

Spotlight on specialist services: UK healthcare for people with M.E.

Analysis of data on M.E. prevalence and commissioned services, shared by Clinical Commissioning Groups, Health Boards and Health and Social Care Trusts in England, Wales, Scotland and Northern Ireland

Action for M.E.
July 2017



Foreword

Every one of us has the right to access appropriate medical care for ourselves and our loved ones. If we become ill, we should all have the reassurance of knowing that our GP is able to refer us to appropriate care that supports the best possible outcome.

For hundreds of thousands of children and adults living with the chronic, neurological condition M.E., this is simply not happening.

Our report, based on responses to a Freedom of Information request that Action for M.E. sent to commissioning NHS organisations across the UK, shows that these vulnerable patients are being neglected.

It reveals that less than a third of NHS organisations hold any data on M.E. prevalence, and that vast numbers of adults and children with M.E. do not have access to any specialist service at all.

It is not acceptable that, in 2017, GPs are often forced to tell those affected by this complex, fluctuating condition that there is little they can offer.

In order to accurately assess and meet the needs of their local population, NHS commissioning boards must collect data on M.E. prevalence. There must be a consistent clinical pathway for adults and children with M.E. to ensure that health professionals are able to appropriately refer to specialist healthcare, regardless of where they live.

Based on our report, Action for M.E. will collaborate with people with M.E., clinicians and other M.E. organisations to produce a blueprint for specialist services.

We will also approach NHS organisations and ask them to work with us on developing a method to collect data on M.E. prevalence and implementing a clinical pathway in their locality. Together, we can end the ignorance, injustice and neglect experienced by people by M.E.

Sonya Chowdhury
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What difference does good care make?

Ignorance, injustice and neglect are a daily reality for many people with the chronic, neurological condition M.E. Even in its mildest form, M.E. can have a significant impact on an individual's life, and accessing the appropriate and timely healthcare to which they are entitled can be a considerable challenge.

Glen, who has M.E., told us about the challenges he has faced in accessing good-quality care – and the difference it made when he did.

“I felt I was simply not being listened to or taken seriously. I was being dismissed without the benefit of a clinician's experience and expertise that I desperately needed.

“I finally met a GP who was wonderful. Crucially, she listened to me. She took an interest and she investigated more thoroughly than any of the 10+ GPs I'd seen in the year before meeting her. For the first time, I was spoken to like an intelligent adult.

“I remain so grateful to her for having looked at me with a fresh perspective and for giving me the benefit of her expertise. The simple skills of listening and giving considered opinions have been what make a difference for me.”

Sharing her story with us for an article in our membership magazine, *InterAction*, Sally told us about her experience:

“I had never had any NHS treatment or advice on managing M.E. apart from my GP saying do less, rather than more. It took me a lot of energy, letters, tenacity and tears to get a referral and funding to a more specialist service, out-of-area. It was willing to include me in its pilot domiciliary service in which two specialists worked with me one-to-one. For several years they visited me at home and did regular phone appointments.

“I made progress in small steps, ending in me visiting them at the hospital in which they were based. I was very fortunate in having two exceptionally good professionals who were very dedicated to their work and to helping me. They were willing to work at my speed and encouraged me to build up my confidence and stamina through goals of my choosing. When my treatment came to an end, they worked hard to ensure that I had some ongoing NHS treatment in my home area.

“I still have M.E. but it is not limiting my life in the way it was. I have strategies to cope with living with a chronic and painful illness, am more mobile, and more connected to my local community. I am now a member of my local community choir – something that previously I could only dream of.”

Why M.E. matters

Myalgic Encephalomyelitis (M.E.) is a long-term, fluctuating, neurological condition that causes symptoms affecting many body systems (see Appendix 1). Within the NHS, a diagnosis of chronic fatigue syndrome (CFS) or CFS/M.E. is often given (see Appendix 2). M.E. affects an estimated 250,000 adults and children in the UK, and its impact can be devastating.

Everyone with M.E. is entitled to personalised, patient-led healthcare that best meets their needs, and one of the founding principles of the NHS was to deliver a comprehensive service that meets everyone's clinical needs.¹ This report outlines how policy and practice must be improved to address some of the barriers faced by patients in securing this healthcare.

Action for M.E.'s 2017 survey of parents of children with M.E. found that 96% of respondents felt a lack of understanding of M.E. negatively impacted on the support they receive.² Our *M.E. time to deliver* report found that 97% of adults with M.E. had stopped or reduced social contact and 87% had stopped or reduced paid work.³

What we found

To find out more about health services across the UK, Action for M.E. submitted a Freedom of Information (FOI) request (see Appendix 3) to a total of 234 UK NHS organisations (see Appendix 2), ie. Clinical Commissioning Groups, Local Health Boards, and Health and Social Care Trusts. With at least partial responses from 186 organisations (an 80% rate of response), we found:

- Only 27% of all UK NHS organisations (63 out of 234) confirmed that they have any data on how many people in their locality have M.E. leaving service commissioners unable to identify scale of need for services – see p 7.
- Only 44% of all UK NHS organisations (103 out of 234) told us that they commission a specialist service for M.E., and many large areas such as Northern Ireland have no provision at all. Vast numbers of people with M.E. do not have access to any specialist service, and current services are overwhelmed with the level of need – see p 9.
- NHS organisations told us about 25 different services to which people with M.E. are being referred, suggesting uncertainty about treatment and care pathways, and patients potentially being routed to inappropriate care – see p 15.

What we will do now

Based on the findings in this report, Action for M.E. will ask each NHS organisation in the UK to work with us on developing a framework for collecting data on M.E. prevalence and clinical pathways that can be replicated in other localities, and engage with policy-makers on implementing this across the UK.

We will also work with health professionals, people affected by M.E. and other M.E. organisations to explore how we can develop a national blueprint for appropriate, patient-led specialist M.E. services that consistently meet the needs of people with M.E.

How many people have a diagnosis of M.E.?

It is estimated that there are 250,000 people in the UK with M.E., based on research that shows that 0.2–0.4% of the population have the condition.⁴

People with M.E. frequently fail to secure a clear diagnosis, which can be for a number of reasons. There is no confirmed test to diagnose M.E., rather it is only diagnosed when other conditions with similar symptoms have been ruled out. While a diagnosis can be valuable in accessing welfare and social services, many people with M.E. are frequently misdiagnosed with other conditions⁵ which can prolong the process of securing a correct diagnosis of M.E.

This means that diagnosis rates are likely to understate the number of people with M.E. in a particular area.

How many NHS organisations record M.E. prevalence in their locality?

Only 63 organisations (27%) in the UK confirmed that they had any data on record about how many people have M.E. Of these:

- 30 organisations provided information on numbers of people with a diagnosis – although it should be noted that these numbers were often vastly below the rate expected (based on the national estimate) suggesting possible under-diagnosis or problems with the data.
- 33 organisations provided estimates based on national population data.

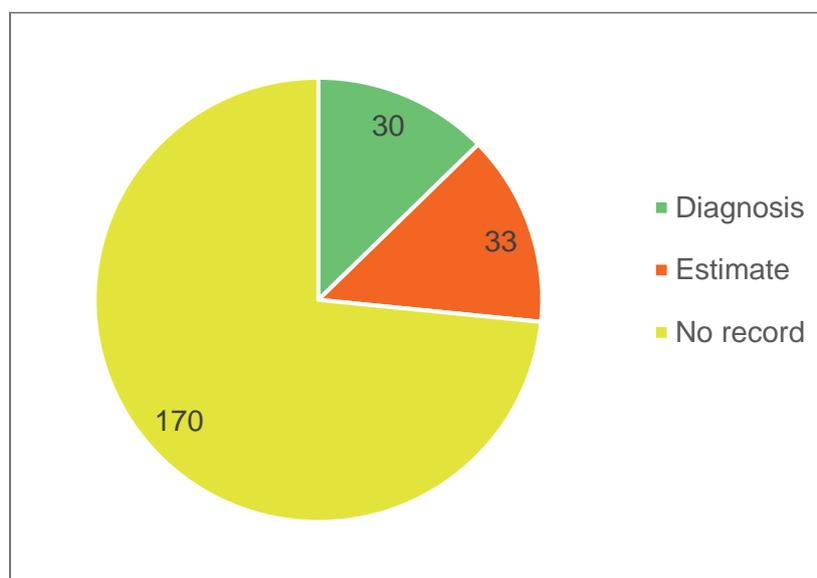


Fig 1. The number of NHS organisations that record prevalence of M.E.

This means that 170 (73%) were either unable to provide diagnosis rates/did not seek to make an estimate of their local population with M.E., or failed to respond to our FOI request.

You can access our interactive map showing numbers of people diagnosed/estimated with M.E. via www.actionforme.org.uk/spotlightonservices to see how data on this has been recorded by NHS organisations across the UK.

The information illustrates the estimated or actual rates of M.E. recorded by NHS organisations. This may not itself be accurate, and some NHS organisations do not collect any of this information, so this data is not a representation of prevalence of M.E. throughout the UK.

Under-reporting of the prevalence of M.E. can leave service commissioners unable to identify scale of need for services. Even where services are provided locally, they may not adequately meet need. Some people with M.E. can be housebound and as such would require a home-visiting service. We believe that widespread and consistent recording of this information would identify likely currently unmet need, which would demonstrate the benefits of investing in increased provision of appropriate treatment for people with M.E.

Case study: Stockport CCG

Stockport Clinical Commissioning Group does not have information on how many people have M.E. in its locality.

There is a community service commissioned through Stockport NHS Foundation Trust, which costs £179,000 annually. A member of the Stockport M.E. Group, a local support group, told us, “In my experience it is often difficult for people to be directed by GPs to the Stockport clinic. But once there, they receive an excellent service which helps educate them about the condition and how best to manage symptoms.”

They went on to say that “prevailing ignorance amongst GPs and hospital staff around the illness” had some of the greatest negative impact on people with M.E. GPs needed better training around the condition, and if one thing could be improved they would “have a defined pathway for diagnosing and helping with the illness.”

Stockport M.E. Group is currently “working with NHS staff and officials to address the shortcomings and gaps in service for people within Greater Manchester.”

How many NHS organisations commission specialist M.E. services?

Responding to our FOI request, a number of NHS organisations said that they did commission a specialist M.E. service.

We found that:

- 44% organisations (103 out of 234) said that they have a local specialist service
- 34% (79 organisations) confirmed that they did not commission a service
- 22% (52 organisations) did not answer this question.

The scope of our Freedom of Information request did not ask for additional details, so this report does not make any comment on the quality or nature of services.

Fig 2 shows the percentages of NHS organisations in each region of England or devolved nation who answered our question on whether they commission a local specialist service. The answers are broken down into whether they specified that the service specialised in M.E., or whether the service specialises in Occupational Therapy (OT) or another type of service. A number of organisations did not specify what kind of service it was. The table also includes the percentage of organisations who answered that they did not have a specialist service for people with M.E. at all.

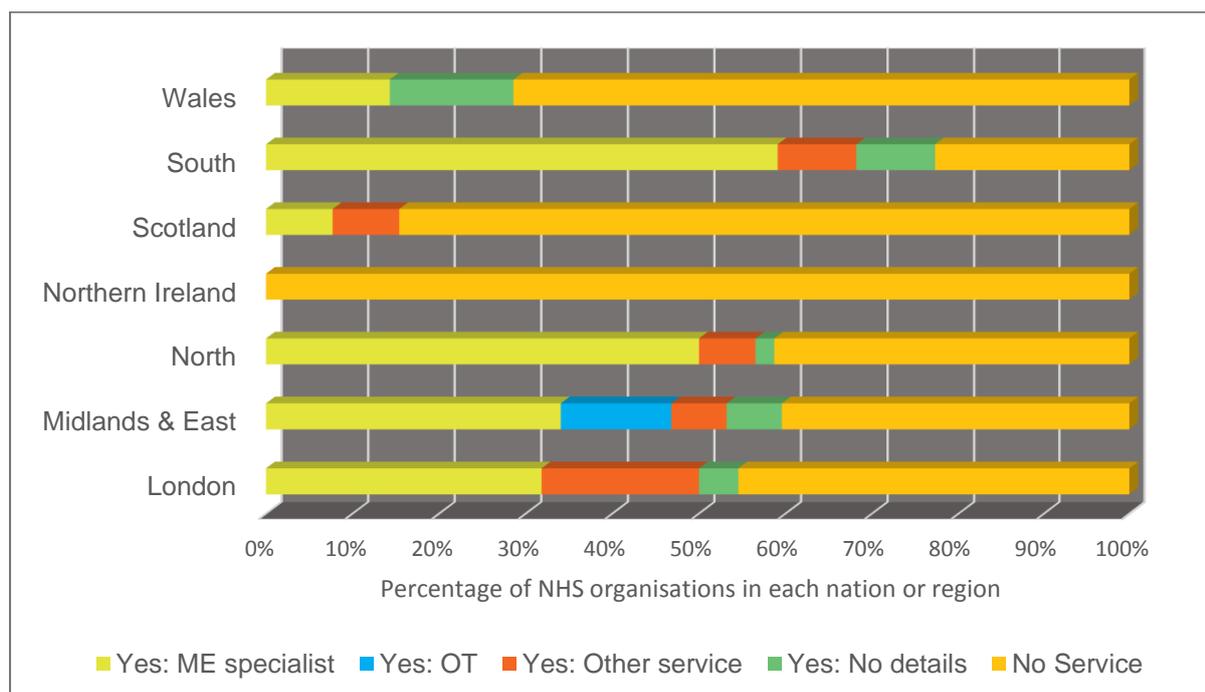


Fig 2. The percentage of NHS organisations that have a specialist secondary service for people with M.E., broken down into devolved nations and English regions, the latter reflecting the boundaries used by NHS England⁶

It is important to note that, where specialist services are provided, it is often jointly commissioned by several organisations. This means that the actual number of such services is lower than the figures suggest as shared services are counted multiple times. For example, six NHS organisations refer patients to the Essex Chronic Fatigue Service. This produces apparent ‘hotspots’ where neighbouring organisations each say that they have a specialist service.

However, the reality can be that one service is taking referrals from several geographical areas. This is an approach that both stretches the resources of the service, and can require people with M.E. to travel increased distances in order to access the service, which can be especially challenging for people who are severely affected.

This exacerbates the difficulties people with severe M.E. have in accessing services. Of the 250,000 people with M.E. in the UK, an estimated 25% are severely or very severely affected. They may be house or bed bound, unable to properly care for themselves or even wash properly, and can experience severe cognitive difficulties and be extremely sensitive to light and noise.

Case study: Cardiff and Vale University Health Board

There are no specialist services provided by Cardiff and Vale University Health Board. Between 17 and 32 people have been diagnosed with M.E. each year since 2010, with a total of 153 new cases in the last six years.

In 2014 the Welsh Government published a report on recommendations on M.E. and Fibromyalgia services.⁶ Recommendations included each Health Board establishing a clinical lead for the conditions, identifying specialists and developing effective pathways for children and adults. However these recommendations have not been implemented since publication.

A member of M.E. Support in Glamorgan (MESIG) spoke about how the lack of services had affected people with M.E. “GPs are really ignorant of the illness – there’s nowhere to send anybody anyway. There are a couple of sympathetic GPs, but an awful lot of the GPs are afraid of the illness because they don’t have anywhere to send patients.”

The Health Board also stated that they had not sent any M.E. patients to out-of-area services in the past six years. That reflects the experience in MESIG, with one person saying that their daughter was assessed as severe at the Romford M.E. Centre and offered three weeks further treatment, but the authority in Wales wouldn’t pay.

“There are many desperate people in our group, crying out for help, who remain very ill” because of the lack of services, says the MESIG member. When asked what one thing they would change, they said, “There should be a specialist that is able to visit. My daughter is housebound and in bed a lot of the time.”

Even where services are provided locally, those with severe and very severe M.E. face additional barriers in accessing and using services. Current provision is often insufficiently equipped and resourced to deliver domiciliary services to meet the particular care needs of these patients and the management approaches used may not appropriate for people with severe M.E.

Of the 103 organisations who said they had a specialist service, roughly one fifth (22 organisations) made reference to occupational therapy or pain management services. While some people with M.E. find these services helpful,³ they are not necessarily specialist M.E. services specifically designed for people with the condition, delivered by a practitioner who has experience of M.E.

You can access our interactive map showing what local services are commissioned for people with M.E. via www.actionforme.org.uk/spotlightonservices

Please note that not all NHS organisations responded to our FOI request, so there may be M.E. services that are not included in this map. Please visit Action for M.E.'s local services directory at www.actionforme.org.uk/find-local-services and enter your postcode to see what other services might be in your area, or get in touch if you're aware of a service that is not listed.

Case study: NHS Fife

Keith Anderson, M.E./CFS Clinical Nurse Specialist, is based in Fife. A member of M.E. Support Group Fife said of the service, “Keith is a greatly appreciated individual and his work as a lone ranger in the region is much appreciated by his patients. He is the M.E. service – there is nothing else.”

Keith says the service is “based on experience and application of nursing models, methods of treatment and helping people manage themselves better. I co-ordinate care between services, which helps care to be delivered more directly and efficiently.”

The service currently has 1,118 open cases, with 650 new cases opened since 2010. Based on his experience, and the population of Fife, Keith believes the general estimation of prevalence (approximately 1 in 200 people) is too low.

When asked about what other services would ideally be available, M.E. Support Group Fife said that they should build on Keith’s provision by having a “motivated consultant who is given time and support to lead a service; multi-disciplinary professionals.” They also commented that, because Keith is only qualified to treat adults, “the biggest problem is a lack of service provision for children/young people.”

Commenting on this, Keith said that there is a care plan pathway for children and young people with M.E. that consults with paediatric services, child psychology services, family support services unit, educational psychology, Children and Adolescent Mental Health Services (CAMHS), and community social work. “Paediatric services are based through CAMHS because that is often the only infrastructure that is available.”

Asked about how to improve provision, Keith said that services are split into silos, which prevents effective and appropriate treatment at the right time. “There’s such a constellation of symptoms that can involve neurology, gastroenterology, medicine. The patient journey becomes so complicated and convoluted. Because of this, I’ve often missed the opportunity to give guidance and advice when patients need it.”

How many NHS organisations in each region referred to an out-of-area service?

We asked NHS organisations whether they referred any of their patients to out-of-area services, ie. services that they did not commission. Of the 97 that responded to this question, as illustrated by Fig.3, only 42 said that they did – this equates to 18% of all NHS UK organisations in the UK.

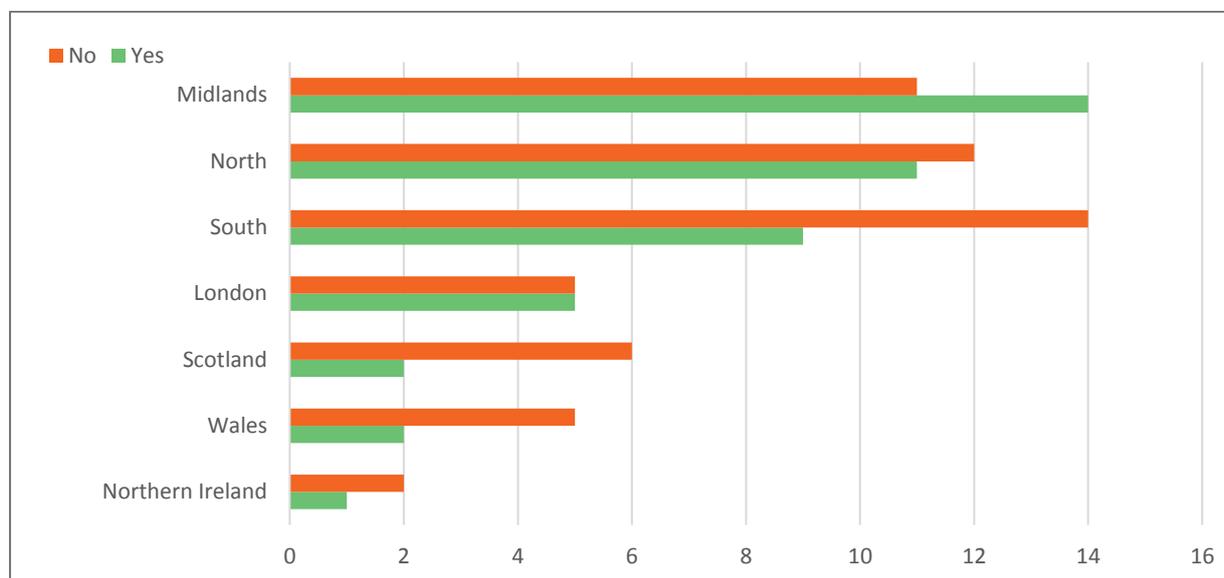


Fig 3. The number of NHS organisations that referred patients out-of-area, broken down into regions and devolved nations

When we asked about the cost of these referrals, only 18 (equating to 8% of all UK NHS organisations) could tell us what they were charged for out-of-area services. The answers varied greatly, from approximately £700 in a year to more than £100,000.

These numbers do not tell us about the variation in costs for referral, because there is no detail regarding how many patients this service cost covered or what kind of treatment they received, but do demonstrate a variability in service access.

There is a need for more services to be commissioned that are designed with the full engagement of people with M.E. This should be done strategically, targeting areas of the UK that currently have the most scant provision. There needs to be greater resourcing of M.E. services, so that there is sufficient capacity for them to treat the number of people with M.E. within the area they cover.

Case study: Northern Ireland Health and Social Care Trusts

There are five Health and Social Care Trusts (HSCTs) in Northern Ireland: Belfast, Northern, South Eastern, Southern, and Western. Four did not record any information on diagnosis or estimated prevalence of M.E. Western HSCT had diagnosed between 12 and 24 patients each year since 2012.

The Patient and Client Council (PCC) is an independent body to provide a patient voice on health and social care in Northern Ireland. Since 2013, the PCC has been collecting patient information on M.E. in order to provide an interface between patients, professionals, support groups and decision makers in the Health and Social Care Board. The PCC states that there are 7,000 cases of M.E. in Northern Ireland, revealing a huge gap in the knowledge of health trusts when it comes to either prevalence or incidence.

None of the Trusts have specialist M.E. clinics. Belfast HSCT has an Occupational Therapy service for patients with an M.E./CFS diagnosis; this replaces a previous Chronic Fatigue Syndrome Clinic, which closed in 2014 following the retirement of the lead consultant.

Patients in Northern Ireland are likely to be referred onto services to treat individual symptoms, including neurology, endocrinology, rheumatology or pain management. Southern HSCT stated that patients were largely managed in primary care.

In June 2017, the charity Hope 4 M.E. and Fibro Northern Ireland announced that it had successfully lobbied for all 365 GP practises in Northern Ireland to receive updated information on M.E., stating that it had taken the organisation “six years to bring us to this welcome and much needed move by the Department of Health.”⁸

Other voluntary organisations supporting patients in Northern Ireland include M.E. Support Northern Ireland and FMS/M.E. Awareness NI. There is also a network of local support groups, which some of the HSCTs refer patients to following diagnosis.

What other non-specialist services can people with M.E. access?

In our FOI request, Action for M.E. asked what local services people with M.E. were referred to, excluding any specialist M.E. services that were available (see Appendix 1 for further detail). The answers listed here were given by NHS organisations and we have not ascertained any further information about the details of each service.

We found that 45% of all UK NHS organisations (106 out of 234) refer people with M.E. to non-specialist services that may be able to assist with symptom management. In some cases, organisations refer to more than one service – see Fig.4 – and in total they referred to 25 different services or sources of support.

This information is limited by the fact that individual NHS organisations, and even individual clinical services, operate and deliver treatments differently.

Of those that answered this question, 17 out of 106 said that they referred patients onto local charities, commonly mentioning a local support group. While local support groups are valuable, in particular those operating in an isolated or extremely under-resourced area, this result suggests an over-reliance on these voluntary services which are often provided by people who are ill themselves.

Less than half (43 of 106 respondents) answered that the referral depends on the individual circumstances of the patient. While healthcare should be responsive to the needs and symptoms of each patient, there is an issue with having no defined clinical pathway that can act as a broad template. Where referral decisions are decided solely at the level of the clinician, it can lead to inconsistent treatment based on the knowledge of the particular clinician. This is particularly worrying given that many GPs, and clinicians more widely, continue to have insufficient knowledge of M.E.

We note that 47 out of the 106 organisations that responded to this question gave responses that appear to refer to symptom management approaches, rather than specific clinical services; the reasons for this are unclear. We have grouped these together as “Other” (see Fig. 4) as follows:

- 11 organisations said they referred patients to “cognitive behaviour therapy”
- eight organisations said they referred patients to “exercise programmes” with seven of them specifically referring to “graded exercise therapy”
- three organisations said they referred patients to “adaptive pace therapy”
- two organisations said they referred patients to “graded behaviour therapy”
- an additional 21 answers that were unique; these are listed in Appendix 4.

This lack of clarity regarding onward referrals is especially concerning given recent guidance, published by the Joint Commissioning Panel for Mental Health, that M.E. is a functional somatic syndrome, and that patients with M.E. should be referred to services for Medically Unexplained Symptoms (MUS).⁹

M.E. is not MUS, and categorising it as such contradicts the World Health Organisation’s International Classification of Diseases¹⁰ which states it is a neurological condition. It also leads to people with M.E. being given inappropriate treatment which is ineffective at best, and can even lead to harm.

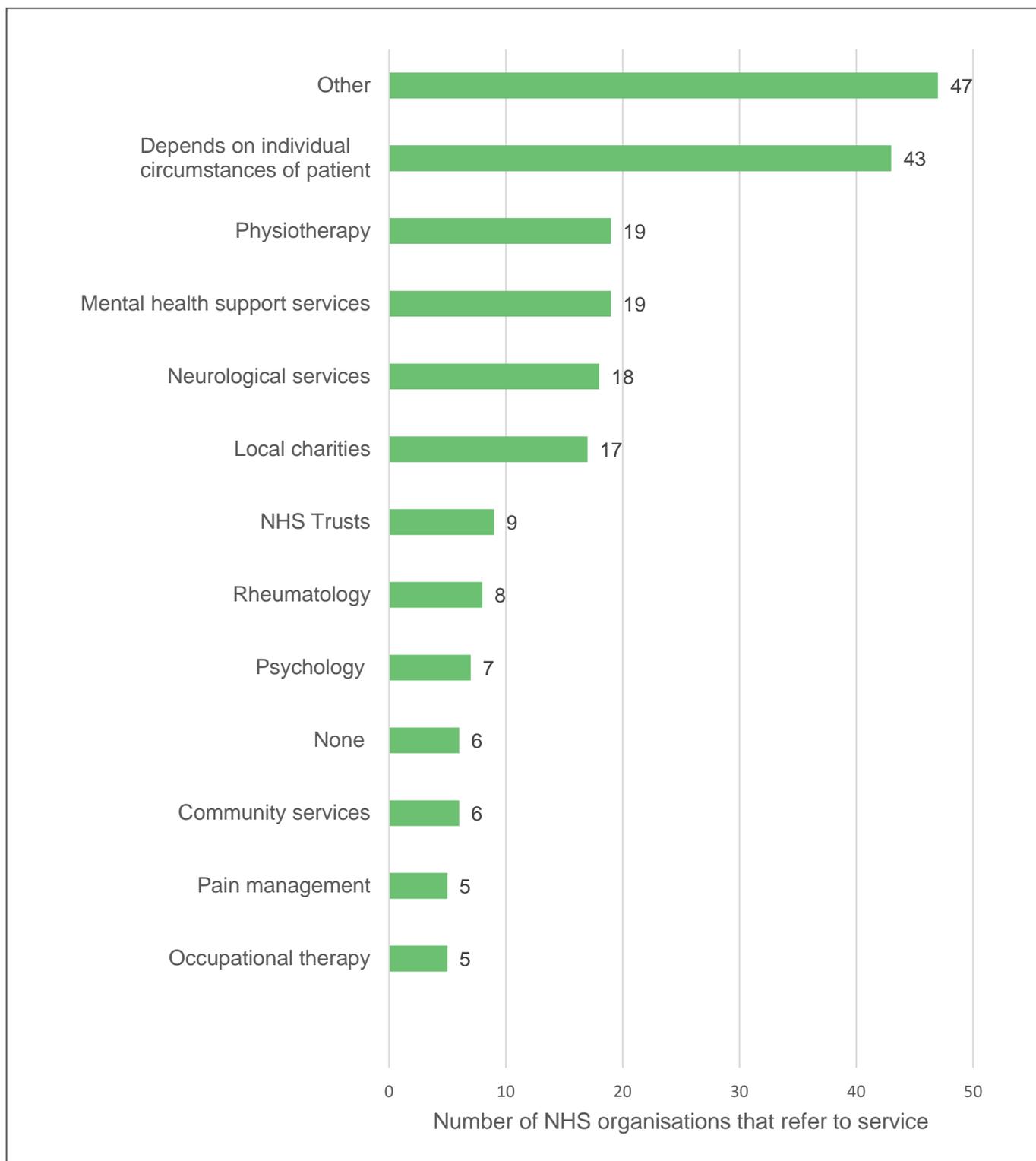


Fig 4. The secondary services that people with M.E. are referred on to by NHS organisations throughout the UK.

The wide range of experiences reported to Action for M.E. by people with M.E. show that the symptom management approach most commonly cited as helpful is pacing, though it does not provide benefit to all. Some find GET and/or CBT helpful; others find they make no difference, or make their symptoms worse. In Action for M.E.'s 2014 survey, 54% of respondents found CBT helpful while 12% found it made their condition worse. 35% found GET helpful while 49% found it made their condition worse.³

Given that there are no treatments that reliably offer significant improvements for everyone with M.E., clinicians must receive clear information on the neurological nature of the condition, and be supported to offer flexible, person-centred care based on a clear clinical pathway.

The NICE guideline for M.E. says, “Shared decision-making between the person with CFS/M.E. and healthcare professionals should take place during diagnosis and all phases of care.”¹¹ This should include actively empowering patients to seek out further information about the management approach most appropriate for them.

Case study: North Norfolk, South Norfolk and West Norfolk CCGs

Norfolk is covered by the Norfolk and Suffolk M.E./CFS Service, based in Lowestoft. This clinic is an Occupational Therapist led specialist service provided by East Coast Community Health Care. From April 2015 to March 2016, there were 412 referrals to the service: 96 from North Norfolk, 124 from South, and 73 from West, as well as 119 from Norwich CCG.

On the available services, an individual from local support group M.E. Support Norfolk said that it had little positive impact despite “some Occupational Therapists (OTs) being a fantastic asset.” They commented that “people are just not given enough time to explain complex conditions” resulting in variable diagnoses and service. The service needs more capacity in order to meet need, in particular a specialist consultant, paediatric help, and a greater number of OTs.

M.E. Support Norfolk assists people with M.E. in a range of areas, such as obtaining a correct diagnosis and help with welfare benefits. The group said they “have to fill a huge gap in East Anglia. Norfolk is a huge area and the M.E. clinic cannot cope – it is scratching the surface. There is no other provision for M.E. patients in this area. We have helped more than 300 benefit claimants in the last few years. I feel professional health services rely too much on voluntary support groups and take them for granted.”

Next steps

Based on the findings from this report, Action for M.E. will:

- approach each NHS organisation in the UK and ask them to work with us on developing a method to collect data on M.E. prevalence and clinical pathways, and engage with policy-makers on implementing this across the UK.
- work with health professionals, people affected by M.E. and other M.E. organisations to explore how we can develop a national blueprint for appropriate, patient-led specialist M.E. services.

How can you take action?

You can make a difference by working with us to take action to help end the ignorance, injustice and neglect experienced by people with M.E.

You can do this by:

- sharing what you know to raise the profile of M.E. and its impact – you can find key facts at www.actionforme.org.uk/what-is-me
- offering empathy and practical support to people affected by M.E. – find out how at www.actionforme.org.uk/you-can-make-a-difference
- raising knowledge and understanding of M.E. by sharing this report, our resources and films about M.E. on social media to raise knowledge and understanding of M.E.
- sharing your skills, expertise and time to support our work – contact us (see p 19) to find out more
- adding your voice to thousands of others affected by M.E. by becoming an Action for M.E. supporting member and joining our movement for change – visit www.actionforme.org.uk/join-us

Based on the findings laid out in this report, Action for M.E. will engage with policymakers to improve access to appropriate services for children, families and adults with M.E. across the UK. You can do the same by contacting your local representative or health professional and ask them to consider the findings we've laid out in this report, highlighting that:

- NHS organisations should be recording how many people have M.E. in order to meet urgent need
- more specialist services need to be commissioned to prevent children, adults and families affected by M.E. being denied access to medical care
- sharing accurate information with primary care professionals about the impact of M.E. and the services available will mean more people with M.E. being referred to appropriate support.

See our campaign toolkit at www.actionforme.org.uk/campaign-toolkit for ideas and tips on engaging with decision-makers at a local and national level.

Together we can secure much needed improvements in care, support and services for children, adults and families affected by M.E. across the UK.

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Acknowledgements

This report was authored by Katie McMahon, Policy Officer, Action for M.E., with input from Clare Ogden, Head of Communications and Policy, and Sonya Chowdhury, Chief Executive.

Action for M.E. is also immensely grateful to the following people:

- Action for M.E. Medical Advisors, Dr Gregor Purdie and Dr Julia Newton, and Trustees Jane Young and Katherine Thomas, for their insight and expertise
- Andrew Chapman for quantitative analysis of responses to our FOI request, and producing interactive maps of this data
- Individuals from M.E. Support in Glamorgan, Stockport M.E. Group, M.E. Support Norfolk and M.E. Support Group Fife for sharing their experiences
- Louise Skelly, Patient and Client Council, for providing information on her organisation's work
- Keith Anderson, M.E./CFS Clinical Nurse Specialist, for sharing his professional experience
- Christine Oliver, East Midlands CFS/M.E. Network Coordinator, for her feedback and ongoing collaboration
- Rhiannon Sanders, the Whitehouse Consultancy, for support in shaping the purpose and parameters of this report.

Appendix 1: What is M.E.?

Myalgic Encephalomyelitis (M.E.) is a long-term, fluctuating, neurological condition that causes symptoms affecting many body systems, more commonly the nervous and immune systems. M.E. affects an estimated 250,000 adults and children in the UK. People with M.E. experience severe, persistent fatigue associated with post-exertional malaise, the body's inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms.

Severe and persistent fatigue or exhaustion most, or all of the time, is one of the main symptoms of M.E. This feels very different from ordinary tiredness. Simple physical or mental activities, or combinations of activities, can leave people with M.E. feeling utterly debilitated. They can also experience an increase in other symptoms. The impact of this may be felt straightaway but it can typically take a day or two to kick in, and is not significantly improved by resting. This is a key feature of the way M.E. affects people, and is known as post-exertional malaise.

In its guideline for M.E./CFS, the National Institute for Health and Care Excellence (NICE)¹⁰ acknowledges that the physical symptoms of M.E. can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions. More recent research shows that M.E. scores lower on health-related quality of life tests than most other chronic conditions.¹²

People with M.E. face a number of barriers in accessing appropriate, timely and patient-led healthcare. Firstly, many experience delays in getting a diagnosis because there is no specific test that can detect M.E. Other illnesses with some similarity in symptoms must be excluded before a patient can have their condition confirmed.

Secondly, there is no single pharmaceutical cure for M.E. There are a number of treatment approaches that can support patients in managing their symptoms, and different things work for different people. This variation means that it can be difficult for doctors and patients to know whether a particular approach will be appropriate and effective in each individual's case. At health service level, this means that there are difficulties in deciding which services should be provided.

Action for M.E.'s *M.E. time to deliver* survey of more than 2,000 people with M.E. found that more than half of respondents (54%) had not attended an NHS M.E./CFS clinic at all in the past five years.³ *M.E. time to deliver* asked what barriers people had experienced in accessing NHS services; 49% it was a lack of NHS specialists in their area, while 38% said long waiting times for treatment or referral. When we asked what would make a real difference to their healthcare, nearly three-quarters (69%) chose "a better-informed GP" as their top answer.

Appendix 2: Notes on terminology

The following terms are used throughout this report:

Myalgic Encephalomyelitis (M.E.) is the term we have used consistently throughout this report for the condition that, within the NHS, is often diagnosed as chronic fatigue syndrome (CFS) or CFS/M.E. In Scotland, the term ME-CFS is used. We recognise that the terms M.E. and/or CFS may in fact refer to a number of conditions, or sub-groups of the same condition. A number of UK services use the term CFS, so in our FOI request we asked about either M.E. or CFS in order to capture all relevant information. We have assumed that services are using CFS synonymously with M.E., though we cannot guarantee that this is the case as we did not ask individual NHS organisations for further information regarding their definitions.

NHS organisations is used to refer to bodies throughout the UK that are responsible for commissioning health services. These are:

- Clinical Commissioning Groups in England
- Health and Social Care Trusts in Northern Ireland
- Local Health Boards in Wales
- Health Boards in Scotland

Specialist services are NHS health services for adults and children with M.E., with staff who specialise in the condition and symptom management approaches.

Non-specialist services are those that are not exclusively for M.E. People with M.E. can be referred to them, and these services may specialise in some other way. For example, a particular group of conditions, such as a service for neurological conditions, or a specific type of treatment, such as pain management services.

Local support groups are normally run by volunteers, who often have M.E. themselves, and offer information, advice and support. Examples of some of the services they may offer include regular meetings and social events, information and advice on welfare benefits and healthcare, and newsletters and publications. Some also campaign on key issues facing people with M.E. in their area including access to appropriate health and social care, and welfare benefits.

Appendix 3: Methodology and Freedom of Information request

The following FOI request was submitted in December 2016 to 234 NHS organisations across the UK

I am writing to submit the following questions to [the organisation], under the Freedom of Information Act. Where possible, please could you answer all questions with reference to the period since January 2010 and break down the results by year.

- 1 *How many people in [the organisation] are:
 - a. Diagnosed with myalgic encephalomyelitis/chronic fatigue syndrome (M.E.)?
 - b. Estimated to have M.E.?*
- 2 *Are there specialist local services for people with M.E. commissioned within [the organisation]? If yes:
 - a. What services are commissioned?
 - b. How much does it cost annually to run each service?*
- 3 *What other local services are people with M.E. directed to after diagnosis?*
- 4 *Have people diagnosed with M.E. in the locality been referred to out-of-area specialist M.E. services? If any:
 - a. How many were referred?
 - b. What was the overall cost to [the organisation] for the out-of-area provision of specialist services for people with M.E.?*

If the information is not held, I would be grateful if you could give an overview as to why this is the case.

Of 207 Clinical Commissioning Groups in England, seven Local Health Boards in Wales, 14 Health Boards in Scotland and five Health and Social Care Trusts in Northern Ireland, 186 were able to provide at least partial information to the request, equal to an 80% response rate.

These responses were summarised and analysed, looking for significant results and to break down response by English regions and devolved nations.

Based on the responses, we also chose a handful of localities to look at in greater depth, providing the case studies throughout this report. Our choice was based on:

- the amount of information provided by NHS organisation in question
- the extent of services available in each locality
- ensuring a variety of urban/rural localities

After choosing the five localities, we contacted local M.E. support groups or patient organisations to ask for patients' experiences of M.E. health services. This qualitative evidence was used to supplement our data.

Appendix 4: Onward referrals

As outlined on p 15, NHS organisations refer adults and children with M.E. on to a wide range of services. The 21 unique responses we received were given verbatim as:

- Expert Patient Programme
- Parabl Talking Therapies
- Physical Health (Improving Access to Psychological Therapies - IAPT)
- Secondary and tertiary services
- Return to work services
- General medicine
- Infectious diseases
- Psychiatry
- Centre for Integrative Care (Glasgow Homeopathic Hospital) clinic
- Dietetics
- Local authority
- Paediatric services
- CCG spot-purchases services
- Seen by consultants within acute services contract
- M.E. is part of neurology pathway
- Sentinel Healthcare Southwest Community Interest Company
- Online support services
- Primary care
- Community neurological rehabilitation team
- Talking therapies
- Sleep hygiene

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