e. not advised to get heart rate monitors and blood pressure monitors? This was what helped me take my own readings and get diagnised by heart consultant with n.m.h. In America they are using them to help people pace. Lots of evidence to show lots of people with m.e. have n.m.h and abnormal heart and oxygen and recovery from exercise. When I asked my dr in salford if I could have heart tested he said no as I was too young. He flat out lied. It was only because I mentioned it to an endocrinologist that I got refered for tests and diagnosed. My g.p. should have known that heart rate and blood pressure and abnormal nervous system are symptoms. Also testing for n.m.h is not standard procedure at c.f.s consultation at hospital. It should be as it helps give physical explanation of what is going on and help manage, pace and improve symptoms.”

"Although not in the area I found it of tremendous benefit to be a member of the Stockport M.E.group When I attended the group I found the talks and other input excellent and also I met people who had M.E."

"Trafford has felt like a desert in terms of M.E."

"having to attend hospital so many times this year for investigations and procedures it made me realise I need to relearn my pacing skills and reconnect with the Stockport group [as there is nothing in Trafford]"

"It is still new to me and I am just learning about the condition"

"Too much psychology and graded exercise. No proper exclusion testing. People misdiagnosed who don't meet criteria as lack of Dr knowledge. CBT GET is waste of NHS money and dangerous. Psychiatry big issue for children [edit].

Salford Royal dept bad, Dr [edit] doesn't understand ME and is offensive *youve taught your body to sleep too much that's why you are ill"" etc Metabolism clinic Salford Royal Dr [edit] should be expanded and integrated with ME CFS dept.

Community care services eg CIL, Blue Sci Trafford, Big Life, Angel, need to be educated on ME so people get non NHS help and aren't discriminated against. Achievable to fix this. Also social services and DWP need educating."

"Existing biomedical research on ME needs be used eg micrbiome, abnormal bran scans etc. ask Invest in ME charity. Some national charities and politics are preventing patients getting help - massive barrier."

"I find any form of gentle exercise unhelpful on bad days and taking it easy on good days. "Graded" exercise as promoted by specialists just makes me feel they don't really understand my form of M.E. NO matter how careful I am, I inevitable relapse unexpectedly and after 11 years struggling with it, shows some of it is out of my control."

"My relapse s are severy I. e. Bedridden in a darkneed room. I live alone. I don't take up a hospital bed but I have to pay thousands of pounds for care. Cheap social care should be provided. I feel discriminated against because I have to pay for care.

I have had the condition for [edit] many years but misdiagnosed with depression. Only got diagnosed with CFS 18 months ago and still awaiting treatment.

CBT helped me manage the emotional aspects of ME, it made no difference to my symptoms. GET and pacing make my symptoms worse, specially GET. I take a wide range of pain meds - anti inflamatories, pain killers, anti spasmodics, neuropathy meds, 26 a dat all together, just so I can function."

"like many, have many other illnesses, sometimes masked by ME symptoms. Diabetes, Migraines, Hypothyroidism etc."

Find a summary of this report **'Tired of explaining : Experiences of services for ME/CFS patients in Trafford and Greater Manchester - Summary report'** which can be found on our website at Healthwatchtrafford.co.uk/about-us/our-reports.

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influence
improve

If you require this publication in an alternative format, please contact us

0300 999 0303
07480 615 478
info@healthwatchtrafford.co.uk
@healthwatchtraf
Healthwatchtrafford.co.uk

Floor 5, Sale Point
126-150 Washway Road
Sale, M33 6AG

healthwatch Trafford

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