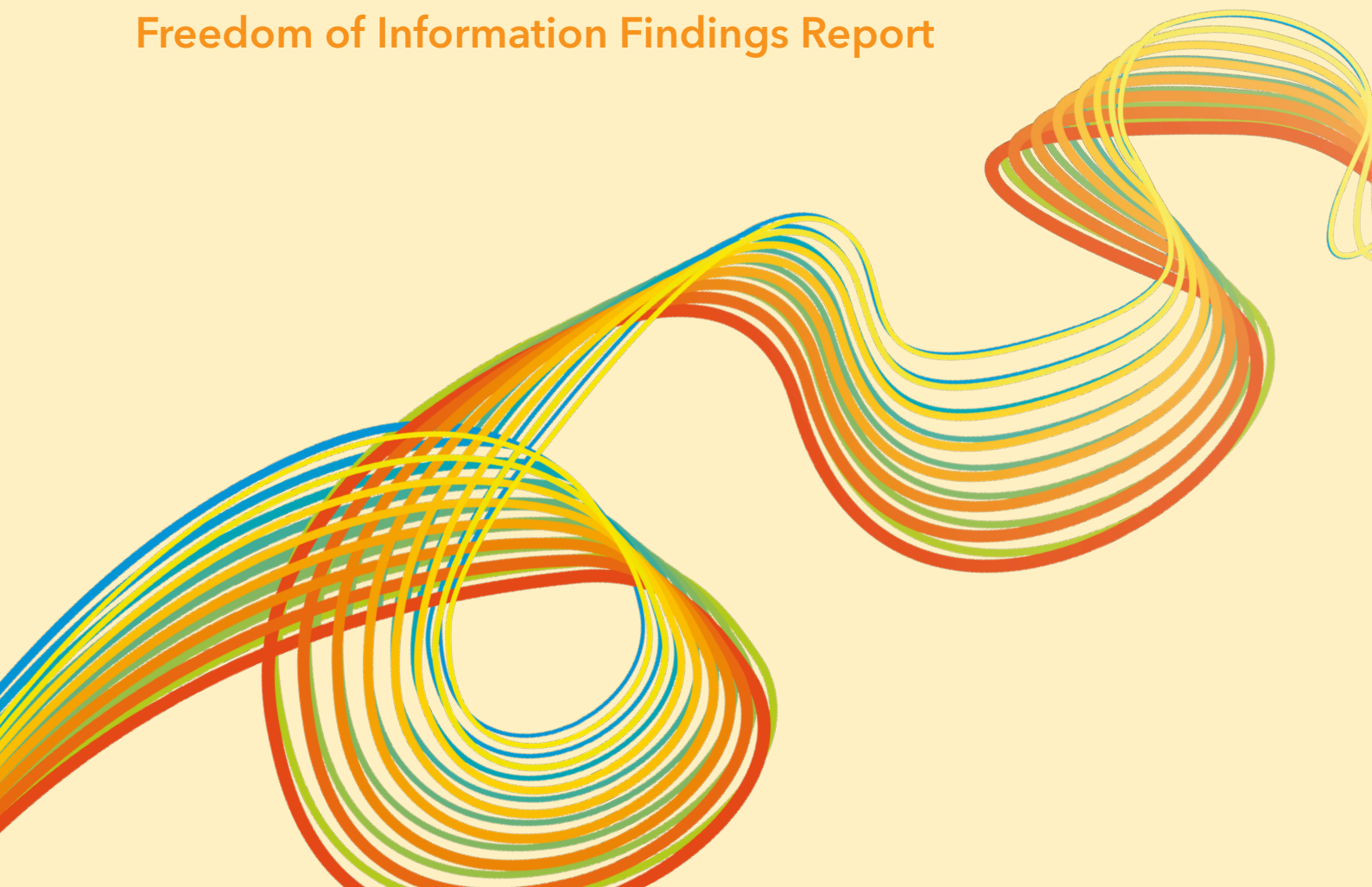




Patchy, Misunderstood and Overlooked

Implementation of the
NICE Guideline [NG206] on
Myalgic Encephalomyelitis/
Chronic Fatigue Syndrome in England

Freedom of Information Findings Report



Foreword	3
Executive summary	4
Overview of data	5
Question 1 The implementation of the NICE Guideline	6
Question 1.a The timeline for implementation of the NICE Guideline has not been implemented	6
Question 2 Number of patients receiving care	7
Question 3 Number of patients with a personalised health and care plan	7
Question 4 Additional training to support implementation of the NICE Guideline	8
Question 5 Additional written information for health professionals and patients	8
Conclusions	9
Where do we go from here?	10
Appendix 1: FOI text	11



We conducted this FOI as an exercise to explore how the implementation of the 2021 NICE Guideline has played out and to better understand the state-of-play of ME/CFS services across England. The ME/CFS community have expressed concerns and their lived experience and instincts are well founded by this new data.

Whilst we are pleased with the levels of responses and cooperation from the NHS Trusts and Integrated Care Boards (ICBs) contacted, unfortunately it paints a picture of inadequate and uncoordinated services provided for ME/CFS patients at a primary care level across England.

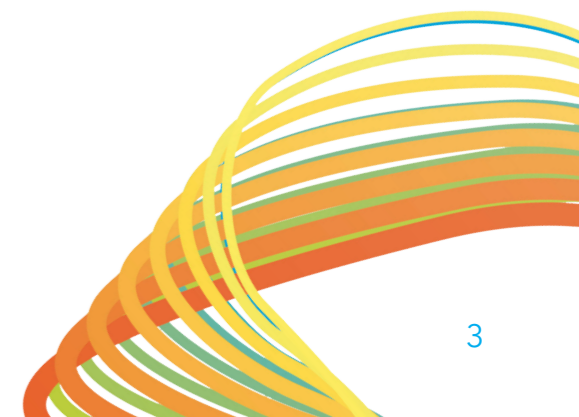
We understand that the FOI data demonstrates a snapshot of provision, but it clearly highlights there remains significant gaps in provision for patients with ME/CFS starting right at the root of diagnosis.

The need for more accurate accountability to ensure that clinicians are best equipped to support the complex needs of patients with ME/CFS, has never been clearer.

It is apparent that there remains a lack of understanding of the pathways for patients who present symptoms of ME/CFS. Many of the responses highlighted that there is little to no central data gathering, and lack of follow through in support services through to a personalised care and support plan.

We look forward to using this information gathered to work with the ICBs and NHS Trusts across England to assist them in best supporting the ME/CFS community.

Sonya Chowdhury
Chief Executive
Action for M.E.



This Freedom of Information request (FOI) was conducted by Connect Public Affairs on behalf of Action for M.E. The project is intended to be a data collection and analysis exercise to assess the real-term implementation of the 2021 NICE Guideline on ME/CFS across Integrated Care Boards (ICBs) and NHS Trusts in England.

We contacted all 162 ICBs and NHS Trusts as part of the process, of which 109 responded. The following report provides a summary of the data collected as part of five FOI questions. The text of these questions can be found in Appendix 1 on the final page of this report.

The basis of our questions focussed on the broad implementation of the NICE Guideline by NHS Trusts/ICBS rather than more targeted questions such as children’s services. This was to ensure we covered the entirety of the Guidelines roll out and gained the full, nation-wide picture of ME/CFS services.

Though NICE Guidelines are not compulsory, they are intended to guide healthcare professionals on how they care for people with specific conditions. They are important to those who commission NHS services and, ultimately, their adherence improves the quality of care for patients.

The results of our FOI were therefore not only disappointing; they show a lack of care and understanding for people living with ME/CFS.

Shockingly, only 28% of NHS Trusts and ICBs have implemented the 2021 NICE Guideline. Fewer than one in four NHS Trusts/ICBs are able to track their ME/CFS patients and two thirds of NHS Trusts and ICBs hold no information whatsoever on their ME/CFS patients.

This was reinforced by the fact that only one in ten (21,927) of the estimated 250,000 patients are currently recorded as having ME/CFS in the medical system. This begs the question, how many people with ME/CFS are falling through the cracks?

This response shows that ME/CFS is still not taken seriously by the medical profession. Despite a Government Delivery Plan on ME/CFS being near completion, we feel there is still a long way to go before people with this disease are afforded the recognition and care that they deserve.

As an example, the data shows that only one in five people with ME/CFS have a personalised care and support plan in place. Worse still, one quarter of NHS Trusts/ICBs with ME/CFS services inexplicably do not know whether their patients have a personalised care and support plan in place. This must be information kept as standard.

This report highlights the disjointed nature of NHS commissioning services in England. The implementation of the new ICS system presents a unique opportunity to improve patient care for the better. There must however be accountability to prove that NHS Trusts/ICB’s are meeting their duty of care.

We hope that this serves as a wakeup call and highlights that at present, this accountability is simply not there. It backs up the experience of people living with ME/CFS that we, a charity, hear on a daily basis; that people living with ME/CFS result feel isolated, left behind, forgotten or even “hidden from society.” We demand change.

Contacted	162
Responses / acknowledgements	109
% Response	67.28%
Responses with data	90
% Response	55.56%



Has [NHS Trust NAME/ICS NAME] implemented the NICE Guideline [NG206] on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: diagnosis and management, which were published on 29 October 2021?

Yes	25
No	6
Information not held	23
No ME/CFS service	37
No response	71
Total	162

Key points:

- Of those who indicated that they held an ME/CFS service, 25 services (27.78% respondents with data) said they had implemented the NICE Guideline.
- The majority of qualitative answers indicated that most NHS Trusts/ICBs commission their services and therefore do not hold the data on ME/CFS patients at a central level.
- Many NHS Trusts/ICBs indicated that they do not take responsibility for the implementation of the guidelines of specialist services for conditions such as ME/CFS.
- 60 of the 90 responding NHS Trusts/ICBs do not hold data on patients with ME/CFS (66.67%).

If the NICE Guideline [NG206] on the diagnosis and management of ME/CFS has not been implemented, what is the intended timetable and deadline for implementation?

Data set	1
Under review	5
Data not available	2
Not applicable	85
No response	70
Total	163*

Key points:

- Five out of the six respondents who responded 'no' to the implementation of the guidelines indicated that the implementation was under review.
- Only two of the respondents said that the data was not available.
- The majority of respondents felt that this question was not relevant for them to answer.

*163 total due to Hampshire & Isle of Wight ICB having a different breakdown of information according to delivery

How many patients with a diagnosis of ME/CFS are receiving care from [NHS Trust NAME/ICS NAME] as of the date of this FOI request?

No. of trusts with ME/CFS services that can provide data	22
No. of patients diagnosed across the UK	21,927
ME/CFS services but unknown number	6
Not applicable	135

Key points:

- 22 respondents indicated that they had an ME/CFS service (24.45% respondents with data).
- The number of patients on record with a diagnosis of ME/CFS and receiving care was indicated to be 21,927 people in total. This is likely below the number of people who are currently receiving care, as a number of respondents asked questions around numbers in primary or secondary care, and/or indicated that these numbers were estimations due to the lack of ability to adequately search for ME/CFS code on their system.
- Six respondents indicated that they had ME/CFS services but were not able to provide the number of patients with an official diagnosis of ME/CFS.
- Three respondents who indicated that they have an ME/CFS service in Question 1 answered that this question was not applicable to them.

Of those receiving care for ME/CFS from [NHS Trust NAME/ICS NAME], how many have a personalised care and support plan in place as of the date of this FOI request? (14/10/2022)?

No. of patients with a personal care and support plan	4,673
Percentage of patients	21.31%
ME/CFS services but unknown number	6
Not applicable	141

Key points:

- Of the respondents who indicated that they have ME/CFS services, a total of 4,673 people with ME/CFS are understood to have a personalised care and support plan. This equates to 21.31% of the 21,927 people with ME/CFS indicated in the previous question.
- Six of the 25 respondents who have an ME/CFS service did not have available data on the number of patients with a personalised care and support plan.

What training has been provided by [NHS Trust NAME/ICS NAME] for healthcare professionals on the implementation of the NICE Guideline [NG206] on diagnosis and management of ME/CFS since 29 October 2021?

Delivered	2
Some	3
Training available	3
None	11
Unknown	1
Not applicable	143
Total	163*

Key points:

- 143 of the respondents indicated that this question was not applicable to them. Of the remaining 20 who did answer five indicated that they had delivered at least some training on the implementation of the NICE Guideline.
- A further three indicated that training was available for healthcare professionals to take up, should they require it.
- 11 respondents indicated that there was no training provided for healthcare professionals on the implementation of the Guideline.
- Only one respondent did not know whether the training was available.

The purpose of conducting this FOI exercise was to understand how NHS Trusts/ICBs have been implementing the NICE Guideline NG206 on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in England.

Action for M.E. is the only charity supporting people of all ages with ME/CFS through healthcare, information, support and advocacy services. This work puts us in daily contact with the ME/CFS community, hearing their stories and understanding their experiences with ‘the system’. We fully understand the pressures that the NHS is under, the demands on NHS staff and are grateful for the incredible work they do. What is clear, however, is that ME/CFS is not taken seriously and consistently enough within the NHS and patient care, in many cases, is merely an afterthought. Our experience of delivering holistic healthcare services repeatedly highlights the lack of access to appropriate healthcare for people with ME/CFS, not least through a current eight month waiting list to see our GPs.

The FOI data shows that nearly 67% of Trusts and ICBs do not hold data on patients with ME/CFS. This is staggering and goes some way to explaining the inconsistent and often broken pathways people with ME/CFS report experiencing. It also indicates that NHS Trusts/ICBs may not be aware of the scale of the problem within their geographical remit due to poor data collection. The full application of the NICE Guideline will underpin the formation of a patient pathway that delivers for all. As part of this, there must be a duty on NHS Trusts/ICBs to collect data on ME/CFS diagnosis and use this information to inform a long-term strategy.

It is also concerning that so many NHS Trusts/ICBs do not have any designated ME/CFS service. If a patient turns up for care and is presenting with ME/CFS symptoms, not only will they not know where to turn, the healthcare professional will not be able to point them to the best course of action for care. It is little wonder that many of the people we work with on a daily basis feel they are isolated, left behind and “hidden from society”.

The advent of the NICE Guideline and the imminent release of the Government’s Delivery Plan does indicate that there is appetite to change the way we care for people with ME/CFS. Encouragingly, five out of six respondents who explicitly said that the NICE Guideline has not yet been implemented in their NHS Trust/ICB indicated that implementation is under review. We hope that this results in the NICE Guideline being adopted more widely.

We appreciate that treatment of ME/CFS is complex and requires specialist training of staff and clinicians. Without an appropriately trained workforce, pathways for people with ME/CFS will remain patchy and uncertain. When asked what training has been given to healthcare professionals in their organisation on the NICE Guideline, only 14% of respondents said the question was applicable to them. Of those it was applicable to, only five had said they had offered some form of training. These damning statistics highlight a glaring issue; ME/CFS is not being taken seriously.

What written information is being provided to health professionals and patients on websites in line with the recommendations on diagnosis and management in the NICE Guideline [NG206]?

Resource available	19
In development	9
No further resource	11
Unknown	3
Not applicable	121
Total	163*

Key points:

- 19 respondents (21.11%) indicated that they have provided written information to health professionals and patients in line with the NICE Guideline.
- A further nine (10%) said that the written information was in development.
- 11 (12.22%) said that there was no further resource being provided to health professionals.
- This signifies that only 39 out of 90 respondents (43.33%) have records of whether there is further information on the NICE Guideline being provided.

*163 total due to Hampshire & Isle of Wight ICB having a different breakdown of information according to delivery

Action for M.E. is calling for the full application of the NICE Guideline across England.

To achieve this, we have four key calls to action:

- 1 People** - Ensure the needs of adults and children with ME/CFS are fully, and explicitly, considered in local commissioning arrangements
- 2 Pathways** - Ensure access to healthcare meets the NICE Guideline criteria and where it does not, NHS Trusts/ICBs should be explicit why not
- 3 Continuation** - Continued access to specialist ME/CFS healthcare services including consideration for a Continuing Healthcare Assessment and an integrated health and care personal budget, where necessary
- 4 Learning** - Promote and encourage training in ME/CFS by accessing CPD-accredited resources such as Action for M.E.'s [Learn about ME podcasts](https://www.actionforme.org.uk/support-others/for-healthcare-professionals/learn-about-me/)¹ for Health and Social Care Workers and the [ME/CFS e-learning module](https://www.studyprn.com/p/chronic-fatigue-syndrome)² for clinicians on PRN developed by Dr Muirhead et al.

When commissioning health services, it is paramount that those who live with a given disease always come first. We are calling for a greater emphasis to be put on people with ME/CFS as local commissioning arrangements are set out.

The NICE Guideline should serve as best practice for healthcare professionals and NHS Trusts/ICBs. With its correct implementation, we should see improvements in care pathways and progress towards resolving the postcode lottery of services, as exemplified through the results of this FOI. We are calling for NHS Trusts/ICBs to meet the NICE Guideline and where they do not, be required to explain why. This means that people with ME/CFS in their area can be better informed of how to access adequate care, what to expect and ensure accountability of commissioning bodies. It is recognised that this will not fully meet the needs of people with ME/CFS, especially those with greater levels of severity. It will, however, be an important start. People with ME/CFS benefit from individual personalised care and support plans and this should form a core aspect of Guideline adherence and should be reviewed at NHS Trust/ICB commissioning level on a regular basis. The symptoms of ME/CFS vary between individuals and fluctuate in severity over time, this is why a continued care plan is so vital to people with ME/CFS. Finally, for healthcare professionals standardised written information and online resources will assist their understanding of ME/CFS and what they can expect under the NICE Guideline. We recommend the provision of a suite of online resources that give clear advice and information of which Action for M.E. is well placed to advise. These should be easily accessible and promoted widely. This will drive forward delivery and maintain an informed relationship between clinicians and patients with ME/CFS.

Action for M.E. is calling on the Government to utilise the findings in this report to urgently address the postcode lottery of services for ME/CFS. The Government and the NHS must use best practice examples for ME/CFS care and learn from those that are currently delivering quality and specialist plans. This regional disparity of care cannot continue.

We urge local and national political representatives to engage with this report and question their local NHS Trusts/ICBs on their approach to ME/CFS treatment.

¹ <https://www.actionforme.org.uk/support-others/for-healthcare-professionals/learn-about-me/>

² <https://www.studyprn.com/p/chronic-fatigue-syndrome>

Dear [NAME]

I am writing to you under the Freedom of Information Act 2000 to request the following information from [NHS TRUST NAME/ICS NAME] on behalf of Action for M.E.

Please can you provide me with the following information:

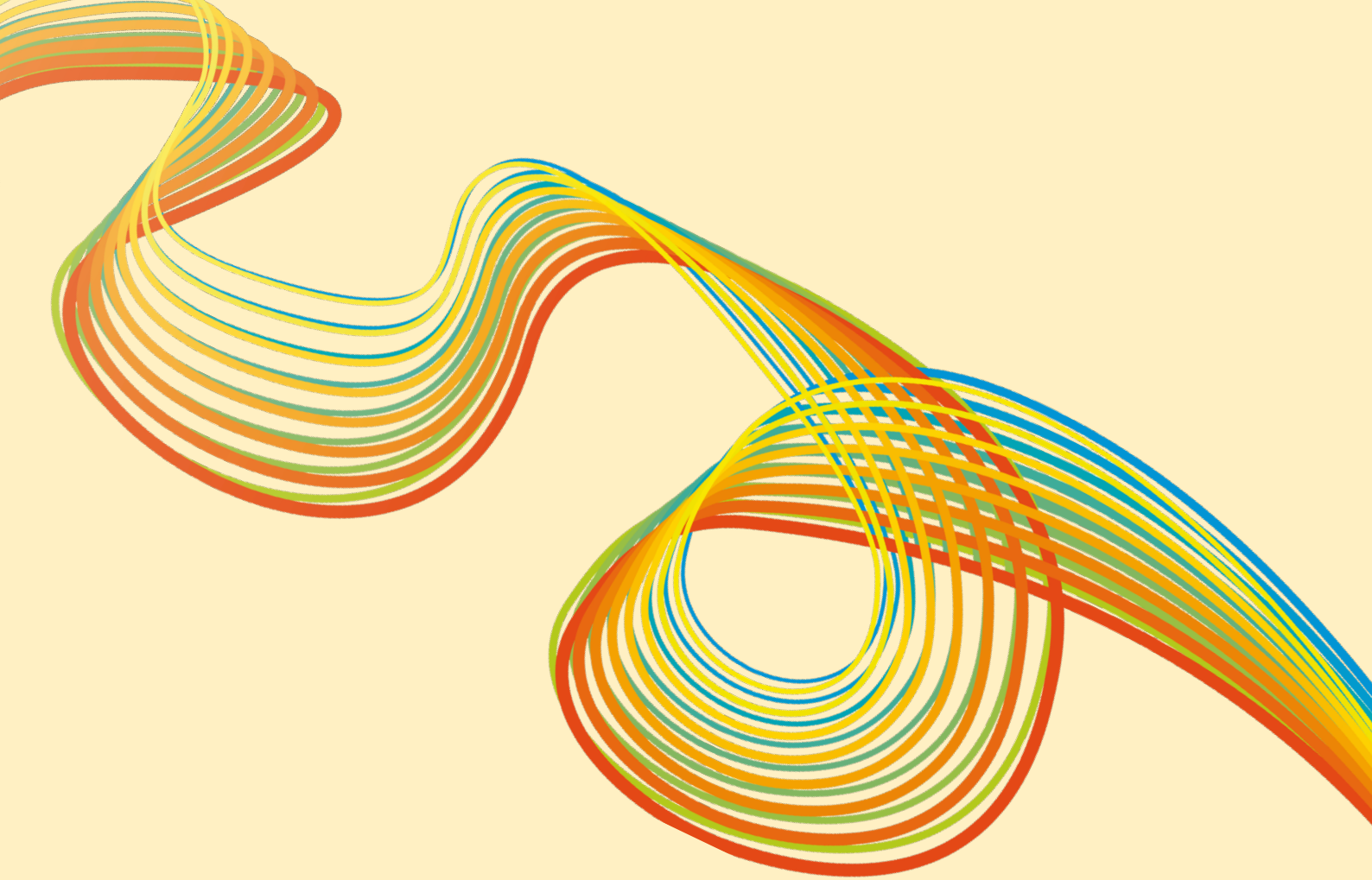
1. Has [NHS TRUST NAME/ICS NAME] implemented the NICE guidelines [NG206] on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: diagnosis and management, which were published on 29 October 2021?
 - 1.a. If the NICE guidelines [NG206] on the diagnosis and management of ME/CFS have not been implemented, what is the intended timetable and deadline for implementation?
2. How many patients with a diagnosis of ME/CFS are receiving care from [NHS TRUST NAME/ICS NAME] as of the date of this FOI request?
3. Of those receiving care for ME/CFS from [NHS TRUST NAME/ICS NAME], how many have a personalised care and support plan in place as of the date of this FOI request?
4. What training has been provided by [NHS TRUST NAME/ICS NAME] for healthcare professionals on the implementation of the NICE guidelines [NG206] on diagnosis and management of ME/CFS since 29 October 2021?
5. What written information is being provided to health professionals and patients on websites in line with the recommendations on diagnosis and management in the NICE guidelines [NG206]?

Please provide the information in a word document.

If you have any queries, please do not hesitate to contact me via email on policy@actionforme.org.uk to discuss this request further.

Thank you in advance for your assistance and I look forward to hearing from you.

Yours sincerely,
Sonya Chowdhury, Chief Executive, Action for M.E.
Sent by Connect on behalf of Action for M.E.



For more information about Action for M.E.'s work,
please visit our website at www.actionforme.org.uk
or follow us on twitter [@actionforme](https://twitter.com/actionforme)
or contact us on media@actionforme.org.uk

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