

**Patient
Experience
Report:**

healthwatch
Trafford

**Experiences of services
for Fibromyalgia patients
in Trafford**

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Executive Summary

Fibromyalgia is a condition characterised by widespread pain, which may also cause fatigue, affect cognitive functioning including memory and cause poor sleep quality. It may affect as many as 1 in 20 people¹, which in Trafford would equate to roughly 11,330 residents living with the condition².

Healthwatch Trafford was made aware that services for people with Fibromyalgia may not always be accommodating their needs. This piece of work was designed to look at the experiences of people diagnosed with Fibromyalgia in accessing local services. In order to investigate this, a survey was developed which was distributed both online and in paper form. Although we placed particular emphasis upon services in the Trafford and Greater Manchester areas, we also received responses from across the UK and internationally. Of the 738 responses received, 19 were from people resident in Trafford, 71 in Greater Manchester, and 729 were UK residents. The relevance of the UK data is explained in our 'points to note' section.

Our research has discovered that a large majority of respondents from all areas were unable to study or work full time. The impact of Fibromyalgia upon people's lives was widespread, with 94% of Trafford respondents feeling that their quality of life had been impacted in some way. Of these, 41% reported that their ability to look after personal care needs (including eating, bathing and dressing) had been affected. Consequently, over a third of Trafford respondents have at least one carer. The social and economic impact of Fibromyalgia therefore is unlikely to be limited to patients with the condition, but friends and family members acting as carers as well.

When accessing GP services, Trafford respondents generally felt more positively about their experience than those from elsewhere in the UK. Those in Trafford reported their GPs to be more knowledgeable about Fibromyalgia than was reported in the rest of the country. Despite this, the percentage of GPs judged to not be knowledgeable about Fibromyalgia still stood just above 50% for Trafford, indicating a need for better GP education on Fibromyalgia. Lack of GP knowledge was also suggested by a focus group member as a factor underlying misdiagnosis: over half of Trafford residents reported either originally having Fibromyalgia misdiagnosed as something else, or having had symptoms of another condition mistakenly attributed to Fibromyalgia.

Patient education on Fibromyalgia by medical professionals was also low; nearly a third of Trafford residents were not offered information by the NHS on their condition. This proportion of patients who are not provided reliable information are likely to be going elsewhere to access this, with one respondent specifically commenting that they had turned to the internet for information. Given the variance in information to be found online, this is concerning and it may be assumed that some patients are therefore receiving inaccurate information. In addition to problems accessing information, attending GP appointments was said to be made difficult by inflexible appointment times and memory problems caused by

¹ <http://www.nhs.uk/Conditions/Fibromyalgia/Pages/Introduction.aspx>

² 2011 Census: <http://www.infotrafford.org.uk/strategicpriorities>

Fibromyalgia. It is also worth noting that a higher proportion of Trafford residents stated that they did not see their GP regarding Fibromyalgia, whilst the need for self-management was also highlighted more frequently by Trafford respondents. This may indicate that those who did not feel satisfied by the service provided by GPs for Fibromyalgia simply stopped attending, and these results may therefore not be accurate. This was the case with several at our focus group, who felt disheartened by their GPs responses, and had consequently stopped attending.

Whilst the survey results regarding Trafford GP services seemed to be more positive than nationwide, experience of secondary services was generally less favourable. Many patients commented upon a lack of access to pain management services, supported by statistics that 24% of Trafford residents had been referred to this service, in comparison to the UK average of 43%. When looking at services used and diagnosis, we discovered that many respondents did not seem to know who had diagnosed them, often citing 'specialist', 'hospital' or 'consultant'. This suggests a lack of clarity regarding the treatment and services that they are accessing, compounded by a number of patients who were unsure how to access their medical records.

In addition to this lack of clarity, other problems in secondary care services included a lack of knowledge of Fibromyalgia and poor interpersonal care. Trafford residents reported that over 80% of non-specialist hospital staff were said to either not have much knowledge of, or to not understand Fibromyalgia; much higher than the rating nationwide. They also reported hospital staff to be more likely than GPs to sometimes, rarely or never speak to them with respect and fairness and to listen to them.

Experience of the hospital environment was another issue reported by UK residents, with chairs lacking lumbar support and a lack of wheelchair transport between departments. Finally, inpatient experience was generally rated negatively. 88% of people who had been inpatients from Trafford felt hospital staff did not understand Fibromyalgia and accommodate them. A recurring theme was that people felt wards and staff to be inflexible and to not take their Fibromyalgia into account during treatment. Specific concerns included sleep disruption, change in medication times, bright lights, noises and being treated as if mobility problems were not valid.

Recommendations

Specific recommendations to tackle the issues highlighted include:

- Implementing appointment reminders, where possible. This is to mitigate against memory problems involved with Fibromyalgia, which may otherwise cause difficulty with attending GP and specialist appointments.
- Patients to be made aware that they can access their medical records, including test results and letters from specialists. This is to help patients who may have memory difficulties and to reduce confusion over which services are being accessed and to allow patients to keep track of their treatment.
- Explore the possibility of offering longer GP appointments to those with Fibromyalgia. This is in order to allow those with cognitive difficulties or complex histories adequate time to explain reason for attendance and to reduce the common complaint of feeling 'rushed'.
- Increase GPs and GP practices' awareness of specialist services available that may be of use to Fibromyalgia patients, including pain management services, and those that Trafford CCG commission from outside of Trafford.
- Flexibility in appointment time should be offered to those with Fibromyalgia. This is because Fibromyalgia often causes difficulties which vary with time of day, such as particular stiffness in the morning or increase cognitive difficulties in the afternoon.
- To ensure that hospital facilities are suitable for Fibromyalgia patients, particularly in rheumatology, neurology, pain management and phlebotomy departments. This should include providing chairs with back support and wheelchair availability between departments.
- Mandatory education of GP and hospital staff regarding Fibromyalgia, including symptoms and impact upon quality of life.
- Investigation into the feasibility of adjusting inpatient facilities to take Fibromyalgia into consideration when treating other illnesses. This should include the possibility of low-noise and light areas for those with sensory sensitivities and those who may require longer periods of sleep.
- Update CMFT trust's website and ensure it is kept up to date: currently, rheumatology clinic times at Trafford General Hospital and Altrincham Hospital are inaccurate.

Introduction

This report has been produced by Healthwatch Trafford. The Healthwatch network is made up of local Healthwatch across each of the 152 local authority areas and Healthwatch England, the national body. We are an independent organisation and as a Local Healthwatch we help people get the best out of their local health and social care services; whether it's improving them today or helping to shape them for tomorrow.

It was brought to our attention through complaints and comments that people with Fibromyalgia in Trafford felt that services were not always meeting their needs. As Healthwatch is evidence-based, we decided to conduct a piece of work to investigate the scope of these problems; to discover the numbers affected and the specific issues faced.

A survey was therefore produced to give people with Fibromyalgia the opportunity to share their experiences of using local services. The questions were informed by informal interviews conducted at South Manchester Fibromyalgia Support Group and further research online. The final survey was then put online at the end of July 2016 and remained open for 3 weeks. In order to ensure as many people were reached as possible, the survey was then shared via the Healthwatch Trafford website, social media, local Fibromyalgia networks and certain Fibromyalgia online communities. Paper copies were also distributed to local Rheumatology clinics.

Fibromyalgia as a condition

The exact cause of Fibromyalgia is unknown, however the condition is characterised by widespread pain. This pain may be continuous or it may vary in severity. Whilst it may be felt throughout the body, certain areas may be worse. Experience of pain differs and may be felt as an ache, a burning sensation, a sharp or stabbing pain. Pain sensitivity is also heightened, with some people finding that even the slightest touch is painful, or that pain persists for longer than usual.

Alongside pain, there are other symptoms associated with fibromyalgia, which some people may or may not suffer from. These include:

- fatigue
- poor sleep quality, also known as non-restorative sleep
- sensitivity or intolerance to sound, light and smells
- cognitive problems such as trouble remembering and learning new things, problems with attention and concentration and slowed or confused speech ("brain fog")
- stiffness and muscle spasms
- headaches and nausea
- stomach pain including irritable bowel syndrome, such as bloating, diarrhoea and constipation
- dizziness, tingling, numbness, prickling or burning sensations in your hands and feet (pins and needles)
- restless legs syndrome
- unusually painful periods (in those that menstruate)

- feeling too hot or too cold
- psychological difficulties such as anxiety and depression

Although awareness of Fibromyalgia is growing, the cause is yet to be definitively determined. Although several avenues of research exist, this is outside the remit of this report. In addition to a lack of consensus regarding the cause of Fibromyalgia, there is currently no cure or universally agreed treatment. In the UK, no specific NICE guidelines exist regarding Fibromyalgia and referrals to specialists and treatments depends largely upon the individual's GP. This may lead to inconsistent access to treatment even within a local authority area.

Despite the uncertainty of cause, it is undisputed that Fibromyalgia has a widespread impact. NHS choices cites that, according to some estimates, nearly 1 in 20 people may be affected to some degree. Given the vast numbers of people who may be living with Fibromyalgia, the quality of care that is provided - and levels of knowledge and understanding on the part of health professionals - will have a huge impact nationally and locally.

Current services/provision of care

Although many NHS services are commissioned by Trafford CCG, there is currently no advice or guidance as to which services to refer Fibromyalgia patients to and therefore much of this is down to the individual GP. This report has highlighted the most frequently referred to services as including rheumatology, physiotherapy, neurology, psychological services (including CBT), occupational therapy, pain management, complementary therapies, and hydrotherapy.

Rheumatology clinics are available in Altrincham Hospital, Trafford General Hospital, Salford Royal NHS Foundation Trust and University Hospital South Manchester (Wythenshawe) hospitals. Both Altrincham and Trafford Hospitals offer nurse-led and general rheumatology clinics, however upon investigation the website information regarding times of these clinics was out of date. A specialist rheumatology centre in the Manchester Royal Infirmary also exists, however this centre does not deal with Fibromyalgia as a primary condition.

A Fibromyalgia coping skills course is offered by Trafford General Hospital. This can be attended by patients who have been referred by a rheumatology consultant based at the hospital. This process begins with a one-on-one assessment with an occupational therapist or physiotherapist who will discuss the Fibromyalgia course with the patient. If they wish to take part, they will then be added to the waiting list for the next group; currently it runs about three times a year, according to demand. The course is seven weeks long, has a maximum of ten patients per group and covers a multitude of topics. These include graded exercise therapy, pain, sleep hygiene, long- and short-term goal setting, pacing, relaxation, fatigue management, and mindfulness. A one-off follow up session is conducted after discharge to monitor how these techniques have been put into practice.

If need be, this course can refer on to Active Trafford. Active Trafford is run by Trafford Leisure and can receive referrals by many bodies, including GPs and other

medical professionals. The scheme is currently under review and was set to undergo many changes by the end of October 2016. Information provided in this report may therefore change or become outdated. Currently Active Trafford offers five complementary visits to a centre of the patient's choice, accessing services such as swimming, exercise classes or use of the gym. With the impending review, this is set to change to eight weeks of membership for an as-yet unconfirmed fee, however some activities such as community chair-based exercise classes and walking groups are currently scheduled to remain free of charge. One-to-one guidance from a personal trainer is available on the existing scheme, which may remain for a set number of visits after the scheduled change of service. After the allotted time with Active Trafford is finished, a number of concessionary memberships are available* and the scheme is happy to discuss options tailored to personal circumstances with the individual. Active Trafford also is currently expanding STAMP strength and balance classes, following a pilot scheme. These include postural stability and circuits; these classes will be available in Urmston and Altrincham, and may be more widely available in the future.

Points to note

As this survey was conducted by Healthwatch Trafford, questions were accordingly aimed at collecting the experiences of people living and working in Trafford. Our remit only extends to these services, however we did not limit responses to people living in this area. This decision was made to allow a regional and national context to Trafford services and residents' experiences. This has enabled comparison and the potential to assess where Trafford is excelling and areas that may need improvement.

Those living in other Local Healthwatch areas will have their results passed on to the relevant Healthwatch, who can make a decision over what they wish to do with the information. This report will also be given to Healthwatch England, who will decide what to do with the findings.

The analysis of the data is divided into three segments, with the first two including responses from those in the Trafford area and those in the Greater Manchester area. The third category of data includes results from the rest of the country; these include experiences from the whole of the United Kingdom but exclude the Isle of Man and other Crown Dependencies. The Greater Manchester data generally includes responses from Trafford, and the UK generally includes the Greater Manchester data, excepting qualitative responses where the scope and included data for each area is clearly stated.

A higher proportion of UK respondents reported being affected more severely by Fibromyalgia than those in Trafford. Whilst this may be the case, it should also be noted that there may be a response bias responsible for this finding. It is possible that those who responded outside of our target area were more driven to reply due to the severity of symptoms, whereas responses from Trafford were more actively sought. However, it is also possible that the small sample size from Trafford is not representative and that a higher percentage of residents are severely affected than our current figures show.

Methodology

The survey was designed with input from numerous sources, including aspects adapted from previous research undertaken by Healthwatch Trafford, assistance from The South Manchester Fibromyalgia Support group on their experiences and existing measures of quality of life. The questions were designed to gather both quantitative and qualitative information on the participants' experiences both of local services and of living with Fibromyalgia more generally. The survey was not designed to act as part of medical or clinical research, and questions were specifically tailored toward experiences. Symptoms and specific treatment were therefore excluded from the remit.

In order to ensure that the survey reached as many people as possible during our limited timeframe, we decided to use an online survey. This allowed us to disseminate the survey quickly via our social media accounts, on forums and allowing us to email links to local networks and support groups. In addition to this, we printed a number of copies for those who did not have access to the internet or whom otherwise a paper copy was more appropriate. These paper copies were also delivered to rheumatology clinics in the Greater Manchester area. We would like to thank Altrincham Hospital, Trafford General and University Hospital of South Manchester (Wythenshawe) for their positive response.

The survey was constructed using SurveyMonkey and the link to it, and to the page on our website containing the link, were both shared and emailed. Data was collected between 1st August and 22nd August of 2016, with the survey closed after 3 weeks. A total of 738 responses were received. Of these, 19 were from people resident in Trafford, 71 in Greater Manchester, and 729 UK residents. The results were then collated and analysed.

Findings

82% unable to work or study full time

[Trafford residents with Fibromyalgia]

How would you describe your current level of Fibromyalgia?

In Trafford, 82% of respondents stated that their symptoms were moderate or severe, and thus were not able to work or study full-time. This is consistent with levels in Greater Manchester (79%) and the UK (87%); with such levels of people prevented from engaging with work or studying to their full capabilities, it is certain that the severity of these symptoms will have real consequences upon quality of life, welfare, education, employment and economic activity.

How long have you had Fibromyalgia?

Respondents from Trafford had been living with Fibromyalgia for longer than those in Greater Manchester and the UK. 71% reported having the condition for over 5 years in Trafford, whilst this figure was at 55% in Greater Manchester and 54% in the UK.

94% report quality of life has been affected

[Trafford residents with Fibromyalgia]

Ability to look after personal care needs (eating, bathing etc) affected in 41%

[Trafford residents with Fibromyalgia]

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

94% of Trafford respondents stated that their quality of life has been affected in some way (with 94% in Greater Manchester and 98% in the UK). Of these, Fibromyalgia has affected 77% of people's ability to enjoy recreational hobbies, 71%'s ability to perform routine chores (such as household chores, shopping or getting around) and 65%'s ability to socialise with friends. Additionally, 41% of Trafford respondents have had their ability to look after personal care needs (such as eating, bathing, dressing or getting around the house) affected. Despite this difference, these figures are still extremely high throughout all three areas and suggest high proportions of people whose lives have been negatively impacted by the condition.

87% have a co-occurring illness

[Trafford residents with Fibromyalgia]

Do you have any co-occurring illnesses?

This impact upon quality of life is likely to be further exacerbated due to the high levels reported of co-occurring illnesses; 87% in Trafford reported having other medical conditions, with 84% in Greater Manchester and 79% in the UK reporting the same. This suggests that these patients are more likely to have complex health needs, possibly including more frequent use of NHS services. A graph illustrating type and frequency of reported co-occurring illnesses can be found [here](#) [page number].

38% have at least one carer

[Trafford residents with Fibromyalgia]

Do you have a carer?

Given the large proportion of people whose ability to perform routine chores and look after personal care needs has been affected, it is unsurprising that a number of respondents reported having at least one carer (Trafford, 38%; 45% Greater Manchester; 46% UK). The economic impact of this condition is likely to be exacerbated by the fact that many of these carers are family members or friends. Given the reduction in functioning reported across multiple areas, it is reasonable to suggest that a number of these carers may have to reduce their hours in work, or otherwise limit activities.

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

Trafford and Greater Manchester had fewer respondents diagnosed by Rheumatologists than the UK (Trafford: 53%; Greater Manchester: 58%; UK: 64%), which seems to be partly due to the higher diagnosis rate by 'other specialists' in Trafford and Greater Manchester. These specialists included neurologists and pain management specialists.

Of note is the number of respondents who did not specify which type of specialist diagnosed them (answers included 'hospital', 'specialist' or 'consultant'). This lack of further information may indicate that people are unsure who diagnosed them, and which area of medicine they were under at the time.

63% have not been offered information on Fibromyalgia by the NHS

[Trafford residents with Fibromyalgia]

Were you offered any information from the NHS on living with the condition?

Of those diagnosed by the NHS, a large proportion of respondents reported never having been offered information on Fibromyalgia (63% in Trafford, 53% in Greater Manchester and 58% in the UK). It is reasonable to suggest that, in lieu of reputable information provided by healthcare professionals, many of these people will instead turn to the internet for their information. The quality of information gained online is variable, and therefore accuracy cannot be guaranteed. Indeed, when asked about the care they had received from GP services, one respondent from Greater Manchester commented:

“I think more information should be shared with patients about this [condition]- I had to find out about it via the internet.” Greater Manchester

If yes, was that information helpful?

Trafford residents generally reported the information they received to be helpful (86%) whilst this figure was closer to half of respondents elsewhere (Greater Manchester: 60%; UK: 48%). This skew may be due to the small response size in Trafford, due to the prerequisite of having received information at diagnosis reducing the number who could answer.

56% have experienced misdiagnosis

[Trafford residents with Fibromyalgia]

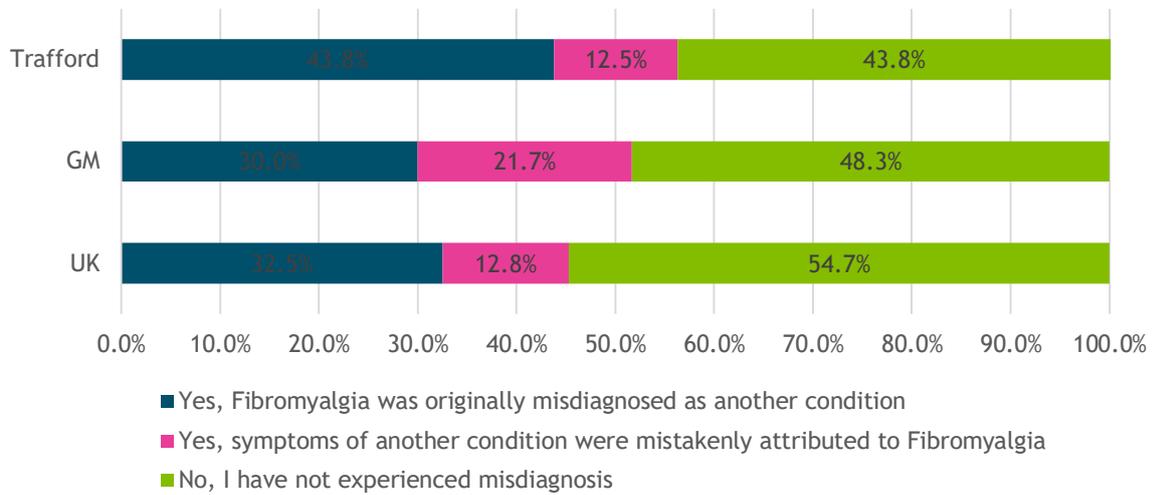
Have you experienced any misdiagnosis?

This statistic covers both people who have experienced symptoms of another condition being mistakenly attributed to Fibromyalgia as well as those for whom Fibromyalgia was misdiagnosed as another condition. The former is likely to have serious ramifications concerning delayed treatment, particularly if serious or life-threatening conditions are mistakenly attributed to Fibromyalgia. As a common symptom of many conditions is tiredness or pain, if new or worsened instances of these are not thoroughly investigated, it may lead to worsened long-term prognosis; aside from additional suffering.

The proportion of people reporting Fibromyalgia being misdiagnosed as another condition is also high. Treatment received during this period of misdiagnosis may be unnecessary and ineffective, and patients are likely to be suffering with Fibromyalgia for longer without targeted treatment or appropriate management techniques. Although we cannot be sure of the cause of these instances of

misdiagnosis, it was suggested during our focus group that many patients believe that medical professionals lacking knowledge regarding Fibromyalgia may underlie a large proportion of these incidences.

Have you experienced any misdiagnosis?



24% do not know how to access their medical records
 [Trafford residents with Fibromyalgia]

Do you have copies of, or know how to access, your medical records (including test results and letters from consultants to GP/s)?

Due to the structure of this question, it can be assumed that 24% of people not only do not know how to access their medical records, but would like to, as not wanting to access them was a separate category. The figure of those unaware of how to do so is even higher in Greater Manchester (38%) and the UK (50%). This widespread lack of awareness is likely to have an impact upon patients, especially given the problems with cognitive functioning (including memory) that affects many people with Fibromyalgia. If patients cannot remember which tests have been run (and corresponding results), and do not remember what specialists have said, this may affect patient understanding of their own care and treatment.

65% took over a year to be diagnosed after first reporting to their GP

[Trafford residents with Fibromyalgia]

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

As Fibromyalgia is largely a diagnosis of exclusion, running tests to rule out other conditions is likely to take time, and it is likely that this explains some of the delay in diagnosis. In Trafford, 65% of respondents took over a year to be diagnosed after first reporting to their GP. Many take much longer, however, with 18% in Trafford taking over five years to receive a diagnosis, and similar rates in Greater Manchester (23%) and the UK (24%). With such large proportions of people waiting years to receive a diagnosis, it is likely that they are not accessing Fibromyalgia-specific care during this period.

53% of GPs reported to not be knowledgeable about Fibromyalgia

[Trafford residents]

33% of GPs reported to be unsupportive regarding Fibromyalgia

[Trafford residents]

How does your GP talk about Fibromyalgia?

In Trafford, respondents said that over half of GPs were not knowledgeable about Fibromyalgia. This was mirrored both in Greater Manchester (61%) and the UK (62%), suggesting that a lack of knowledge is a nationwide issue. The number of GPs reportedly unsupportive of Fibromyalgia was also high, with 33% in Trafford, 35% in Greater Manchester and 41% in the UK. Additionally, 20% of GPs in Trafford were stated to be neither knowledgeable or supportive; this lack of understanding or support is likely to have a substantial impact upon patient experience. Trafford GPs appear to be more supportive regarding Fibromyalgia than GPs nationally, however the high figures are still a cause for concern.

24% of GPs sometimes, rarely or never speak with respect, listening to the patient

[Trafford residents]

Would you say that your GP/s speak to you with respect and listens to you?

Again, Trafford reports better GP interpersonal care than Greater Manchester or nationally. Good interpersonal care is important for multiple reasons, such as increasing capacity to self-manage chronic medical conditions, adopt preventative health behaviours and act upon medical recommendations³. 24% of Trafford residents reported that their GP sometimes, rarely or never speak to them with respect; this figure is at 38% in Greater Manchester and 41% in the UK. Although Trafford is doing better than national levels regarding this, this figure is still high. It should therefore be a priority to ensure that patients perceive their GPs are being respectful and listening to their concerns.

Difficulties in accessing GP services due to being bed/housebound, memory problems, inflexible appointment times and waiting times to see a named GP

[GM & Trafford residents]

Do you experience any difficulty in obtaining or attending GP appointments due to your Fibromyalgia?

Trafford has a lower proportion of people experiencing difficulties in obtaining or attending GP appointments at 50%. Of those with issues, inflexible appointment times were a problem for 19% of residents; a particular problem for those whose Fibromyalgia may cause problems with either morning or afternoon appointments (due to stiffness in the morning or brain-fog/fibro-fog⁴⁵ getting worse in the afternoon). 31% cited waiting times to see a specific GP as a problem, likely to impact people with long term health conditions more than others due to desire for continuity of care.

Anecdotally, those in the Trafford area that we spoke to in person often reported diagnosis taking a long time due to continually seeing different GPs, with no one able to see the ‘bigger picture’ and link symptoms to the overall condition. In the qualitative aspect of this question, respondents cited numerous other problems. This included problems due to being bedbound or housebound, suggesting a lack of home visits; memory problems, suggesting a lack of reminder services of appointments (such as texts); and poor attitudes by medical professionals regarding Fibromyalgia.

Is there anything else you would like to say about the service that your GP has provided for your Fibromyalgia?

“Since I joined this practice I have had the best of care” Trafford

³ <http://healthcarecomm.org/about-us/impact-of-communication-in-healthcare/>

⁴ https://en.wikipedia.org/wiki/Clouding_of_consciousness

⁵ <http://www.nhs.uk/Conditions/Fibromyalgia/Pages/Symptoms.aspx>

In Trafford, experiences of GP services have been mixed, with the same number of occurrences of the theme ‘GP services have not been helpful’ and ‘GP is supportive/sympathetic’. This discrepancy in care quality is likely to have a huge impact upon patient experience. As GPs act as gatekeepers to many further services and treatment available on the NHS - if patients feel they are listened to, it is reasonable to assume they would be correspondingly more likely to see their GP and thus access care. This seems likely, given that 30% of Trafford residents stated that they do not see their GP regarding Fibromyalgia, in comparison with 19% in Greater Manchester saying the same and 16% nationally.

“I am tired of being stigmatised and abused and ignored” Greater Manchester

“One doctor ignored my symptoms and totally dismissed it as my mental health or illness [...] I came away frustrated and angry” Greater Manchester

Greater Manchester showed higher reports of GPs being dismissive of or disbelieving in Fibromyalgia, although many also reported good interpersonal care from their GP. This links with the higher numbers citing inconsistency of care as a problem:

“The particular GP that I prefer, and wait six weeks for an appointment with, is great. Others at that practice [...] are ignorant, dismissive and condescending, and treat me as a hypochondriac, malingerer, attention- or drug-seeker...” Greater Manchester

“My GP is understanding, patient and kind” Greater Manchester

Fewer Trafford residents (23.5%) have been referred to pain management than the UK average (42.7%)

Trafford residents highlighted the need for self-management more often than those in Greater Manchester, suggesting that it is possible that those who reported not seeing their GP regarding Fibromyalgia are turning to self-management instead. This is related to comments that GPs did not provide long-term treatment, and that medication seemed to be the only treatment available, once short-term courses had been exhausted.

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

In Trafford, higher percentages of people were referred to psychological services (including CBT) than elsewhere: 41% of respondents in Trafford, in comparison to 24% in Greater Manchester and 20% in the UK. Given frequent comments regarding Fibromyalgia being treated as a psychological, rather than physiological, condition, this may suggest a predominant attitude by GPs in the Trafford area in which treatment path to pursue.

Referrals to pain management showed large differences depending on area (Trafford: 24%; Greater Manchester: 32%; UK: 43%), with Trafford reporting much lower than referral rates nationwide. This raises the question of whether pain management services are available in the Manchester area, and if so, why patients with Fibromyalgia are not accessing them at similar rates to patients in the UK as a whole.

82% of non-specialist hospital staff don't have much knowledge of, or do not understand Fibromyalgia

[Trafford residents]

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

In the Trafford area, 82% of respondents answered that most non-specialist hospital staff either didn't have much knowledge of or do not understand Fibromyalgia. This was much higher than Greater Manchester (68%) or the UK (65%), although figures were nevertheless still above 50% in all areas, suggesting this is a nationwide issue.

This statistic was also much higher than the percentage of GPs perceived to not be knowledgeable about Fibromyalgia (53% in Trafford, 61% in Greater Manchester and 62% in the UK). This suggests that lack of knowledge is similar in primary and secondary services in Greater Manchester and the UK, but far more prevalent in secondary services in Trafford.

38% report that hospital staff sometimes, rarely or never speak to them with respect and fairness, listening to them

[Trafford residents]

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

38% of respondents from Trafford felt that hospital staff sometimes, rarely or never spoke to them with respect and fairness, listening to them. This figure is similar to those in Greater Manchester (36%) and the UK (42%), and is likely to have a huge impact upon patient experience in accessing these services.

Whilst this figure is similar for GP and hospital services for Greater Manchester and the UK, Trafford once again shows a difference between GP and hospital services. Hospital staff are reported to be much more likely (38%) than GPs (24%) to sometimes, rarely or never speak with respect and fairness, listening to the patient. When considered alongside previous results concerning reported lack of knowledge amongst hospital staff, it appears that secondary services may be performing more poorly in respects to Fibromyalgia than primary care.

Difficulties in accessing specialist services due to being refused/not given referral(s), memory problems, aggravation of Fibromyalgia symptoms and inappropriate facilities

[UK, GM & Trafford residents]

Do you experience any difficulty in obtaining or attending specialist (non-GP) appointments due to your Fibromyalgia?

Trafford residents had the highest proportion of respondents with no difficulty in obtaining or attending specialist appointments, at 53%. Inflexible appointment times was the most frequent problem encounter by those in Trafford. In Greater Manchester and the UK, the most commonly encountered problem was that the Fibromyalgia may mean that the respondent couldn't attend on the day. Many of the reports of difficulties filed under travel/transport were elaborated upon in the other category, often explaining that this difficulty was due to the condition itself. Examples included getting on and off buses, sitting on public transport for long stretches or finding somewhere to park in the car park that is close enough to walk.

Other problems mentioned nationwide included being refused or not given referral(s), memory problems (leading to forgetting appointments) and aggravation of Fibromyalgia symptoms caused by attending the service. Inappropriate facilities were also flagged as a problem, with chairs lacking lumbar support and lack of wheelchair transport between departments (such as rheumatology to phlebotomy). Although these were mentioned by UK respondents, it may be that these problems are more widespread and therefore warrants further investigation.

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

In Trafford, the most common themes were poor interpersonal care (rude, lack of sympathy or poor manner) and long waiting times.

“[The consultant] state learn to [live] with the pain. Also stated he will get paid [whether] I see him or not. I was very distressed and felt there is no help for me and I’m struggling with the pain and the fatigue. I feel alone with this horrible condition.” Trafford

“I don’t think he [consultant] has much sympathy and his manner leaves a lot to be desired” Trafford

“Waiting time to see consultants is very long, now only get to see consultant once a year and then only get few minutes to explain problem or to [administer] injections.” Trafford

The comments regarding interpersonal care echo the findings from other questions, with some hospital staff perceived by those in Trafford to be lacking in knowledge and interpersonal treatment. Another theme regarded being referred back to primary care without further support, and in Greater Manchester, this also incorporated the need for re-referrals due to time-limits on secondary care:

“Continuity of care is [scarce], finding myself needing to be re referred to another trust or consultant to keep up therapies [...] I was told my “time was up” with Manchester recently and now waiting to go locally” Greater Manchester

Hospital facilities were criticised in both Trafford and Greater Manchester for being inappropriate for people with Fibromyalgia. These comments included chairs not providing enough support and a lack of travel service available for Fibromyalgia patients.

Greater Manchester residents also cited long waiting times, poor interpersonal care and a new theme: treatment either assuming a psychological cause or not addressing non-psychological aspects. This was something that respondents felt particularly strongly about, with strength of feeling evident from those who had been offered psychological or psychiatric treatment, often to the exclusion of other treatments or services. In addition to this, some respondents felt that their condition had been dismissed or that hospital staff felt that Fibromyalgia didn’t exist. Although this relates to reported poor interpersonal care, this refusal to acknowledge their condition is likely to also impact treatment and services the individual can access.

Despite this, some comments were positive, suggesting that certain areas of Greater Manchester are excelling in treatment of Fibromyalgia - if not waiting times for these services:

“The rheumatology dept at Bolton [...] are fantastic. Really knowledgeable, caring and the introduction programme they run is invaluable in learning to live with Fibro. Ideally though the assistance and treatment should continue with periodic checkups and medication reviews. Also I’m still on a waiting list for hydrotherapy after 2 years!!!!” Greater Manchester

Have you ever been an inpatient (for any condition) whilst having Fibromyalgia?

Those in Trafford were most likely to report having experienced inpatient care whilst having Fibromyalgia (Trafford: 50%; Greater Manchester: 41%; UK: 40%).

88% of respondents felt that hospital staff did not understand and accommodate their Fibromyalgia during inpatient care

[Trafford residents]

If yes, did hospital staff understand your Fibromyalgia and accommodate you?

After accounting for those who answered that they had not been an inpatient whilst having Fibromyalgia, just 12% of respondents in Trafford felt that hospital staff understood their Fibromyalgia or accommodated them. This figure was at 17% in Greater Manchester and 11% in the UK. This implies that a large number of people felt that their condition was not understood or accommodated by hospital staff, and that this is a national problem.

In regards to your Fibromyalgia, is there anything else about inpatient services you would like to mention?

Trafford respondents mentioned a lack of knowledge and understanding on behalf of hospital staff, as well as staff being dismissive of, or denying their condition.

“Lack of understanding leads to frustration. I recently had gall bladder removed which brought on a flare of Fibromyalgia which staff didn’t understand the symptoms.” Trafford

Facilities were again noted to be unsuitable for Fibromyalgia, such as not having a quiet area. In addition to these problems, it was highlighted that operations and treatment for other conditions can exacerbate Fibromyalgia symptoms. This seems to be compounded by reports of inflexibility. In both Trafford and Greater Manchester, staff were reported to not take Fibromyalgia into consideration when treating other conditions.

“I found a major difficulty was that the ward were inflexible about their routine [...] the disruption to my sleep and medication patterns made me significantly more unwell.” Greater Manchester

“I need to be positioned near the toilets as I have mobilities problems but this didn’t happen after one op. When I asked to be wheeled to the loo the staff looked at me like I was faking.” Greater Manchester

“It was horrific! They did nothing to accommodate my Fibromyalgia, if anything they made me feel I was being difficult.” Greater Manchester

Whilst Greater Manchester respondents frequently mentioned poor interpersonal care, there was also a report of good understanding of Fibromyalgia. This demonstrates the discrepancy between experiences of services not only between areas but between individuals.

Case Study

The following is the experience of a 62 year old Trafford resident who has been living with Fibromyalgia for several years:

“It took years for me to be diagnosed. It was well over ten years ago since I first started going to see somebody because I was having problems. I just get pushed away. They did do lots of tests. Because I had something wrong with my blood, and they knew it was something wrong, they just didn’t know what was wrong with me. Just millions of tests. And then I wasn’t very happy with the rheumatologist consultant they sent me to, mainly because he was just so rude. He’d start talking on the phone whilst he was consulting with you with other patients, it was just so rude. And then one day he put me in the next room and then forgot about me for ages. And it was just things like that that he would do. Or people would come into the room and he’d start talking about other people. It just didn’t feel right that he was doing things like that and in the end I went to my doctor and said that I wanted to change consultants and I actually went to Wythenshawe. So, I eventually got the diagnosis from Wythenshawe from a rheumatologist there. And they were very good, I mean they did loads of tests, they probably did more than Trafford did. And then eventually, but it went on for years, and eventually I got the diagnosis.

“I think maybe they realised what it was when, because one morning when working, I couldn’t get out of bed. I had to phone to work sick and say I can’t come in because I can’t get out of bed. She said well, have you been sick, have you got a headache, what is it? I said I don’t know I just can’t get out of bed. I can’t even get out of bed to go to the toilet. It was so debilitating; it was absolutely horrendous. And it’s still hard to explain now. But they were very good at work and I did go back part time, but I couldn’t even walk down the corridor to the toilets without wanting to lie down. And my memory didn’t work and I couldn’t do things, it was horrendous. I just went home and I was off a long time and in the end I took voluntary redundancy.

“The doctors are ok, but I don’t know whether they really understand how you’re feeling. And it does make you feel down. You cry at the least thing really. It’s probably a bit of depression as well. If anything goes wrong, you cry at it. And you’re thinking, why are you crying at that? It does make you feel down and it makes you feel tired. Sometimes, even sitting down doesn’t really help, you need to lie down.

“I do put up with a lot of the pain. And you’ll probably find that people with Fibromyalgia probably do put up with things. And you just get on with it, because what else can you do? I try to keep active. Sometimes you can do too much, and then I get pains in my knees and hips, but it doesn’t make me stop doing things. Because if you sat down and didn’t do anything it’d just seize up. So it’s just getting on with things.

“I’ve had no other treatment other than medication. Lots of medical tests and medication and wrists splits. I wouldn’t say the medication is perfect, it’s not perfect. I’m doing physio at the moment because I had a fall, the dog pulled me over and I damaged my shoulder. The physiotherapy department there has been very good with that injury. I mentioned the fibromyalgia to them, but whether they take it into consideration, I don’t know. They’ve never questioned me about it, asked me where the pain is, or anything. One of the exercises they’ve given me this morning was hurting my wrists and I said I can’t do that, I do have Fibromyalgia, and they just told me to do it a different way. They didn’t say, oh, how does the Fibromyalgia affect you. No discussion into that part. But maybe they feel that I’ve come in with a specific injury and that’s it, that’s all they’re dealing with. They didn’t say anything about the Fibromyalgia, there was no reaction. I don’t know if maybe they didn’t know [what it was].

“Because it’s not something we can see physically, you do feel that you are a bit of a fraud. You do feel like you’re making things up. I don’t always feel believed. I feel like how can I possibly have all these things wrong with me, when you can’t see anything... and they are sympathetic. I do know another lady who has it, she has different symptoms, but I don’t think she gets much sympathy and doesn’t feel that the doctors are interested.

“I don’t know whether they can do anything to help you - how can they stop you feeling fatigued, or feeling pain, besides medication? And because nothing’s been offered to make me feel any different than that. If it ever gets as bad as it did when I first had it, I don’t know what I’d do. Because that was really bad, I couldn’t do anything. It went on for a couple of years. I could go to the shops but when I got back I had to lie down. And I do still feel tired - I don’t sleep very well either.

“I try not to go to the doctors as often now, I go as little as possible, because I feel like I’m wasting their time. And I hate wasting people’s resources. So I try not to go back unless I’m so bad that I’ve got to go back. So I do put up with a lot. Unless it’s absolutely excruciating and I can’t stand the pain, I don’t go. I just carry on and put up with it. They put you on a repeat prescription, so I go once a year to check that. Unless I’m unwell for another reason, I can’t see the point because I don’t feel that there’s anything that they can do unless I’m really bad. “And like I said, I don’t want to waste their time. And you do feel a bit like that, because it’s not something they can see - it is physical, but because it’s not something they can see, you just put up with it. It’s sometimes a general impression given that it’s in my head. I just get on with it. They don’t know what to do, they don’t know what the answer is. And neither do I.”

Full Results Data

Location

1. What is your local authority (local council)?
2. If you have been diagnosed with Fibromyalgia, in which local authority (local council) were you living at the time?

Fibromyalgia as a condition

3. How would you describe your current level of Fibromyalgia?
4. How long have you had Fibromyalgia?
5. In which ways, if any, has Fibromyalgia affected your daily life?
6. Do you have any other co-occurring illnesses? If so, please state which ones
7. Do you have a carer? If you have multiple carers, select all that apply

Diagnosis and records

8. If you have a formal diagnosis of Fibromyalgia, who diagnosed you?
9. Were you offered any information from the NHS on living with the condition?
10. If yes, was that information helpful?
11. Have you experienced any misdiagnosis?
12. Do you have copies of, or know how to access, your medical records (including test results and letters from consultants to GP/s)?

GP services

13. How long did it take to be diagnosed after first reporting symptoms to your GP?
14. How does your GP talk about Fibromyalgia?
15. Would you say that your GP/s speak to you with respect and listens to you?
16. Do you experience any difficulty in obtaining or attending GP appointments due to your Fibromyalgia? If yes, check all that apply
17. Regarding your Fibromyalgia, how often do you see your GP on average each year?
18. Is there anything else you would like to say about the service that your GP has provided you for your Fibromyalgia?

Hospitals and secondary services

19. Regarding your Fibromyalgia, which specialist services, if any, has your GP referred you to? (Check all that apply)
20. Do you find that most (non-specialist) hospital staff have knowledge of Fibromyalgia and understand your condition?
21. Would you say that hospital staff speak to you with respect and fairness, listening to you?
22. Do you experience any difficulty in obtaining or attending specialist (non-GP) appointments due to your Fibromyalgia? If yes, check all that apply
23. In respect to your Fibromyalgia, is there anything else about hospital services that you would like to mention?

Inpatient services

24. Have you ever been an inpatient (for any condition) whilst having Fibromyalgia?
25. If yes, did hospital staff understand your Fibromyalgia and accommodate you?
26. In regards to your Fibromyalgia, is there anything else about inpatient services you would like to mention?

Demographic information

27. Age range
28. Do you consider yourself to have a disability?
29. Which gender do you consider yourself?
30. Which ethnic group do you identify as most?
31. Religion/Belief
32. Sexual Orientation
33. Do you consider yourself to be a carer?

Location

What is your local authority (local council)?

Greater Manchester

Answer Options	Response Percent	Response Count
Trafford	26.8%	19
Bolton	7.0%	5
Bury	7.0%	5
Manchester	19.7%	14
Oldham	8.5%	6
Rochdale	1.4%	1
Salford	9.9%	7
Stockport	14.1%	10
Tameside	2.8%	2
Wigan	2.8%	2
<i>answered question</i>		71
<i>skipped question</i>		0

What is your local authority (local council)? If you have been diagnosed with Fibromyalgia, in which local authority (local council) were you living at the time?

Greater Manchester

Answer Options	Response Percent	Response Count
I have not been formally diagnosed with Fibromyalgia	2.9%	2
Trafford	26.1%	18
Bolton	8.7%	6
Bury	5.8%	4
Manchester	18.8%	13
Oldham	8.7%	6
Rochdale	0.0%	0
Salford	10.1%	7
Stockport	11.6%	8
Tameside	2.9%	2
Wigan	2.9%	2
City of London	1.4%	1
<i>answered question</i>		69
<i>skipped question</i>		2

Fibromyalgia as a condition

How would you describe your current level of Fibromyalgia?

Trafford

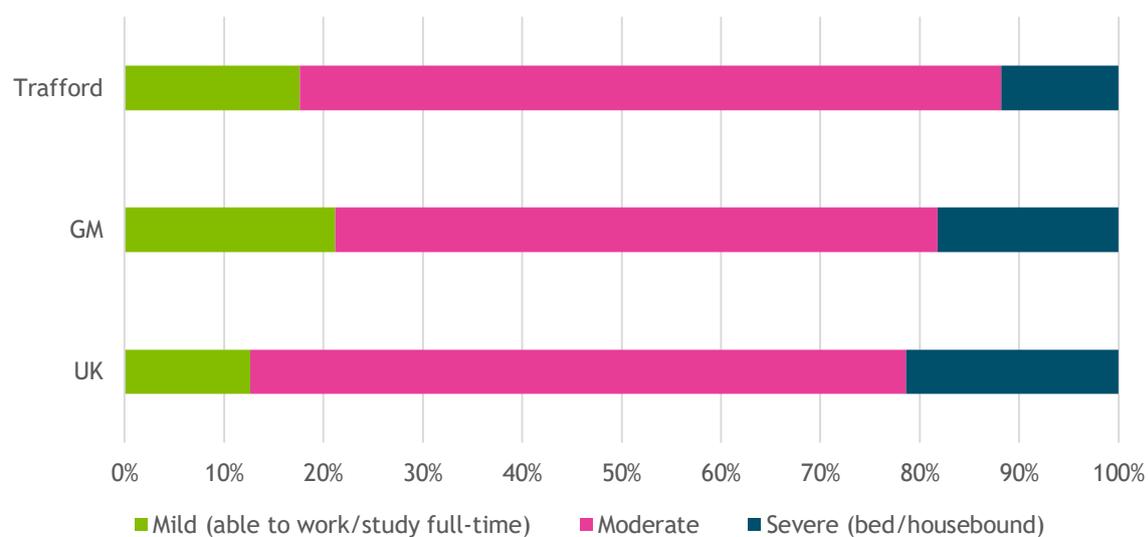
Answer Options	Response Percent	Response Count
Mild (able to work/study full-time)	17.6%	3
Moderate	70.6%	12
Severe (bed/housebound)	11.8%	2
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

Answer Options	Response Percent	Response Count
Mild (able to work/study full-time)	21.2%	14
Moderate	60.6%	40
Severe (bed/housebound)	18.2%	12
<i>answered question</i>		66
<i>skipped question</i>		5

UK

Answer Options	Response Percent	Response Count
Mild (able to work/study full-time)	12.6%	90
Moderate	66.0%	472
Severe (bed/housebound)	21.4%	153
<i>answered question</i>		715
<i>skipped question</i>		14



How long have you had Fibromyalgia?

Trafford

Answer Options	Response Percent	Response Count
12 months or less	0.0%	0
1-2 years	5.9%	1
2-5 years	23.5%	4
5-10 years	23.5%	4
10-15 years	11.8%	2
15-20 years	29.4%	5
20 years or more	5.9%	1
<i>answered question</i>		17
<i>skipped question</i>		2

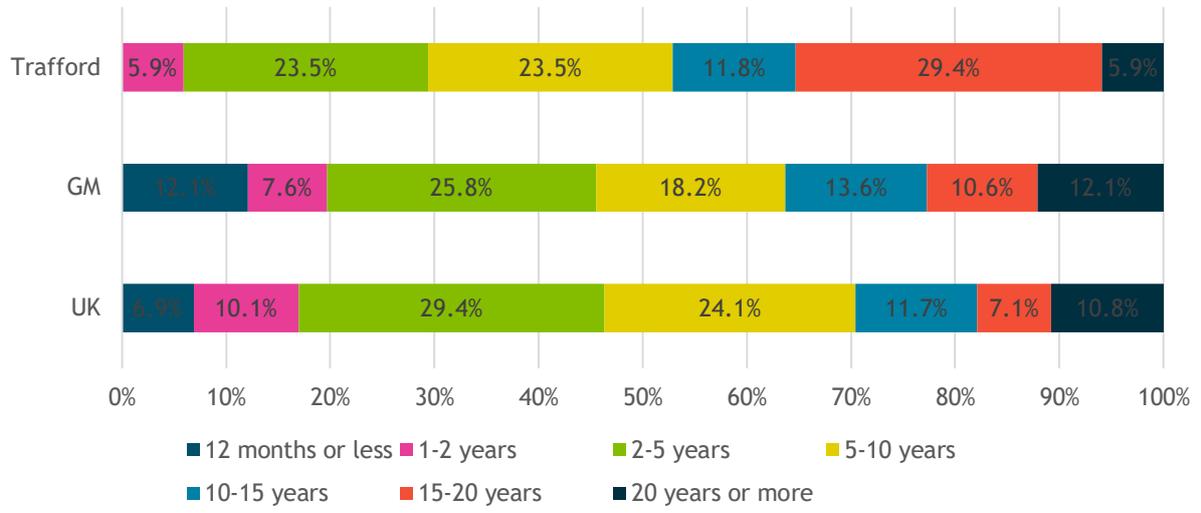
Greater Manchester

Answer Options	Response Percent	Response Count
12 months or less	12.1%	8
1-2 years	7.6%	5
2-5 years	25.8%	17
5-10 years	18.2%	12
10-15 years	13.6%	9
15-20 years	10.6%	7
20 years or more	12.1%	8
<i>answered question</i>		66
<i>skipped question</i>		5

UK

Answer Options	Response Percent	Response Count
12 months or less	6.9%	49
1-2 years	10.1%	72
2-5 years	29.4%	210
5-10 years	24.1%	172
10-15 years	11.7%	84
15-20 years	7.1%	51
20 years or more	10.8%	77
<i>answered question</i>		715
<i>skipped question</i>		14

How long have you had Fibromyalgia?



In which ways, if any, has Fibromyalgia affected your daily life? (Tick all that apply)

Trafford

Answer Options	Response Percent	Response Count
Ability to work/study (including voluntary work)	64.7%	11
Ability to socialise with family/friends	64.7%	11
Ability to enjoy recreational hobbies	76.5%	13
Ability to perform routine chores (such as household chores, shopping or getting around)	70.6%	12
Ability to look after personal care needs (such as eating, bathing, dressing or getting around the house)	41.2%	7
None of the above	5.9%	1
<i>answered question</i>		17
<i>skipped question</i>		2

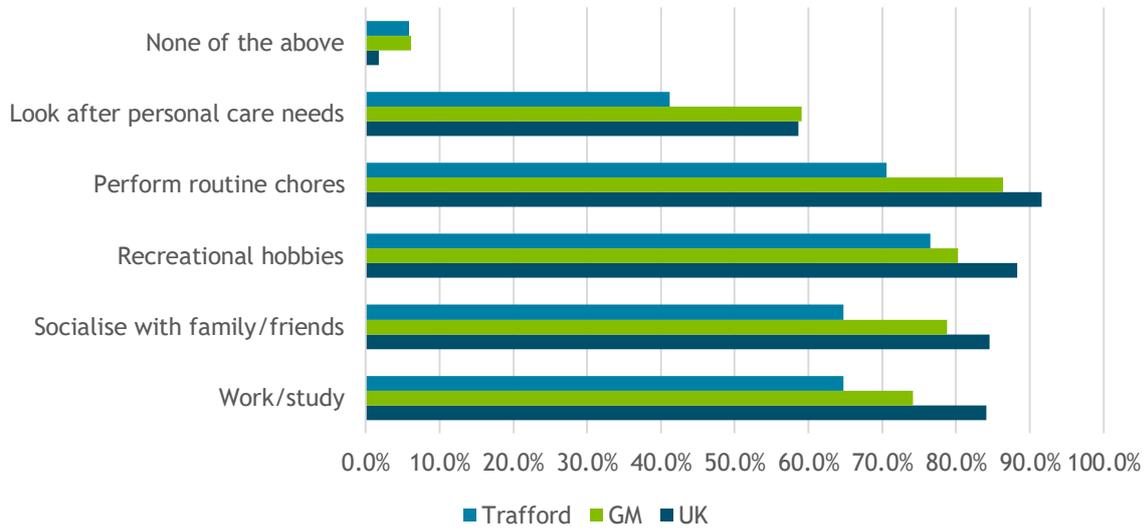
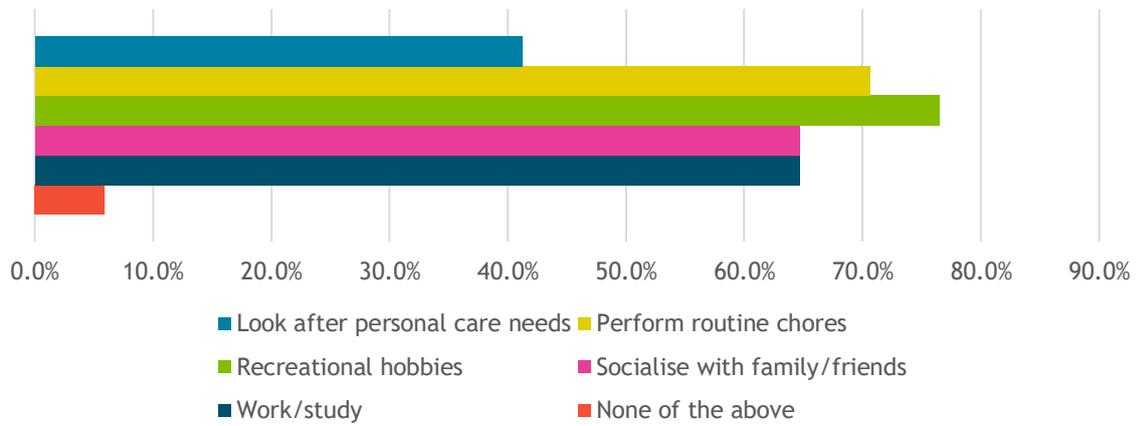
Greater Manchester

Answer Options	Response Percent	Response Count
Ability to work/study (including voluntary work)	74.2%	49
Ability to socialise with family/friends	78.8%	52
Ability to enjoy recreational hobbies	80.3%	53
Ability to perform routine chores (such as household chores, shopping or getting around)	86.4%	57
Ability to look after personal care needs (such as eating, bathing, dressing or getting around the house)	59.1%	39
None of the above	6.1%	4
<i>answered question</i>		66
<i>skipped question</i>		5

UK

Answer Options	Response Percent	Response Count
Ability to work/study (including voluntary work)	84.1%	601
Ability to socialise with family/friends	84.5%	604
Ability to enjoy recreational hobbies	88.3%	631
Ability to perform routine chores (such as household chores, shopping or getting around)	91.6%	655
Ability to look after personal care needs (such as eating, bathing, dressing or getting around the house)	58.6%	419
None of the above	1.8%	13
<i>answered question</i>		715
<i>skipped question</i>		14

In what way, if any, has Fibromyalgia affected your daily life? (Trafford only)



Do you have any co-occurring illnesses?

Trafford

Answer Options	Response Percent	Response Count
No	13.3%	2
Yes (please specify)	86.7%	13
<i>answered question</i>		15
<i>skipped question</i>		4

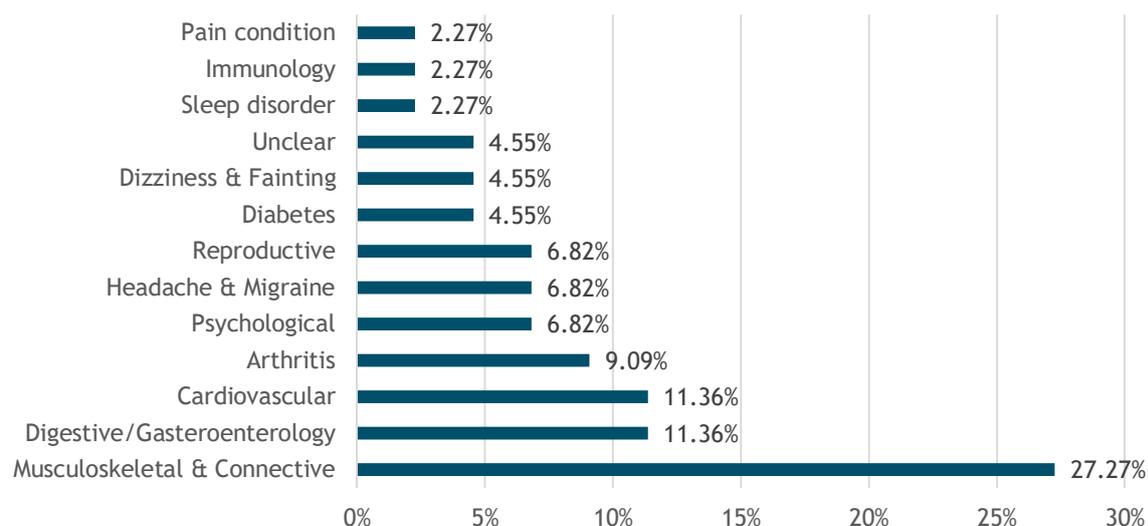
Greater Manchester

Answer Options	Response Percent	Response Count
No	15.6%	10
Yes (please specify)	84.4%	54
<i>answered question</i>		64
<i>skipped question</i>		7

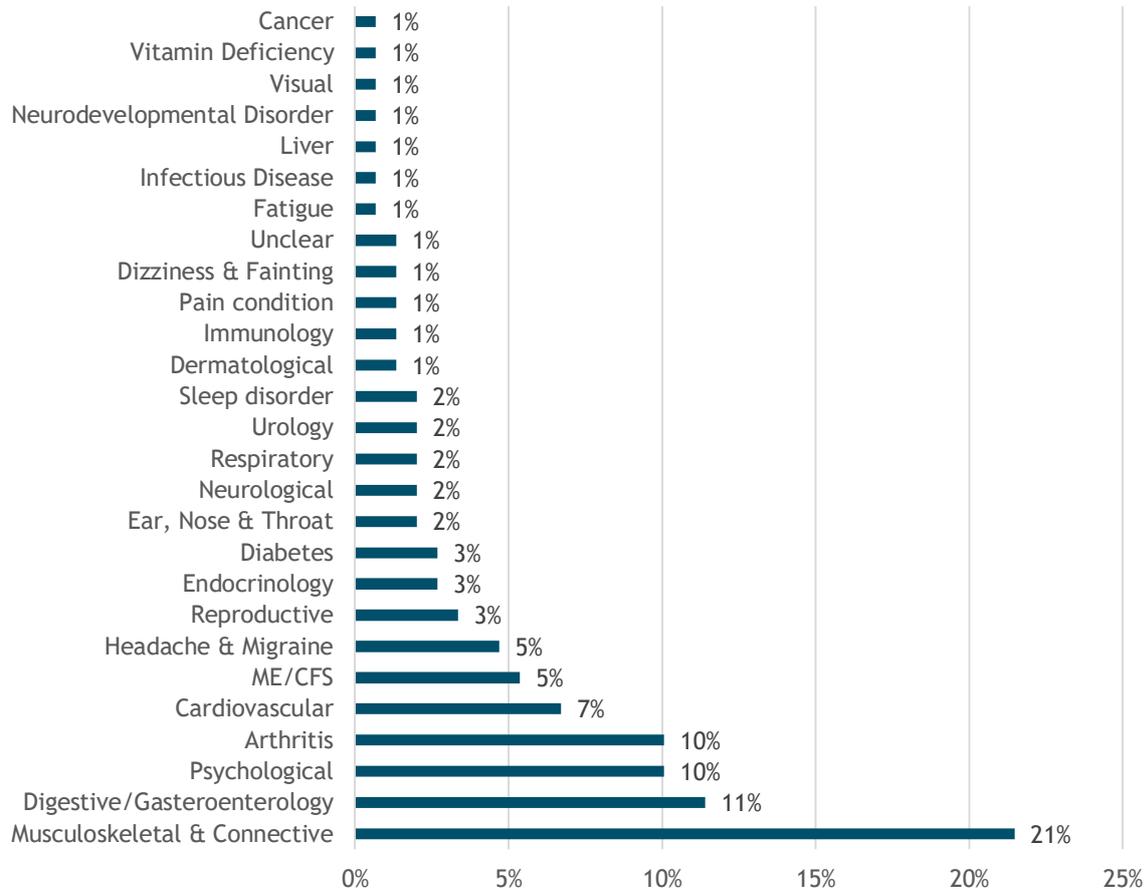
UK

Answer Options	Response Percent	Response Count
No	21.5%	151
Yes (please specify)	78.5%	552
<i>answered question</i>		703
<i>skipped question</i>		26

Co-occurring illnesses (Trafford)



Co-occurring illnesses (Greater Manchester)



Do you have a carer?

Trafford

Answer Options	Response Percent	Response Count
I have a nurse or other professional carer	0.0%	0
A family member acts as a carer (including partner)	37.5%	6
A friend acts as a carer	12.5%	2
Other carer	0.0%	0
I do not have a carer	62.5%	10
<i>answered question</i>		16
<i>skipped question</i>		3

Greater Manchester

Answer Options	Response Percent	Response Count
I have a nurse or other professional carer	3.1%	2
A family member acts as a carer (including partner)	43.1%	28
A friend acts as a carer	7.7%	5
Other carer	0.0%	0
I do not have a carer	55.4%	36
<i>answered question</i>		65
<i>skipped question</i>		6

UK

Answer Options	Response Percent	Response Count
I have a nurse or other professional carer	2.0%	14
A family member acts as a carer (including partner)	44.7%	319
A friend acts as a carer	3.2%	23
Other carer	2.0%	14
I do not have a carer	53.7%	383
<i>answered question</i>		713
<i>skipped question</i>		16

Diagnosis and records

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

Trafford

Answer Options	Response Percent	Response Count
Own GP	17.6%	3
Another GP at my practice	0.0%	0
Locum GP	0.0%	0
At a specialist Fibromyalgia Clinic	5.9%	1
Rheumatologist	52.9%	9
Private doctor or paid service	5.9%	1
Physiotherapist	0.0%	0
Other Specialist (please specify)	17.6%	3
<i>answered question</i>		17
<i>skipped question</i>		2

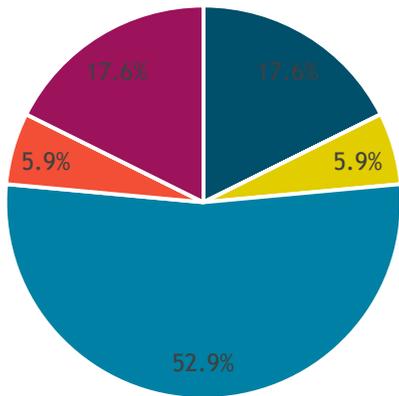
Greater Manchester

Answer Options	Response Percent	Response Count
Own GP	20.3%	13
Another GP at my practice	0.0%	0
Locum GP	1.6%	1
At a specialist Fibromyalgia Clinic	1.6%	1
Rheumatologist	59.4%	38
Private doctor or paid service	6.3%	4
Physiotherapist	0.0%	0
Other Specialist (please specify)	10.9%	7
<i>answered question</i>		64
<i>skipped question</i>		7

UK

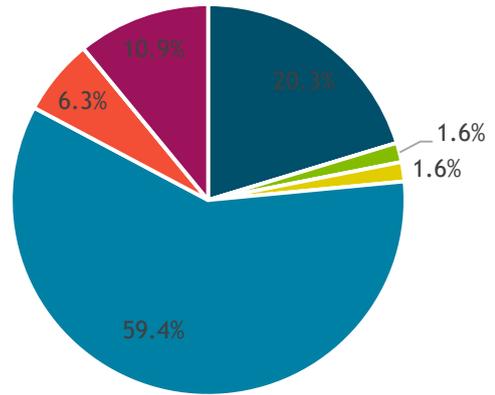
Answer Options	Response Percent	Response Count
Own GP	17.4%	122
Another GP at my practice	3.0%	21
Locum GP	0.9%	6
At a specialist Fibromyalgia Clinic	3.1%	22
Rheumatologist	65.5%	460
Private doctor or paid service	2.1%	15
Physiotherapist	0.9%	6
Other Specialist (please specify)	7.1%	50
<i>answered question</i>		702
<i>skipped question</i>		27

Trafford



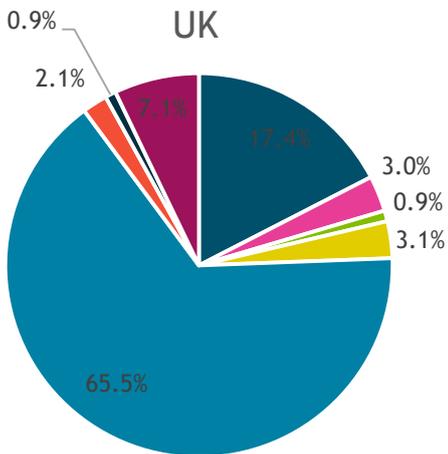
- Own GP
- Rheumatologist
- Other Specialist
- Fibromyalgia Clinic
- Private doctor

GM



- Own GP
- Rheumatologist
- Other Specialist
- Fibromyalgia Clinic
- Private doctor
- Locum GP

UK



- Own GP
- Rheumatologist
- Physiotherapist
- Another GP at practice
- Fibromyalgia Clinic
- Private doctor
- Other Specialist

Other Specialist - Trafford	Categorisation	Count of appearances
	<i>Walk in service</i>	1

Other Specialist - Greater Manchester (excluding Trafford)	Categorisation	Count of appearances
	<i>Neurologist</i>	2
	<i>Unspecified (e.g. 'Specialist', 'Consultant', 'Hospital' etc).</i>	2
	<i>Pain management / clinic</i>	1
	<i>M.E. specialist</i>	1

Other Specialist - UK (excluding GM & Trafford)	Categorisation	Count of appearances
	<i>Neurologist</i>	13
	<i>Pain management / clinic</i>	13
	<i>Unspecified (e.g. 'Specialist', 'Consultant' 'Hospital' etc).</i>	11
	<i>Immunologist</i>	2
	<i>M.E. specialist</i>	1
	<i>Musculoskeletal/Orthopaedic specialist</i>	2
	<i>Chiropractor</i>	1
	<i>Walk in service</i>	1

Were you offered any information from the NHS on living with the condition?

Trafford

Answer Options	Response Percent	Response Count
Yes, from my GP	0.0%	0
Yes, from other specialist or department who diagnosed me	29.4%	5
Yes, from another service or department	5.9%	1
No, I did not receive information	58.8%	10
I was not diagnosed by the NHS	5.9%	1
<i>answered question</i>		17
<i>skipped question</i>		2

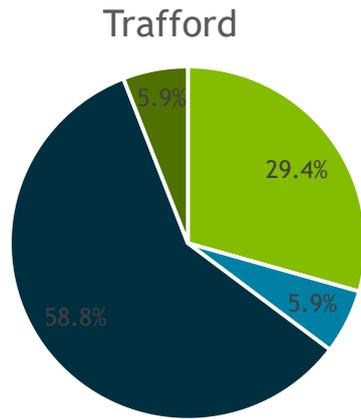
Greater Manchester

Answer Options	Response Percent	Response Count
Yes, from my GP	3.1%	2
Yes, from other specialist or department who diagnosed me	32.3%	21
Yes, from another service or department	9.2%	6
No, I did not receive information	50.8%	33
I was not diagnosed by the NHS	4.6%	3
<i>answered question</i>		65
<i>skipped question</i>		6

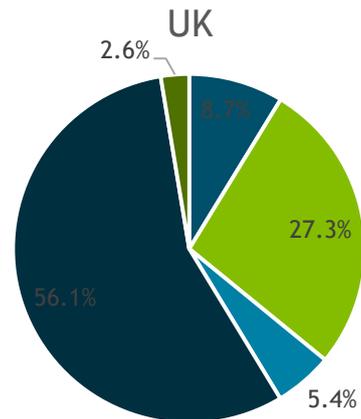
UK

Answer Options	Response Percent	Response Count
Yes, from my GP	8.7%	61
Yes, from other specialist or department who diagnosed me	27.3%	192
Yes, from another service or department	5.4%	38
No, I did not receive information	56.1%	395
I was not diagnosed by the NHS	2.6%	18
<i>answered question</i>		704
<i>skipped question</i>		25

Please note: figures quoted in the report may differ from those in the table. This is because information in the report is concerned with those diagnosed by the NHS, and thus the responses of those not diagnosed by the NHS have been removed from the sample. These figures of those who did not receive information from the NHS were therefore 62.5% in Trafford, 53.2% in Greater Manchester and 57.6% in the UK.



- Yes, from other (who diagnosed me)
- Yes, from other
- No
- I was not diagnosed by the NHS



- Yes, from GP
- Yes, from other (who diagnosed me)
- Yes, from other
- No
- I was not diagnosed by the NHS

If yes, was that information helpful?

Trafford

Answer Options	Response Percent	Response Count
Yes	85.7%	6
No	14.3%	1
<i>answered question</i>		7
<i>skipped question</i>		12

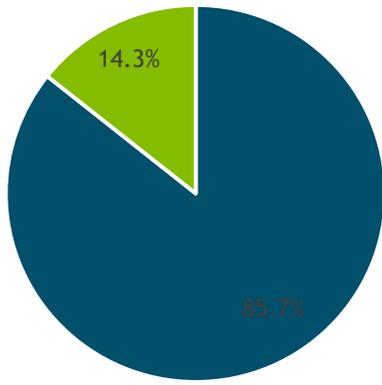
Greater Manchester

Answer Options	Response Percent	Response Count
Yes	59.5%	22
No	40.5%	15
<i>answered question</i>		37
<i>skipped question</i>		34

UK

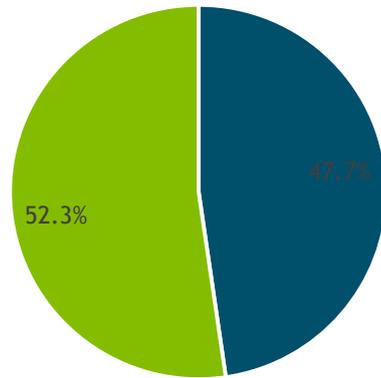
Answer Options	Response Percent	Response Count
Yes	47.7%	174
No	52.3%	191
<i>answered question</i>		365
<i>skipped question</i>		364

Trafford



■ Yes ■ No

UK



■ Yes ■ No

Have you experienced any misdiagnosis?

Trafford

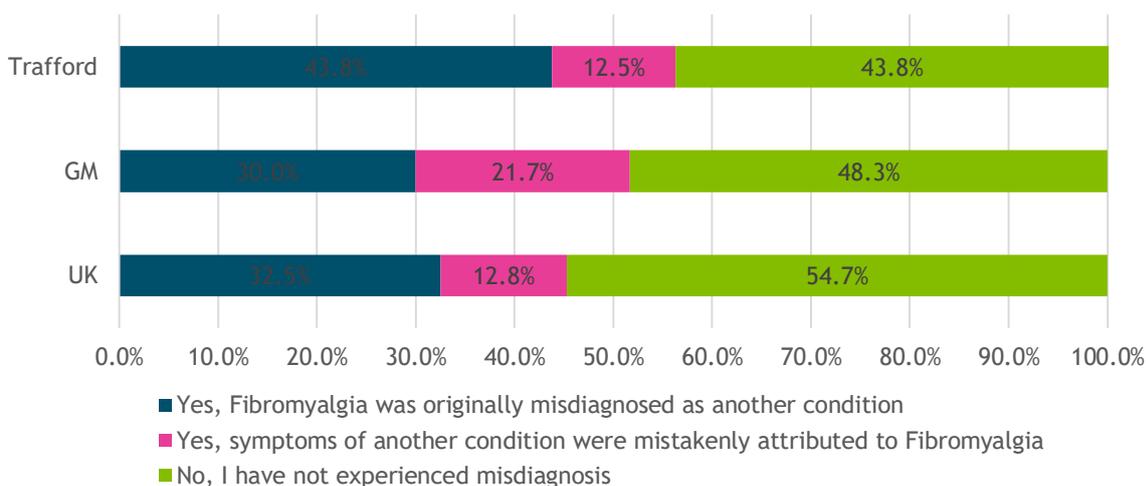
Answer Options	Response Percent	Response Count
Yes, Fibromyalgia was originally misdiagnosed as another condition	43.8%	7
Yes, symptoms of another condition were mistakenly attributed to Fibromyalgia	12.5%	2
No, I have not experienced misdiagnosis	43.8%	7
<i>answered question</i>		16
<i>skipped question</i>		3

Greater Manchester

Answer Options	Response Percent	Response Count
Yes, Fibromyalgia was originally misdiagnosed as another condition	30.0%	18
Yes, symptoms of another condition were mistakenly attributed to Fibromyalgia	21.7%	13
No, I have not experienced misdiagnosis	48.3%	29
<i>answered question</i>		60
<i>skipped question</i>		11

UK

Answer Options	Response Percent	Response Count
Yes, Fibromyalgia was originally misdiagnosed as another condition	32.5%	223
Yes, symptoms of another condition were mistakenly attributed to Fibromyalgia	12.8%	88
No, I have not experienced misdiagnosis	54.7%	375
<i>answered question</i>		686
<i>skipped question</i>		43



Do you have copies of, or know how to access, your medical records (including test results and letters from consultants to GP/s)?

Trafford

Answer Options	Response Percent	Response Count
Yes, I requested copies	41.2%	7
Yes, I was offered copies	0.0%	0
No, but I know how to access them	35.3%	6
No, I don't know how to access them	23.5%	4
No, I don't want to access them	0.0%	0
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

Answer Options	Response Percent	Response Count
Yes, I requested copies	25.8%	17
Yes, I was offered copies	7.6%	5
No, but I know how to access them	24.2%	16
No, I don't know how to access them	37.9%	25
No, I don't want to access them	4.5%	3
<i>answered question</i>		66
<i>skipped question</i>		5

UK

Answer Options	Response Percent	Response Count
Yes, I requested copies	13.5%	95
Yes, I was offered copies	6.2%	44
No, but I know how to access them	27.2%	192
No, I don't know how to access them	49.5%	349
No, I don't want to access them	3.5%	25
<i>answered question</i>		705
<i>skipped question</i>		24

GP services

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

Trafford

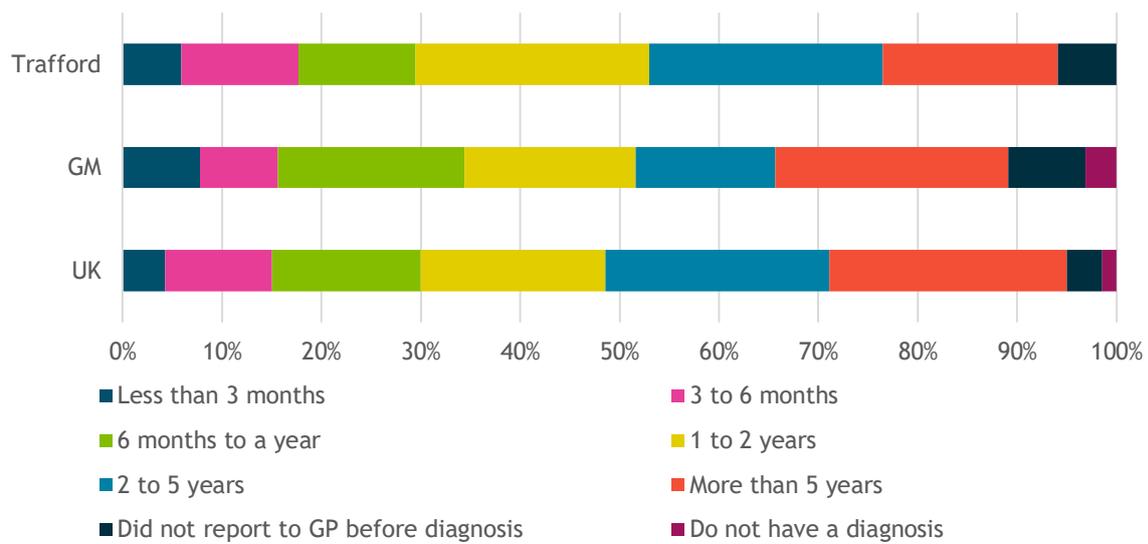
Answer Options	Response Percent	Response Count
Less than 3 months	5.9%	1
3 to 6 months	11.8%	2
6 months to a year	11.8%	2
1 to 2 years	23.5%	4
2 to 5 years	23.5%	4
More than 5 years	17.6%	3
I did not report my symptoms to a GP before diagnosis	5.9%	1
I do not have a formal diagnosis	0.0%	0
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

Answer Options	Response Percent	Response Count
Less than 3 months	7.8%	5
3 to 6 months	7.8%	5
6 months to a year	18.8%	12
1 to 2 years	17.2%	11
2 to 5 years	14.1%	9
More than 5 years	23.4%	15
I did not report my symptoms to a GP before diagnosis	7.8%	5
I do not have a formal diagnosis	3.1%	2
<i>answered question</i>		64
<i>skipped question</i>		7

UK

Answer Options	Response Percent	Response Count
Less than 3 months	4.3%	30
3 to 6 months	10.7%	74
6 months to a year	14.9%	103
1 to 2 years	18.6%	129
2 to 5 years	22.5%	156
More than 5 years	23.8%	165
I did not report my symptoms to a GP before diagnosis	3.6%	25
I do not have a formal diagnosis	1.4%	10
<i>answered question</i>		692
<i>skipped question</i>		37



How does your GP talk about Fibromyalgia?

How does your GP talk about Fibromyalgia?

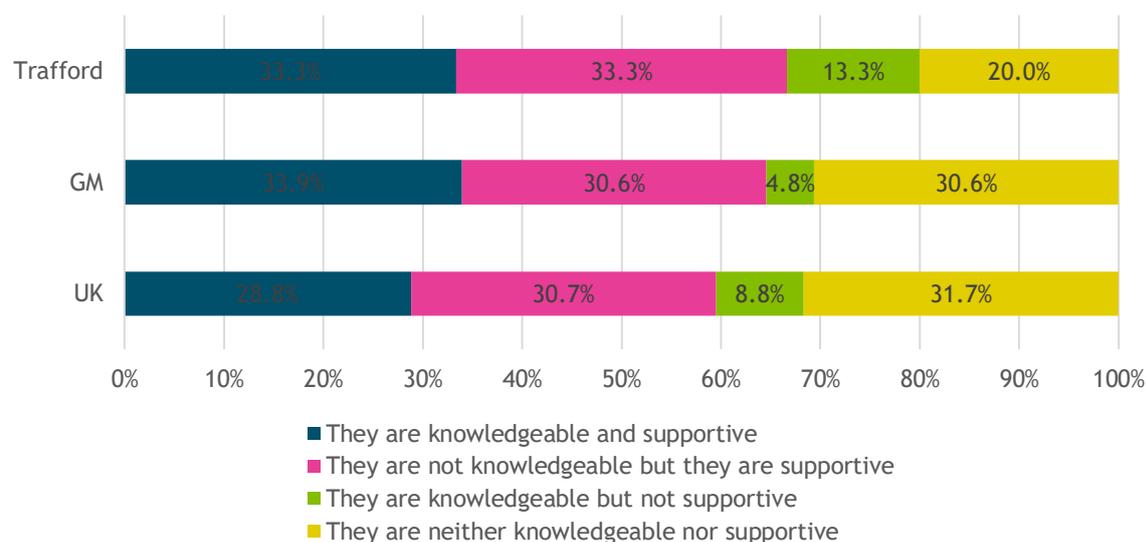
Answer Options	Response Percent	Response Count
They are knowledgeable and supportive	33.3%	5
They are not knowledgeable but they are supportive	33.3%	5
They are knowledgeable but not supportive	13.3%	2
They are neither knowledgeable nor supportive	20.0%	3
<i>answered question</i>		15
<i>skipped question</i>		4

Greater Manchester

Answer Options	Response Percent	Response Count
They are knowledgeable and supportive	33.9%	21
They are not knowledgeable but they are supportive	30.6%	19
They are knowledgeable but not supportive	4.8%	3
They are neither knowledgeable nor supportive	30.6%	19
<i>answered question</i>		62
<i>skipped question</i>		9

UK

Answer Options	Response Percent	Response Count
They are knowledgeable and supportive	28.8%	196
They are not knowledgeable but they are supportive	30.7%	209
They are knowledgeable but not supportive	8.8%	60
They are neither knowledgeable nor supportive	31.7%	216
<i>answered question</i>		681
<i>skipped question</i>		48



Would you say that your GP/s speak to you with respect and listens to you?

Trafford

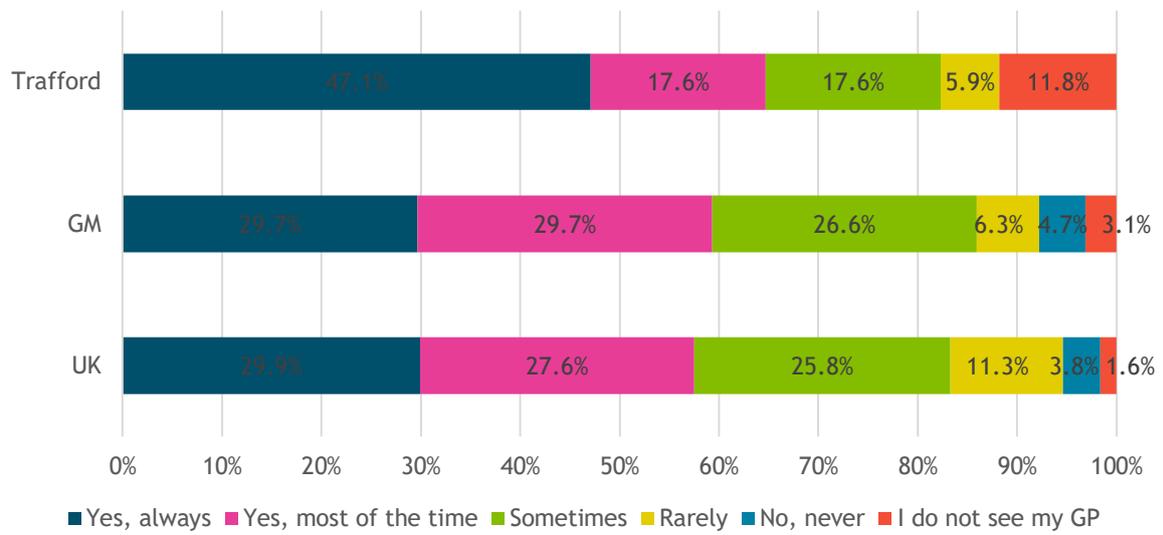
Answer Options	Response Percent	Response Count
Yes, always	47.1%	8
Yes, most of the time	17.6%	3
Sometimes	17.6%	3
Rarely	5.9%	1
No, never	0.0%	0
I do not see my GP	11.8%	2
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

Answer Options	Response Percent	Response Count
Yes, always	29.7%	19
Yes, most of the time	29.7%	19
Sometimes	26.6%	17
Rarely	6.3%	4
No, never	4.7%	3
I do not see my GP	3.1%	2
<i>answered question</i>		64
<i>skipped question</i>		7

UK

Answer Options	Response Percent	Response Count
Yes, always	29.9%	206
Yes, most of the time	27.6%	190
Sometimes	25.8%	178
Rarely	11.3%	78
No, never	3.8%	26
I do not see my GP	1.6%	11
<i>answered question</i>		689
<i>skipped question</i>		40



Do you experience any difficulty in obtaining or attending GP appointments due to your Fibromyalgia?

Trafford

Answer Options	Response Percent	Response Count
I have no difficulty in obtaining or attending GP appointments	43.8%	7
Yes, I have problems due to travel/transport	6.3%	1
Yes, I have difficulties due to waiting times to see a specific GP	31.3%	5
Yes, I have difficulties due to inflexible appointment times	25.0%	4
Yes, I have difficulties as my Fibromyalgia may mean I can't attend on the day	12.5%	2
I have other difficulties (please specify)	0.0%	0
<i>answered question</i>		16
<i>skipped question</i>		3

Greater Manchester

Answer Options	Response Percent	Response Count
I have no difficulty in obtaining or attending GP appointments	34.9%	22
Yes, I have problems due to travel/transport	22.2%	14
Yes, I have difficulties due to waiting times to see a specific GP	39.7%	25
Yes, I have difficulties due to inflexible appointment times	23.8%	15
Yes, I have difficulties as my Fibromyalgia may mean I can't attend on the day	38.1%	24
I have other difficulties (please specify)	3.2%	2
<i>answered question</i>		63
<i>skipped question</i>		8

UK

Answer Options	Response Percent	Response Count
I have no difficulty in obtaining or attending GP appointments	32.9%	224
Yes, I have problems due to travel/transport	16.9%	115
Yes, I have difficulties due to waiting times to see a specific GP	42.0%	286
Yes, I have difficulties due to inflexible appointment times	18.9%	129
Yes, I have difficulties as my Fibromyalgia may mean I can't attend on the day	30.5%	208
I have other difficulties (please specify)	6.3%	43
<i>answered question</i>		681
<i>skipped question</i>		48

**Other difficulties
- Greater Manchester**

Categorisation

**Count of
appearances**

<i>Unable to see chosen GP</i>	1
<i>Bedbound/unable to attend</i>	1
<i>Co-occurring illness</i>	1

**Other difficulties
- UK (excluding GM)**

Categorisation

**Count of
appearances**

<i>Poor attitudes to Fibromyalgia by medical professionals</i>	10
<i>General non-Fibromyalgia reason</i>	7
<i>Bedbound/unable to attend</i>	4
<i>Other</i>	4
<i>Co-occurring illness</i>	3
<i>Aggravates Fibromyalgia Symptoms</i>	3
<i>Availability of carer to attend with or look after dependents</i>	3
<i>Memory problems</i>	3
<i>Unclear</i>	2
<i>Booking system not Fibromyalgia friendly (early in the morning)</i>	1
<i>Fibromyalgia causes mobility problems</i>	1

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

Trafford

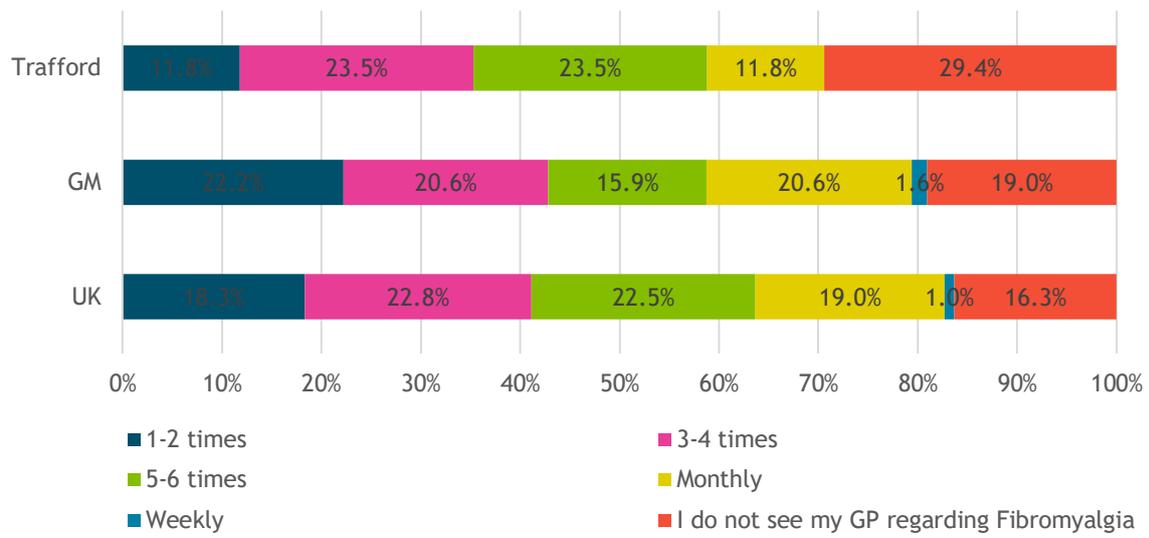
Answer Options	Response Percent	Response Count
1-2 times per year	11.8%	2
3-4 times (once a quarter)	23.5%	4
5-6 times (every two months)	23.5%	4
Monthly	11.8%	2
Weekly	0.0%	0
I do not see my GP regarding Fibromyalgia	29.4%	5
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

Answer Options	Response Percent	Response Count
1-2 times per year	22.2%	14
3-4 times (once a quarter)	20.6%	13
5-6 times (every two months)	15.9%	10
Monthly	20.6%	13
Weekly	1.6%	1
I do not see my GP regarding Fibromyalgia	19.0%	12
<i>answered question</i>		63
<i>skipped question</i>		8

UK

Answer Options	Response Percent	Response Count
1-2 times per year	18.3%	126
3-4 times (once a quarter)	22.8%	157
5-6 times (every two months)	22.5%	155
Monthly	19.0%	131
Weekly	1.0%	7
I do not see my GP regarding Fibromyalgia	16.3%	112
<i>answered question</i>		688
<i>skipped question</i>		41



Is there anything else you would like to say about the service that your GP has provided you for your Fibromyalgia?

Due to time constraints on this project, analysis of qualitative responses in this report includes only data from people living in Trafford and Greater Manchester. If you wish to access the remaining data for your own research or interest, please contact Healthwatch Trafford (details at the end of this report).

Please note that for this question, the Greater Manchester data excludes Trafford. This is to enable direct comparison of issues and prevalence within and outside of Trafford.

Trafford	Categorisation	Count of appearances
	<i>GP services have not been helpful</i>	4
	<i>GP is supportive/sympathetic</i>	4
	<i>Lack of long-term treatment/medication as only treatment</i>	3
	<i>Self-management is needed</i>	3
	<i>Complementary therapies used</i>	2
	<i>Long waiting times</i>	2
	<i>Need to be proactive in seeking care/Physician & patient collaboration</i>	2
	<i>Misdiagnosis/other conditions attributed to Fibromyalgia</i>	2
	<i>Poor GP interpersonal care (GP is condescending, rude, treats as hypochondriac)</i>	1
	<i>GP is not knowledgeable/better training needed</i>	1
	<i>GP is thorough/knowledgeable/helpful</i>	1
	<i>Dismissive/denial of condition</i>	1
	<i>Appointments too short/feel rushed</i>	1

Greater Manchester (excluding Trafford)	Categorisation	Count of appearances
	<i>Lack of long-term treatment/medication as only treatment</i>	7
	<i>GP services have not been helpful</i>	6
	<i>Dismissive of/denial of condition</i>	6
	<i>Inconsistency of care (see different GP each time, different levels of knowledge between GPs, different attitudes towards Fibromyalgia)</i>	5
	<i>Poor GP interpersonal care (GP is condescending, rude, treats as hypochondriac)</i>	5
	<i>GP is supportive/sympathetic</i>	4
	<i>GP is not knowledgeable/better training needed</i>	4
	<i>GP is thorough/knowledgeable/helpful</i>	4
	<i>Lack of services available/not referred to services</i>	3
	<i>Misdiagnosis/other conditions attributed to Fibromyalgia</i>	2
	<i>Lack of information given</i>	2
	<i>GP is great</i>	2
	<i>Abandoned after diagnosis</i>	1
	<i>Referred out of area</i>	1
	<i>Need to be proactive in seeking care/Physician & patient collaboration</i>	1
	<i>Problems with accessing secondary care recommendations through GP (e.g. repeat prescriptions)</i>	1

Hospitals and secondary services

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

Trafford

Answer Options	Response Percent	Response Count
Rheumatology	82.4%	14
Physiotherapy	35.3%	6
Neurologist	17.6%	3
Psychological services (including CBT)	41.2%	7
Occupational Therapy	17.6%	3
Pain Management	23.5%	4
Complementary Therapies	17.6%	3
Hydrotherapy	17.6%	3
Psychiatry	5.9%	1
None	5.9%	1
Other (Please state)	5.9%	1
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

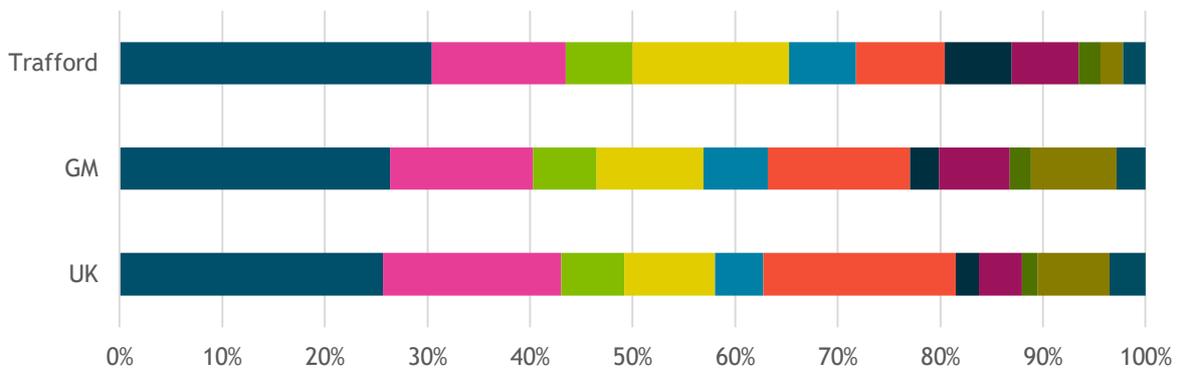
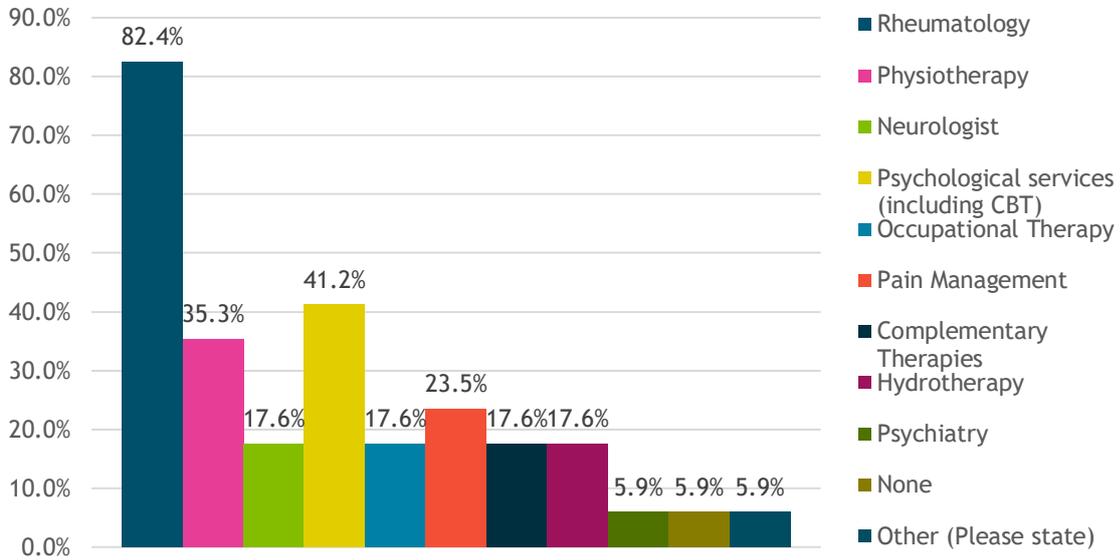
Answer Options	Response Percent	Response Count
Rheumatology	61.3%	38
Physiotherapy	32.3%	20
Neurologist	14.5%	9
Psychological services (including CBT)	24.2%	15
Occupational Therapy	14.5%	9
Pain Management	32.3%	20
Complementary Therapies	6.5%	4
Hydrotherapy	16.1%	10
Psychiatry	4.8%	3
None	19.4%	12
Other (Please state)	6.5%	4
<i>answered question</i>		62
<i>skipped question</i>		9

UK

Answer Options	Response Percent	Response Count
Rheumatology	58.8%	399
Physiotherapy	39.8%	270
Neurologist	14.1%	96
Psychological services (including CBT)	20.3%	138
Occupational Therapy	10.8%	73
Pain Management	43.0%	292
Complementary Therapies	5.2%	35
Hydrotherapy	9.6%	65
Psychiatry	3.4%	23

None	16.2%	110
Other (Please state)	8.0%	54
answered question		679
skipped question		50

Trafford



- Rheumatology
- Physiotherapy
- Neurologist
- Psychological services (including CBT)
- Occupational Therapy
- Pain Management
- Complementary Therapies
- Hydrotherapy
- Psychiatry
- None
- Other (Please state)

Other service - Trafford	Categorisation	Count of appearances
	<i>Services were accessed privately/non-NHS</i>	1

Other service - Greater Manchester (excluding Trafford)	Categorisation	Count of appearances
	<i>Referrals have been for other conditions (may have discussed Fibromyalgia once there)</i>	1
	<i>Patient believes psychiatry/psychological services are unnecessary for Fibromyalgia</i>	1

Other service - UK (excluding GM & Trafford)	Categorisation	Count of appearances
	<i>Comment on quality of service</i>	5
	<i>Referrals for other conditions</i>	4
	<i>Musculoskeletal/orthopaedic clinic</i>	3
	<i>Comment on waiting times</i>	3
	<i>ME/CFS or Fatigue service</i>	3
	<i>Requested referrals/had to be proactive</i>	3
	<i>Ear, Nose & Throat</i>	2
	<i>Endocrinologist</i>	2
	<i>Exercise programme</i>	2
	<i>Fibromyalgia coping skills course</i>	2
	<i>Integrated services/Multidisciplinary</i>	2
	<i>Neurologist</i>	2
	<i>Ophthalmologist</i>	2
	<i>Patient believes psychiatry/psychological services are unnecessary for Fibromyalgia</i>	2
	<i>Services were accessed privately/non-NHS</i>	2
	<i>Comment on treatment</i>	2
	<i>Comment on understanding of Fibromyalgia/poor attitudes by medical professionals</i>	2
	<i>Speech and Language Therapy</i>	1
	<i>Sought help from charity</i>	1
	<i>Urology</i>	1
	<i>Gastroenterology</i>	1
	<i>Was refused referral</i>	1
	<i>Referral/s by other specialist (non-GP)</i>	1
	<i>Podiatry</i>	1
	<i>Nutrition/Dietician</i>	1
	<i>Comment on self-management</i>	1
	<i>Other</i>	5

Do you find that most (non-specialist) hospital staff have knowledge of Fibromyalgia and 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 Fibromyalgia	11.8%	2
Most don't have much knowledge of Fibromyalgia	52.9%	9
No, most do not understand Fibromyalgia	29.4%	5
I have not used hospital services	5.9%	1
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

Answer Options	Response Percent	Response Count
Yes, most understand and treat me appropriately	0.0%	0
Yes, most have some knowledge of Fibromyalgia	21.0%	13
Most don't have much knowledge of Fibromyalgia	35.5%	22
No, most do not understand Fibromyalgia	32.3%	20
I have not used hospital services	11.3%	7
<i>answered question</i>		62
<i>skipped question</i>		9

UK

Answer Options	Response Percent	Response Count
Yes, most understand and treat me appropriately	3.1%	21
Yes, most have some knowledge of Fibromyalgia	15.0%	101
Most don't have much knowledge of Fibromyalgia	32.6%	220
No, most do not understand Fibromyalgia	32.7%	221
I have not used hospital services	16.6%	112
<i>answered question</i>		675
<i>skipped question</i>		54



- Yes, most understand and treat me appropriately
- Yes, most have some knowledge of Fibromyalgia
- Most don't have much knowledge of Fibromyalgia
- No, most do not understand Fibromyalgia
- I have not used hospital services

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

Trafford

Answer Options	Response Percent	Response Count
Yes, always	6.3%	1
Yes, most of the time	43.8%	7
Sometimes	25.0%	4
Rarely	0.0%	0
No, never	12.5%	2
I have not used hospital services	12.5%	2
<i>answered question</i>		16
<i>skipped question</i>		3

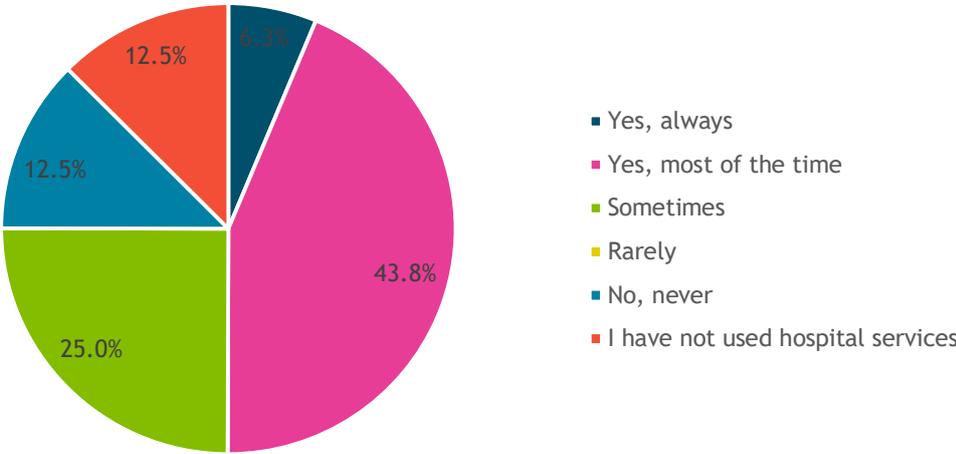
Greater Manchester

Answer Options	Response Percent	Response Count
Yes, always	11.5%	7
Yes, most of the time	37.7%	23
Sometimes	23.0%	14
Rarely	9.8%	6
No, never	3.3%	2
I have not used hospital services	14.8%	9
<i>answered question</i>		61
<i>skipped question</i>		10

UK

Answer Options	Response Percent	Response Count
Yes, always	8.8%	59
Yes, most of the time	33.4%	225
Sometimes	30.0%	202
Rarely	9.2%	62
No, never	2.5%	17
I have not used hospital services	16.2%	109
<i>answered question</i>		674
<i>skipped question</i>		55

Would you say that hospital staff speak to you with respect and fairness, listening to you? (Trafford)



Do you experience any difficulty in obtaining or attending specialist (non-GP) appointments due to your Fibromyalgia?

Trafford

Answer Options	Response Percent	Response Count
I have no difficulty in obtaining or attending appointments	53.3%	8
Yes, I have problems due to travel/transport	13.3%	2
Yes, I have difficulties due to inflexible appointment times	26.7%	4
Yes, I have difficulties as my Fibromyalgia may mean I can't attend on the day	13.3%	2
I have other difficulties (please specify)	6.7%	1
<i>answered question</i>		15
<i>skipped question</i>		4

Greater Manchester

Answer Options	Response Percent	Response Count
I have no difficulty in obtaining or attending appointments	33.3%	19
Yes, I have problems due to travel/transport	28.1%	16
Yes, I have difficulties due to inflexible appointment times	24.6%	14
Yes, I have difficulties as my Fibromyalgia may mean I can't attend on the day	40.4%	23
I have other difficulties (please specify)	17.5%	10
<i>answered question</i>		57
<i>skipped question</i>		14

UK

Answer Options	Response Percent	Response Count
I have no difficulty in obtaining or attending appointments	35.6%	226
Yes, I have problems due to travel/transport	25.6%	162
Yes, I have difficulties due to inflexible appointment times	23.5%	149
Yes, I have difficulties as my Fibromyalgia may mean I can't attend on the day	38.6%	245
I have other difficulties (please specify)	10.7%	68
<i>answered question</i>		634
<i>skipped question</i>		95

**Other difficulties
- Trafford**

Categorisation

**Count of
appearances**

Parking/access due to condition

1

**Other difficulties
- Greater Manchester
(excluding Trafford)**

Categorisation

**Count of
appearances**

Aggravates Fibromyalgia Symptoms

3

Co-occurring illness

3

Difficulty of accessing services

1

Refused/not given referral(s)

1

Re-referrals needed

1

**Other difficulties - UK
(excluding Trafford &
GM)**

Categorisation

**Count of
appearances**

General non-Fibromyalgia reason

13

Difficulty of accessing services

9

Refused/not given referral(s)

8

Co-occurring illness

6

Comment on waiting times

5

Discharged for primary care treatment

5

Aggravates Fibromyalgia symptoms

3

Memory problems

3

Other

3

Unclear

3

Waiting for treatment

3

Availability of carer to attend with or look after dependents

2

Hospital facilities not appropriate (e.g. chairs without lumbar support, lack of wheelchair transport between departments)

2

Requested referral

2

Discharged for primary care treatment

2

Financial

1

Lack of available services

1

Not currently under treatment

1

Poor attitudes to Fibromyalgia by medical professionals

1

Re-referrals needed

1

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

Due to time constraints on this project, analysis of qualitative responses in this report includes only data from people living in Trafford and Greater Manchester. If you wish to access the remaining data for your own research or interest, please contact Healthwatch Trafford (details at the end of this report).

Please note that for this question, the Greater Manchester data excludes Trafford. This is to enable direct comparison of issues and prevalence within and outside of Trafford.

Trafford	Categorisation	Count of appearances
	<i>Poor interpersonal care (rude, lack of sympathy, poor manner)</i>	2
	<i>Discharged back to primary care without further support</i>	2
	<i>Long waiting times</i>	2
	<i>Strain of getting to treatment not worth it/exacerbates symptoms</i>	1
	<i>Time limit on treatment (rather than based on patient experience/response) / discharged before worked</i>	1
	<i>Hospital facilities are not suitable for Fibromyalgia (lack of wheelchairs between departments, chairs do not provide enough support, no travel service available for Fibromyalgia patients)</i>	1
	<i>Lack of long-term treatment</i>	1
	<i>Lack of services available</i>	1
	<i>Appointment length too short/feel rushed</i>	1
Greater Manchester (excluding Trafford)	Categorisation	Count of appearances
	<i>Treatment assumes a psychological cause/does not address non-psychological aspects</i>	3
	<i>Long waiting times in clinics/for appointments</i>	3
	<i>Discharged back to primary care without further support (may need multiple re-referrals)</i>	3
	<i>Hospital facilities are not suitable for Fibromyalgia (lack of wheelchairs between departments, chairs do not provide enough support, no travel service available for Fibromyalgia patients)</i>	3
	<i>Lack of long-term treatment</i>	2
	<i>Poor interpersonal care</i>	2
	<i>Holistic/whole-person approach needed</i>	2
	<i>Dismissive of/denial of condition</i>	2
	<i>Lack of services available</i>	2
	<i>Service is fantastic</i>	1
	<i>Treatment has been helpful</i>	1
	<i>Lack of fibro-specific care</i>	1
	<i>Had to self-fund to get treatment</i>	1
	<i>Time limit on treatment (rather than based on patient experience/response) / discharged before worked</i>	1
	<i>Not offered help with coping (e.g. psychological services)</i>	1
	<i>Difficulty accessing suitable pain relief</i>	1

Inpatient services

Have you ever been an inpatient (for any condition) whilst having Fibromyalgia?

Trafford

Answer Options	Response Percent	Response Count
Yes	50.0%	8
No	50.0%	8
<i>answered question</i>		16
<i>skipped question</i>		3

Greater Manchester

Answer Options	Response Percent	Response Count
Yes	40.7%	24
No	59.3%	35
<i>answered question</i>		59
<i>skipped question</i>		12

UK

Answer Options	Response Percent	Response Count
Yes	40.3%	269
No	59.7%	398
<i>answered question</i>		667
<i>skipped question</i>		62

If yes, did hospital staff understand your Fibromyalgia and accommodate you?

Trafford

Answer Options	Response Percent	Response Count
Yes	7.7%	1
Somewhat	23.1%	3
No	30.8%	4
I have not been an inpatient whilst having Fibromyalgia	38.5%	5
<i>answered question</i>		13
<i>skipped question</i>		6

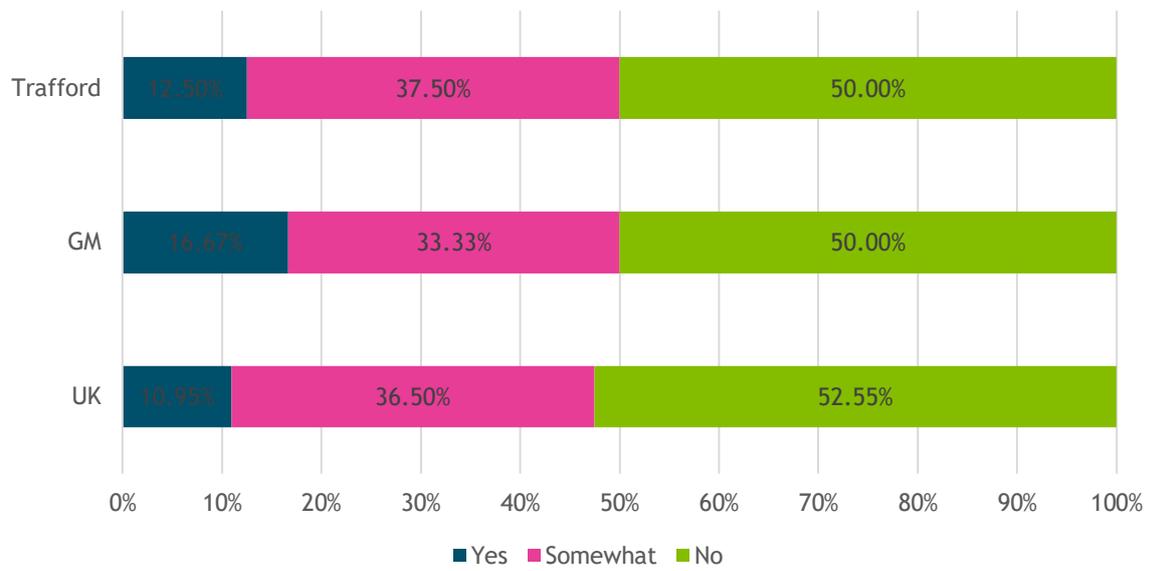
Greater Manchester

Answer Options	Response Percent	Response Count
Yes	8.5%	4
Somewhat	17.0%	8
No	25.5%	12
I have not been an inpatient whilst having Fibromyalgia	48.9%	23
<i>answered question</i>		47
<i>skipped question</i>		24

UK

Answer Options	Response Percent	Response Count
Yes	5.5%	30
Somewhat	18.5%	100
No	26.6%	144
I have not been an inpatient whilst having Fibromyalgia	49.4%	267
<i>answered question</i>		541
<i>skipped question</i>		188

Percentages quoted in the findings section were calculated by removing the respondents that had not been inpatients from the sample. Numbers in the report may therefore vary from those above.



1 Percentages calculated for those who had experienced inpatient care

In regards to your Fibromyalgia, is there anything else about inpatient services you would like to mention?

Due to time constraints on this project, analysis of qualitative responses in this report includes only data from people living in Trafford and Greater Manchester. If you wish to access the remaining data for your own research or interest, please contact Healthwatch Trafford (details at the end of this report).

Please note that for this question, the Greater Manchester data excludes Trafford. This is to enable direct comparison of issues and prevalence within and outside of Trafford.

Trafford	Categorisation	Count of appearances
	<i>Lack of knowledge/understanding</i>	2
	<i>Operations/treatment for other conditions can exacerbate Fibromyalgia symptoms</i>	2
	<i>Dismissive/denial of condition</i>	1
	<i>Facilities not suitable for Fibromyalgia (no quiet area)</i>	1
	<i>Poor quality of care</i>	1
	<i>Inflexibility/Fibromyalgia not taken into consideration when treating other conditions</i>	1
	<i>Lack of long-term treatment</i>	1
	<i>Lack of services available</i>	1
	<i>Appointment length too short/feel rushed</i>	1

Greater Manchester (excluding Trafford)	Categorisation	Count of appearances
	<i>Inflexibility/Fibromyalgia not taken into consideration when treating other conditions</i>	4
	<i>Poor interpersonal care</i>	4
	<i>Poor quality of care</i>	3
	<i>Good understanding of Fibromyalgia</i>	1

Demographic information

Age Range

Trafford

Answer Options	Response Percent	Response Count
17 & under	0.0%	0
18-24	0.0%	0
25-49	41.2%	7
50-64	47.1%	8
65-79	11.8%	2
80+	0.0%	0
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

Answer Options	Response Percent	Response Count
17 & under	0.0%	0
18-24	3.2%	2
25-49	58.1%	36
50-64	29.0%	18
65-79	9.7%	6
80+	0.0%	0
<i>answered question</i>		62
<i>skipped question</i>		9

UK

Answer Options	Response Percent	Response Count
17 & under	0.0%	0
18-24	3.2%	22
25-49	58.2%	394
50-64	33.5%	227
65-79	5.0%	34
80+	0.0%	0
<i>answered question</i>		677
<i>skipped question</i>		52

Do you consider yourself to have a disability?

Trafford

Answer Options	Response Percent	Response Count
Yes	62.5%	10
No	37.5%	6
<i>answered question</i>		16
<i>skipped question</i>		3

Greater Manchester

Answer Options	Response Percent	Response Count
Yes	73.8%	45
No	26.2%	16
<i>answered question</i>		61
<i>skipped question</i>		10

UK

Answer Options	Response Percent	Response Count
Yes	80.1%	538
No	19.9%	134
<i>answered question</i>		672
<i>skipped question</i>		57

Which gender do you consider yourself?

Trafford

Answer Options	Response Percent	Response Count
Male	5.9%	1
Female	94.1%	16
Transgender	0.0%	0
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

Answer Options	Response Percent	Response Count
Male	5.0%	3
Female	95.0%	57
Transgender	0.0%	0
<i>answered question</i>		60
<i>skipped question</i>		11

UK

Answer Options	Response Percent	Response Count
Male	4.2%	28
Female	95.8%	644
Transgender	0.0%	0
<i>answered question</i>		672
<i>skipped question</i>		57

Which ethnic group do you identify as most?

Trafford

Answer Options	Response Percent	Response Count
White British/English/Scottish/Welsh/Northern Irish	100.0%	17
White Irish	0.0%	0
White Gypsy or Irish Traveller	0.0%	0
African	0.0%	0
Caribbean	0.0%	0
Indian	0.0%	0
Pakistani	0.0%	0
Bangladeshi	0.0%	0
Chinese	0.0%	0
Arab	0.0%	0
White & Black Caribbean	0.0%	0
White & Black African	0.0%	0
White & Asian	0.0%	0
Any other ethnic background (please describe)	0.0%	0
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

Answer Options	Response Percent	Response Count
White British/English/Scottish/Welsh/Northern Irish	95.0%	57
White Irish	0.0%	0
White Gypsy or Irish Traveller	0.0%	0
African	0.0%	0
Caribbean	0.0%	0
Indian	0.0%	0
Pakistani	1.7%	1
Bangladeshi	0.0%	0
Chinese	0.0%	0
Arab	0.0%	0
White & Black Caribbean	0.0%	0
White & Black African	0.0%	0
White & Asian	0.0%	0
Any other ethnic background (please describe)	3.3%	2
<i>answered question</i>		60
<i>skipped question</i>		11

UK

Answer Options	Response Percent	Response Count
White British/English/Scottish/Welsh/Northern Irish	94.6%	634
White Irish	0.9%	6
White Gypsy or Irish Traveller	0.0%	0
African	0.0%	0
Caribbean	0.3%	2

Indian	0.4%	3
Pakistani	0.4%	3
Bangladeshi	0.0%	0
Chinese	0.0%	0
Arab	0.0%	0
White & Black Carribean	0.3%	2
White & Black African	0.0%	0
White & Asian	0.9%	6
Any other ethnic background (please describe)	2.1%	14
<i>answered question</i>		670
<i>skipped question</i>		59

Religion/belief

Trafford

Answer Options	Response Percent	Response Count
Christian	52.9%	9
Jewish	0.0%	0
Buddist	0.0%	0
Hindu	0.0%	0
Muslim	0.0%	0
Sikh	0.0%	0
No religion	35.3%	6
Other religion (please describe)	11.8%	2
<i>answered question</i>		17
<i>skipped question</i>		2

Greater Manchester

Answer Options	Response Percent	Response Count
Christian	50.8%	31
Jewish	1.6%	1
Buddist	1.6%	1
Hindu	0.0%	0
Muslim	4.9%	3
Sikh	0.0%	0
No religion	31.1%	19
Other religion (please describe)	9.8%	6
<i>answered question</i>		61
<i>skipped question</i>		10

UK

Answer Options	Response Percent	Response Count
Christian	44.9%	297
Jewish	0.3%	2
Buddist	1.1%	7
Hindu	0.3%	2
Muslim	1.1%	7
Sikh	0.2%	1
No religion	46.1%	305
Other religion (please describe)	6.2%	41
<i>answered question</i>		662
<i>skipped question</i>		67

Sexual orientation

Trafford

Answer Options	Response Percent	Response Count
Straight/Heterosexual	100.0%	16
Gay/Lesbian/Homosexual	0.0%	0
Bisexual	0.0%	0
<i>answered question</i>		16
<i>skipped question</i>		3

Greater Manchester

Answer Options	Response Percent	Response Count
Straight/Heterosexual	91.2%	52
Gay/Lesbian/Homosexual	7.0%	4
Bisexual	1.8%	1
<i>answered question</i>		57
<i>skipped question</i>		14

UK

Answer Options	Response Percent	Response Count
Straight/Heterosexual	93.9%	611
Gay/Lesbian/Homosexual	3.1%	20
Bisexual	3.1%	20
<i>answered question</i>		651
<i>skipped question</i>		78

Do you consider yourself to be a carer?

Trafford

Answer Options	Response Percent	Response Count
Yes	37.5%	6
No	62.5%	10
<i>answered question</i>		16
<i>skipped question</i>		3

Greater Manchester

Answer Options	Response Percent	Response Count
Yes	22.0%	13
No	78.0%	46
<i>answered question</i>		59
<i>skipped question</i>		12

UK

Answer Options	Response Percent	Response Count
Yes	21.9%	145
No	78.1%	518
<i>answered question</i>		663
<i>skipped question</i>		66

Acknowledgements

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- Stephen Hodges, Head of Patient Services for Central Manchester Foundation Trust.
- Fibromyalgia Action UK.



**Your
voice
counts!**



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