

# **Report on a Scottish stakeholder review of the Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome NICE guideline**

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This report was produced independently by Blake Stevenson Ltd to present the views gathered during a stakeholder engagement exercise which was commissioned by the Scottish Government.

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## Executive Summary

Myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS) is a complex chronic medical condition affecting an estimated 250,000 people in the UK. Around 20,000 people in Scotland are living with the condition. The four key symptoms characteristic of the condition are: debilitating fatigue that is worsened by activity; post-exertional malaise (PEM)/symptom exacerbation; unrefreshing sleep and/or sleep disturbance; and cognitive dysfunction. It affects multiple systems and can fluctuate from mild to very severe in individuals and across the population affected.

In October 2021 the updated NICE guideline on ME/CFS was published after some delay due to issues raised predominantly by professional clinical bodies. Despite attempts at facilitating consensus, the final publication received a negative reception by some clinical members and professional bodies but is largely welcomed by patient representatives.

In December 2021, the Scottish Government commissioned Blake Stevenson Ltd to engage with stakeholders, including national charities, local support groups, clinicians, representatives from Royal Colleges and people with lived experience of ME/CFS, to gather their views on the NICE guideline and establish what actions they think are required to implement the NICE guideline in Scotland.

In total 37 stakeholders contributed to the review – 22 through one-to-one or paired interviews and 15 stakeholders during three group discussions. Some stakeholders declined to participate or did not respond to email requests to contribute. Overall the breakdown of stakeholders who contributed to this process were:

- 14 clinicians (from across primary and secondary care);
- 10 third sector ME/CFS organisations/academics; and
- 13 people with ME/CFS or parents of children/young people with ME/CFS.

A short online survey was also distributed to a wider group of stakeholders and 93 people responded.

Stakeholders were asked about the changes made in the NICE guideline. The response from the majority of stakeholders of all types was overwhelmingly positive, with the following areas identified as particularly significant:

- Recognition that people with ME/CFS have experienced stigma and disbelief from the medical profession and validation that ME/CFS is a complex multi-systems condition.
- Non-use of Graded Exercise Therapy (GET) - highlighted as a 'massive step forward' by the ME/CFS community.
- Re-purposing of CBT - now changed to a supportive approach for living with a chronic condition, rather than positioned as a curative.
- Specific reference to severe and very severe ME/CFS and to children and young people in the guidance was welcomed.
- The emphasis on co-production of management and that people are the experts in their own care was acknowledged.
- Stakeholders welcomed the guidance's improved diagnostic criteria and aspirations for specialist care.

In considering the changes in the NICE guideline, stakeholders were asked which aspects should be prioritised. The majority of stakeholders focused on three key elements: ensuring that the practice of GET ends; undertaking education and training with clinicians; and developing specialist services and referral pathways. There was consensus that these needed to be achieved or committed to before the NICE guideline could be implemented.

Discussion identified two aids to implementation: an existing ME/CFS specialist-nurse led service in Fife and the knowledge and experience of ME/CFS third sector organisations. However, there were considerably more barriers:

- Scepticism: the embedded disbelief of some sectors of the clinical community around the veracity of ME/CFS and whether it is psychological rather than biomedical.
- Lack of knowledge: the paucity of training and education about ME/CFS means clinicians lack confidence over diagnosis and management of the condition.
- Lack of specialists: anyone with specialist knowledge tends to have lived experience of ME/CFS rather than develop expertise as a result of clinical pathways.
- Lack of investment: this has signalled to some that ME/CFS is not a priority, and means that education is not in place, nor pathways for management of the condition.

- Lack of ownership: although ME/CFS is defined by WHO as a neurological condition, it does not sit neatly under any one banner, and there is a reluctance to take it on for this reason.

Despite these barriers, feedback suggested that moving forward should concentrate on the development of specialist services, partnership working, the education of current and future clinicians and leadership from the Scottish Government.

Specialist services would combine local, community-based clinics supported by specialist consultant expertise at regional or national level. These could be housed in mainstream services or based around existing successful models such as the Chronic Pain Speciality Network. Learning from the pandemic might enable the use of blended delivery, with the option of virtual clinics. Partnership working, both with ME/CFS patients to draw insight from their lived experience and with third sector organisations who provide peer-to-peer support, would enable development of patient-centred specialist services.

The broad recommendations resulting from this consultation are summarised below:

- The Scottish Good Practice Statement is updated to reflect the changes within the guideline.
- There is a visible commitment to supporting the key changes within the guideline, to help end the scepticism and disbelief.
- The publication of the revised SGPS is accompanied with promotional activities and awareness raising.
- Consideration is given to the most effective approaches to improve GP knowledge, confidence and understanding of ME/CFS through an appropriate education programme.
- Pilot services are funded in a selection of NHS boards to test the development of specialist services with patient involvement and third sector collaboration embedded in the design.
- The option of including ME/CFS as a specialist network within the Modernising Patient Pathway Programme is explored.
- More research into ME/CFS is actively encouraged within the academic sector.

## 1. Introduction

- 1.1 In December 2021, the Scottish Government commissioned Blake Stevenson Ltd to engage with stakeholders, including national charities, local support groups, clinicians, representatives from Royal Colleges and people with the lived experience of ME/CFS community, to gather their views on the ME/CFS National Institute for Health and Care Excellence (NICE) guideline.
- 1.2 This report presents the stakeholders' views of the NICE guideline and the actions they think are required to implement the NICE guideline in Scotland.
- 1.3 In chapter 2, the context for this work and the approach to stakeholder engagement is summarised.
- 1.4 In chapters 3 and 4 the findings from the engagement exercise are presented and Chapter 5 identifies next steps for implementation, summarises the key findings and presents recommendations.

## 2. Background

### Context

2.1 ME or CFS is a complex chronic medical condition affecting an estimated 250,000 people in the UK. Around 20,000 people in Scotland are living with the condition.

The NICE guideline lists four key symptoms:

- Debilitating fatigue that is worsened by activity;
- Post-exertional malaise (PEM)/symptom exacerbation;
- Unrefreshing sleep and/or sleep disturbance; and
- Cognitive dysfunction.

2.2 Other symptoms that may be present include orthostatic intolerance and autonomic dysfunction, temperature hypersensitivity, neuromuscular symptoms, flu-like symptoms, intolerance to certain foods and drinks, heightened sensory sensitivities and pain.

2.3 Individual symptoms, and the severity of symptoms, vary widely for people with ME/CFS and can fluctuate unpredictably in nature and severity over a day, week or longer. Someone with mild ME/CFS may be able to work full time, with adaptations, whilst someone with severe or very severe ME/CFS can be bed-bound, may not be able to swallow and may need to be tube fed.

2.4 ME/CFS can be a mis-understood condition. Disbelief and mis-diagnosis could delay diagnosis and management of the condition and have serious consequences for an individual's health outcomes. The 2021 NICE guideline recognises this, noting that, *“People with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness.”*

### ME/CFS in Scotland and development of the NICE guideline

2.5 Despite a growing recognition of the need for specialist ME/CFS services, actual implementation has been minimal. A report by Scotland's Chief Medical Officer in 2002 recognised the need for ME/CFS-specific services and set out recommendations to deliver on this aim. However, a 2010 assessment against these



recommendations by the Scottish Public Health Network commented that, “recommendations of CMO’s short life working group have not been implemented widely”. The report went on to make 26 recommendations around diagnosis, management, education, training, and research.

- 2.6 More recently, in 2020, the *ME-CFS Healthcare needs assessment briefing* published by the Scottish Public Health Network reviewed progress against the recommendations made and concluded that they all ‘remained relevant’, with the caveat that many should now be considered in the context of the delivery of the Neurological Care and Support Framework, the Re-mobilise, Recover, Re-design Framework, and the General Standards for Neurological Care. Third sector ME/CFS organisations have expressed concern that the recommendations have not yet been implemented.
- 2.7 A *Gathering Views* report from Health Improvement Scotland (HIS) the following year outlined conclusions and recommendations echoing those of previous reports and identified persistent challenges for people living with ME/CFS: lack of understanding and recognition of the condition; slow diagnosis; lack of specialist support for management; and lack of support for self-management.
- 2.8 In October 2021 the updated NICE guideline on ME/CFS was published after some delay. NICE paused the publication due to issues raised predominantly by professional clinical bodies and released a statement that in order to have the desired impact, the recommendations must be supported by those who will implement them. This was followed by a roundtable stakeholder meeting to hear views and address four key issues around diagnosis, graded exercise therapy (GET), children and young people, and cognitive behavioural therapy (CBT), after which the guideline was published. Despite attempts at facilitating consensus, the final publication received a negative reception by some clinical members and professional bodies but is largely welcomed by patient representatives.
- 2.9 GET remains an issue of contention, even with the recommendation in the current NICE guideline that it should not be offered to people with ME/CFS. A core group of clinicians are supportive of trying this approach in certain circumstances whilst ME/CFS representatives are clear that its use is unhelpful, detrimental, and harmful.

- 2.10 In a joint statement in response to the NICE guideline, Royal Colleges commented that, whilst the guidance contained some positive changes, they, “*understate the importance of activity and exercise in the management of ME/CFS and the connection between people’s mental and physical health.*” They also questioned the evidence that informed the guideline, commenting “*there is considerable disquiet in the medical profession and some patient groups about the way the data and evidence have been assessed.*” Link to Royal Colleges joint statement: [Joint statement in response to NICE guidance on ME/CFS | Royal College of Physicians London](#)

### **Guidance in Scotland**

- 2.11 Following the publication of the NICE guideline in 2007, a *Scottish Good Practice Statement (SGPS)* on ME/CFS was developed and published in November 2010 by a Guidance Working Group, chaired by Sir Lewis Ritchie. Its purpose was to provide general practitioners (GPs) with guidance on the diagnosis and clinical management of patients with ME/CFS in Scotland.
- 2.12 Parts of the SGPS are now out of date, given the publication of the NICE guideline. Consideration also needs to be given to whether this is the most effective way of communicating changes, and of delivering information to clinicians and patients in Scotland.
- 2.13 An Implementation Support Note for Long COVID has been published recently to support the implementation of the clinical guideline. The Scottish Government has produced additional targeted information for primary care teams, developed with input from key stakeholders, and positive feedback has been received to date. This could be a more suitable type of vehicle and SIGN has suggested this could be a more practical approach.
- 2.14 In 2020 Scottish Government officials wrote to GPs, all NHS Board Chief Executives, and the Board of Academic Medicine to raise awareness of the change in guidance concerning GET and CBT recommended by the draft NICE guideline, and a cautionary note to accompany the existing SGPS was released online.

### **Implementing the new NICE guideline in Scotland**

- 2.15 The appropriateness or otherwise of the SGPS or an Implementation Note as an information source for the implementation of NICE guidelines in Scotland forms one

element of this research. However, in considering the implementation of the NICE guideline in Scotland, much broader issues around ME/CFS come into play. This research sets out to:

- question stakeholders about the new NICE guideline and what it means for Scotland – this will help inform the update of the SGPS or production of an Implementation Note; and
- explore operational possibilities and short-term actions: with considerations for the priorities of those living with ME/CFS.

## Methodology

2.16 Our approach to undertaking this stakeholder engagement is outlined in the diagram below.



Figure 1: The three phases of stakeholder engagement. Phase 1 involved planning and desk-based review, phase 2 conducted interviews and workshops, and phase 3 involved analysis of responses and producing the report.

- 2.17 Once the team had prepared for the engagement process and designed the question schedule, information sheets, and privacy notices, contact was made with the list of stakeholders provided by the Scottish Government. This list included national ME/CFS charities, local support groups, clinicians, representatives from Royal Colleges and people living with ME/CFS. Following a Scottish Government introductory email the research team contacted the stakeholders to explain the work and to request their participation.
- 2.18 This list was the starting point for contacting potential participants and they were asked to cascade the information to other stakeholders who could be interested in sharing their views. Engagement took place in the following ways:
- one-to-one or paired interviews, by telephone or web-based call;
  - online group discussions; and
  - written responses using an online survey.
- 2.19 In total 37 stakeholders contributed to the review – 22 through one-to-one or paired interviews and 15 during three group discussions. Some stakeholders declined to participate or did not respond to email requests to contribute.
- 2.20 Overall the breakdown of stakeholders who contributed to this process were:
- 14 clinicians (from across primary and secondary care including GPs, occupational therapists, physiotherapists, neurologists);
  - 10 third sector ME/CFS organisations/academics; and
  - 13 people with ME/CFS or parents of children/young people with ME/CFS.
- 2.21 In addition to the interviews and group discussions, a short online survey with three questions was distributed to enable a wider group of participants to contribute their views. This was disseminated through third sector organisations and the original stakeholder list provided by the Scottish Government. The survey was live for three weeks and 93 responses were received in that time. The majority of respondents were people with ME/CFS and their contributions are summarised in Appendix 1.
- 2.22 The non-engagement of some clinical stakeholders means that this review does not fully capture the views of those stakeholders. To obtain a wider view of the thoughts from the clinical community, beyond what is captured in this exercise, other evidence

can be considered such as the joint statement in response to the NICE guideline, which is available here: [Joint statement in response to NICE guidance on ME/CFS | Royal College of Physicians London](#)

- 2.23 The views of the stakeholders that did contribute to this review have informed the content of this report and these are discussed in the next three chapters.

### 3. Findings: Views of the NICE guideline

- 3.1 Stakeholders were asked about the changes made in the NICE guideline and which aspects they welcomed. The responses from the majority of stakeholders, of all types, was overwhelmingly positive.

#### Recognition and validation

- 3.2 The explicit reference to the stigma and the recognition of the complexity of the condition was identified as a key achievement of the guideline and much needed to progress change.

*“We welcomed the explicit reference to the stigma of ME and that people are not always believed or told things are ‘all in their head’”* (Third sector ME/CFS organisation)

- 3.3 Most clinicians, third sector contributors and people living with ME/CFS appreciated the validation of ME/CFS as a complex multi-system disease that required specialist care. A few stakeholders acknowledged that the previous guideline had not done enough to dispel the myths around ME/CFS so they appreciated the recognition of the stigma and disbelief around the condition, noting that, *“we know it is not psychosomatic - and that needs to be stated loud and clear”* (Clinician)

#### Not using Graded Exercise Therapy (GET)

- 3.4 All people living with ME/CFS and representatives of ME/CFS third sector organisations highlighted that not recommending the use of GET in the NICE guideline was a *‘massive step forward’* and *‘nothing short of life changing.’* (Person living with ME). The ME/CFS community were very clear that GET was not only ineffective in treating ME/CFS, but extremely damaging, commenting that, *“the notion that people could exercise themselves out of illness is the wrong thing for ME. Too much exercise worsens the disease. Removal of GET from the guidelines was a real breakthrough”* (Third sector ME/CFS organisation).
- 3.5 The majority of clinicians involved in this review agreed with the non-use of GET, or at least acknowledged the importance of this change to the ME/CFS community. *“[NICE have] abolished recommending CBT and GET – based around psychosocial*

*hypothesis built on faulty beliefs and decondition – it needs [to be consigned to] the history dustbin. This is major.” (Clinician)*

- 3.6 However, a few clinicians felt that GET still had a role to play in treating people with ME/CFS *“it’s probably not harmful to try - increasing exercise might just mean people are wiped out for a couple of days afterwards”.* (Clinician)
- 3.7 Other clinicians questioned the evidence base that prompted this change. One noted that they were, *“Disappointed in the way [GET] was removed, not entirely scientific”* (Clinician) and another added that they, *“question [the] evidence base around a lot of the contents. Often refers to, ‘expert opinion of the committee’. It’s the way I’ve treated throughout my career, so disappointed to see removed.”* (Clinician)
- 3.8 Comments from these clinicians around the importance of exercise in supporting general good health and the risk of deconditioning indicated that they seemed to conflate GET with supported activity programmes and pacing, expressing concern that exercise as a possible way of managing ME/CFS had been removed from the NICE guideline.

### **Re-purposing of CBT**

- 3.9 From the discussions with stakeholders, the re-positioning of CBT as one of a number of possible supportive approaches, rather than as a cure for ME/CFS, was universally welcomed by the ME/CFS community, and by the majority of clinicians who took part. ME/CFS organisations recognised that this was another endorsement of the authenticity of the condition, noting that, *“CBT gave the idea that ME was all in your head, [and] psych intervention like CBT could think your way out of ME. That was cobblers. Now the guidance, which I feel is appropriate, is that CBT should be offered not to cure but to help people live with difficulties of long-term conditions”.* (Third sector ME/CFS organisation)
- “I welcome NICE’s change of stance on CBT - not a curative but a supportive approach for managing the secondary impacts of ME”* (Clinician)
- 3.10 A few clinicians were sceptical about the change in status of CBT, with one noting that, *“the problem is, there’s no pharmaceutical options... CBT and GET are no longer advised but that’s why [individuals] came to secondary care. It makes it difficult to know what therapeutic options are available”.*

## Severe and very severe ME/CFS

- 3.11 Stakeholders, especially those from the ME/CFS community, welcomed the recognition in the guideline that there is a severe and very severe end of the ME/CFS spectrum and that this needs special adaptations and extra care. One third sector organisation explained the importance, *“to distinguish severe and very severe and acknowledge that they need different treatment - they are less likely to fluctuate, more likely to be very severe all the time”*. Another stakeholder, a clinician, commented that, *“the descriptions of those with severe / very severe ME 'hit hard' as they clearly need a very different approach to those with mild / moderate ME”*, further noting that this distinction in severity and identification of scales of illness could help shape future services.

## Children and young people

- 3.12 People with ME/CFS or parents of people with ME/CFS applauded the guideline for the inclusion of specific reference to the way ME/CFS impacts on children’s health, education and family life. *“The guideline had specific consideration for children and severely ill. They have different needs to the general population, so this recognition is helpful”* (Clinician).
- 3.13 Although parents welcomed the recognition of the children and young people in the guideline, they were unhappy with the wording that stated, *“recognise that the following are **not necessarily signs of abuse** or neglect in children and young people with confirmed or suspected ME/CFS.”* Many of the parents lived with the fear of safeguarding issues being raised and they felt that this wording should be *‘very unlikely to be signs of abuse’* and that the medical profession need to work closely with schools and help them understand how they can support children.
- 3.14 In the discussion<sup>1</sup> with parents of children and young people with ME/CFS they hoped that this new recognition would result in more parental involvement in the way that future services are developed and that paediatricians would be part of any specialist team.

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<sup>1</sup> An additional note of the points raised by the parents, that go beyond the NICE guideline, was produced and shared with the Scottish Government.



## Reference to co-production in management of ME/CFS

- 3.15 A few people from the ME/CFS community noted that greater emphasis on patient experience and acknowledgement that people are experts in their own care were highlights of the guidance, along with encouragement to co-produce management strategies.

*“Partnerships between patient and clinician seen as key... felt there was quite a lot of patient involvement, emphasis on pacing”* (Clinician).

- 3.16 However, one clinician noted that the guidelines themselves could be a barrier to genuine co-production as they, *“over medicalise approaches to ME - it can be obstructive in that clinicians will live by the guidelines and sometimes they might not match lived experience - means that patients and clinicians will then go backwards and forwards and wrangle over the detail concentrating on a piece of paper and not their treatment. What is needed instead is genuine co-production of treatment - established relationships with patients as genuine narrative equals”*. (Clinician)

## Mention of specialist teams

- 3.17 Stakeholders from the ME/CFS community highlighted that the guideline made specific reference to specialists. They welcomed the recognition that there should be specialist services and *“that the guidelines place responsibility on GPs for diagnosis and referral to specialists”* (Person with ME/CFS).

- 3.18 However, there were a few stakeholders who wanted more clarity in the guideline about the specialists that should be involved.

*“What was less welcome – who should deliver it? Doesn’t say this. Lots of pass the parcel going on, someone needs to be told this is your disease now get on with it.”*

(Third sector ME/CFS organisation). Another stakeholder noted that, *“Guidelines helpful in confirming what clinicians should be doing but can in themselves be a barrier - everyone is so different and needs work on a continuum so therefore so should care.”* (Clinician)

## Better diagnostic criteria

- 3.19 A few stakeholders from the ME/CFS community noted that the new guideline provided improved diagnostic criteria. *“ME is not a functional disorder and shouldn’t*

*be seen in this way by professionals. Diagnosis has been a complete mess, people not getting a diagnosis and a misunderstanding of what other conditions are” (Third sector ME/CFS organisation)*

3.20 However, a few clinicians noted some of the challenges with the diagnostic criteria, in that:

- the coding on the GP systems needed to be updated to allow for the level of severity of ME/CFS to be added so treatment / management could be adapted accordingly;
- there needed to be a definition of ‘normal’ for the four key symptoms and clarity about what is outside normal parameters, e.g. many other conditions have poor sleep function as a symptom;
- more data on the prevalence levels of the condition disaggregated by severity would more accurately inform the level of need; and
- the three-month timescale for diagnosis seemed ambitious “*very short, given that flu-like viruses can leave people very tired even after this length of time - people who may then go on to recover completely*”. (Clinician)

### **Short term areas of focus and priority**

3.21 In considering the changes in the NICE guideline, stakeholders were asked which aspects should be prioritised. The majority of stakeholders focused on three key elements: ensuring that the practice of GET ends; undertaking education and training with clinicians and developing specialist services and referral pathways.

### **Communicate about GET**

3.22 Although the Scottish Government has already informed all GPs, NHS Boards and Scottish Academical Medical Schools of the draft NICE recommendations against using GET, people with ME/CFS and representing ME/CFS third sector organisations were clear that the immediate priority was to ensure that clinicians follow this recommendation. These stakeholders acknowledged that, “*the challenge now lies in communicating this effectively - need to get a warning out there and ensure it is endorsed and stressed at the highest level.*” (Person living with ME/CFS).

3.23 A few stakeholders with ME/CFS or representing ME/CFS groups expressed concerns about the continued use of GET. One stakeholder said that *“the guideline says doctors mustn’t practise [GET], it doesn’t say will stop doing it. They will continue to offer it and it causes harm, needs to be eliminated via a statutory instrument”* (Third sector ME/CFS organisation). Another stakeholder noted the need to be courageous in recommending an alternative to GET, *“They’re [NICE] endorsing the regime of pacing [without being explicit in this]. Staying within energy envelope – now called activity management. Scotland could be brave and say that they’re recommending pacing”* (Clinician).

### Education and training

3.24 There was consensus from all stakeholders that another key priority was education and training. Insight centred around four main elements:

- raising awareness and acceptance around ME/CFS;
- increasing the knowledge and confidence of GPs or other clinicians to diagnose ME/CFS;
- embedding knowledge about management of the condition in different care settings; and
- general awareness raising amongst other professional services and the general public.

3.25 All stakeholder types highlighted the need to focus on some key messages when educating clinicians. As one clinician explained, *“[we need to] get back to basics: that is belief and acceptance from GPs that ME is a condition and making sure patients know you believe them”*. Although the same stakeholder acknowledged that, *“this is, easy to say but not easy to do and hard to do without personal insight”*. Another stakeholder noted, *“We need training to first dispel myths around ME and secondly to increase confidence in diagnosis, in referring to appropriate specialisms and in providing advice around management of ME”*. (Person with ME/CFS)

3.26 Comments often mentioned instilling confidence in GPs to make a diagnosis by providing them with education, additional resources and the backup of a specialist if they had any doubts over their conclusions. One stakeholder suggested, *“educating people on how to teach PACE and energy management”* (Third sector ME/CFS)

organisation) and another added there should be, *“greater investment in research, training and encouragement towards people choosing ME as a speciality”* (Person with ME/CFS).

### Develop specialist services and pathways

- 3.27 Clinicians and people from the ME/CFS community alike noted that, *“The NICE guideline cannot be implemented in Scotland as there is no infrastructure”* (Clinician) explaining that the guidance issued assumed there were specialist clinics to refer people to, as in other parts of the UK.
- 3.28 Stakeholders commented that although the guideline was comprehensive and presented an idealised version of what ME/CFS services could and should be, *“Until specialist clinics are developed, and this will take some time, GPs need to know where to refer people to”* (Person with ME/CFS). A clinician added that, *“often the problem is which speciality to send the patient to as the condition is so complex. Because it is a diagnosis of exclusion not a positive diagnosis it's often hard to know when to stop testing - for both clinician and patient - specialist clinics could stop the roundabout of constant tests and to-ing and fro-ing in the system”*.
- 3.29 A few stakeholders suggested that there needed to be a piece of work to show the potential financial savings across a range of health and social care services, if a specialist service was in place, with one saying that it would be *“ideal to pilot a service and pathway in one area and roll it out to others if it worked... there is a cost-benefit in investing in pathways and services now.”* (Person with ME/CFS)

### Research

- 3.30 Stakeholders across all types recognised the need for more research to reduce the misunderstanding about ME/CFS. Biomedical evidential research was considered important to improve understanding and potentially increase interest in the condition. *“The other thing people wanted to see was research and trials – almost a hidden condition disregarded by clinicians.”* (Third sector ME/CFS organisation)

### Next chapters

- 3.31 These short-term priorities are explored in more detail in the next two chapters when considering the implementation of the guideline and how to move forward.

## 4. Findings: Implementation of the NICE guideline

- 4.1 A key element of this review was to explore the views of stakeholders as to how the NICE guideline could be practically implemented in Scotland. In holding those discussions, stakeholders were asked about one of the approaches the Scottish Government was considering, which was an implementation note, and all stakeholders were asked what would shape any document that could help to put the new guideline into practice.

### Guidance to support implementation in Scotland

- 4.2 The responses from stakeholders varied in terms of what should shape the content of any guidance and then how the guidance could be applied. There was agreement across all stakeholder types that they did not want to wait for SIGN<sup>2</sup> guidance to be developed. They recognised that this would take years to develop and that something actionable in the shorter term was required.

### Implementation Note

- 4.3 The suggestion of an implementation note received some positive feedback from a few stakeholders in that it could be a very simple solution to communicating the changes introduced in the NICE guideline and that this, potentially, could be produced in a timely fashion. However, there were also queries about how it would be developed and who would be involved. The stakeholders who raised these concerns felt that GPs would traditionally look to NICE or SIGN guidelines so questioned whether it needed to be endorsed and what status it would have, “*where would an implementation note sit?*” (Clinician)

### Scottish Good Practice Statement refresh

- 4.4 The majority of those familiar with the Scottish Good Practice Statement (SGPS) felt that it was still very relevant. They explained that it had been more forward-thinking than the original NICE guideline and once sections were updated in line with the new NICE guideline, e.g. information on children and young people, severe ME, refreshing

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<sup>2</sup> SIGN – Scottish Intercollegiate Guidelines Network produce evidence-based, collaboratively developed clinical guidelines

the biomedical evidence that has emerged since 2010, that this was a better option than the implementation note. They felt that the SGPS contained very practical elements like specific mention of medications, tests, and investigations; all aspects that supported those who used the document.

- 4.5 A few people with ME/CFS went on to explain that they had found the SGPS helpful because even though their GPs were unfamiliar with it, it was a useful reference for them to know what to ask for. *“I referenced it in a meeting with a GP and they had not heard of it”* (Person with ME/CFS)
- 4.6 As well as the main guidance document, the companion documents to the SGPS, aimed at different audiences, were also considered useful. They were described as effective quick reference guides, more likely to be read by professionals and the easy read version that supported people with ME/CFS in *“being their own professional”*.
- 4.7 For the stakeholders familiar with the SGPS, they felt that updating it and the companion documents was the most appropriate approach to implementing the new guideline.

#### **Awareness-raising of any guidance**

- 4.8 There was consensus across all stakeholders about the need to promote whatever guidance is produced. They were clear that any awareness raising of the resource was reinforced with training, investment, and leadership.
- “it’s not enough to put it out there and hope people take notice...it needs to be backed up by ongoing education and quick reference resources”.* (Clinician)
- 4.9 The importance of recognising the demands on clinicians’ time and information overload was highlighted by all stakeholder types. They emphasised that any resource needed to be disseminated but questioned how this could be achieved without more visible commitment and leadership from within the existing systems and structures. *“How do we get people to look at the good practice note? If it sits outside healthcare structures/ communications, a lot of professionals won’t see it”* (Clinician)

## Practical tools and approaches to support the design of the guidance

- 4.10 When considering the practical tools or guidance that can update SGPS or inform another type of guidance note, the stakeholders suggested resources and approaches to support implementation.
- 4.11 For informing the design of the practical guidance note, suggestions included:
- The NICE online tool that aids understanding of the guideline;
  - Drs with ME guide 'Putting it into practice - what the NICE guidelines means for ME/CFS' ([Putting it into Practice: What NICE ME/CFS means for GPs - Doctors with M.E.](#));
  - Materials from the free online learning module<sup>3</sup> promoted by four of the ME/CFS charities developed by Nina Muirhead and based on 10 ME/CFS patient stories [Myalgic Encephalomyelitis | Chronic Fatigue Syndrome | CPD Course \(studypm.com\)](#); and
  - Physios for ME information [Home | Physiosforme](#).
- 4.12 To support the implementation, there were also suggestions as to what actions could be taken to roll out or reinforce whatever guidance is produced. These varied from additional tools and mechanisms to support improved knowledge of the guideline, to strategic actions to raise the profile of ME/CFS and its management. Stakeholders proposed:
- vehicles for disseminating information and raising importance - letter from Chief Medical Officer, Chief Executive Letter (CEL) about ME.CFS from Minister;
  - approaches to CPD for clinicians - small group practice-based learning where GPs tackle a different topic every month, protected learning time to look at guidance and understand more about ME/CFS, delivery of ME/CFS training about diagnosis and care, peer to peer sharing of knowledge - it was felt that this was more powerful

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<sup>3</sup> Funded by the Scottish Government through the Neurological framework and completed by approximately 1000 healthcare professionals in Scotland

*“doctors listen to doctors and likely to have more impact than hearing it from lived experience / third sector”* (third sector ME/CFS organisation);

- resources to support clinicians and build confidence - revised NES module on ME/CFS; quick reference guide for clinicians, incorporate more information into existing systems, e.g. in NHS Lothian the searchable GP system *RefHelp* sets thresholds and gives advice on when and where to refer people to.

## Services

- 4.13 Within the NICE guideline the need for specialist services and care and support managed by multi-disciplinary teams was identified as vital to delivering appropriate provision.
- 4.14 When asked to consider the current management of ME/CFS in Scotland there was a consistent response about the absence of a referral pathway, the paucity of provision, a lack of understanding from generalist services, and, if support was available, it was inconsistent and disjointed. *“There isn't really an infrastructure specific to ME - no specialist teams to refer people to - more interested individuals - tends to be the luck of the draw”* (Clinician).
- 4.15 With the exception of the ME/CFS specialist nurse in NHS Fife, who was described as having a huge caseload, long waiting lists and limited resources, stakeholders of all types struggled to identify examples of good practice. If there was awareness or recognition of some good experiences and ‘pockets of interest’ it was about particular GPs. The current state of provision was summarised by one clinician and echoed the views of people with ME/CFS *“Individual GPs and paediatricians are doing good practice...[but] my view is that it's mainly a disaster area.”*
- 4.16 Stakeholders living with ME/CFS and third sector organisations explained that a large amount of patients are self-managing and there was anecdotal sharing of information as to which *“doctors to look out for - who are the most damaging”* (Person with ME/CFS).
- 4.17 In addition parents of children and young people faced additional challenges when accessing services. They were concerned about allegations of Fabricated or Induced Illness (FII) and the parents interviewed as part of this review described their fear that an allegation of FII could be made if they appeared too knowledgeable or challenged



the opinions of professionals: “Safeguarding is a fear I have to live with” (Parent of child or young person with ME/CFS). As a result of these concerns, parents described their wariness in interacting with medical professionals and suggested that some parents are too scared to accept care because of the potential safeguarding consequences. The absence of specialist services in Scotland was perceived to increase the risk of false FII allegations.

### Aids and barriers to implementation of the NICE guideline

4.18 Whilst a few clinicians expressed concerns about communicating the implementation of the guideline when there were no pathways and limited services to refer into or access, a few other stakeholders noted that this, ‘blank sheet’ could be used as an opportunity to build an appropriate ME/CFS service. Stakeholders identified existing services and supportive third sector organisations as elements of the existing infrastructure that could support the implementation of the NICE guideline, but all stakeholders identified several barriers that would make implementation more challenging.

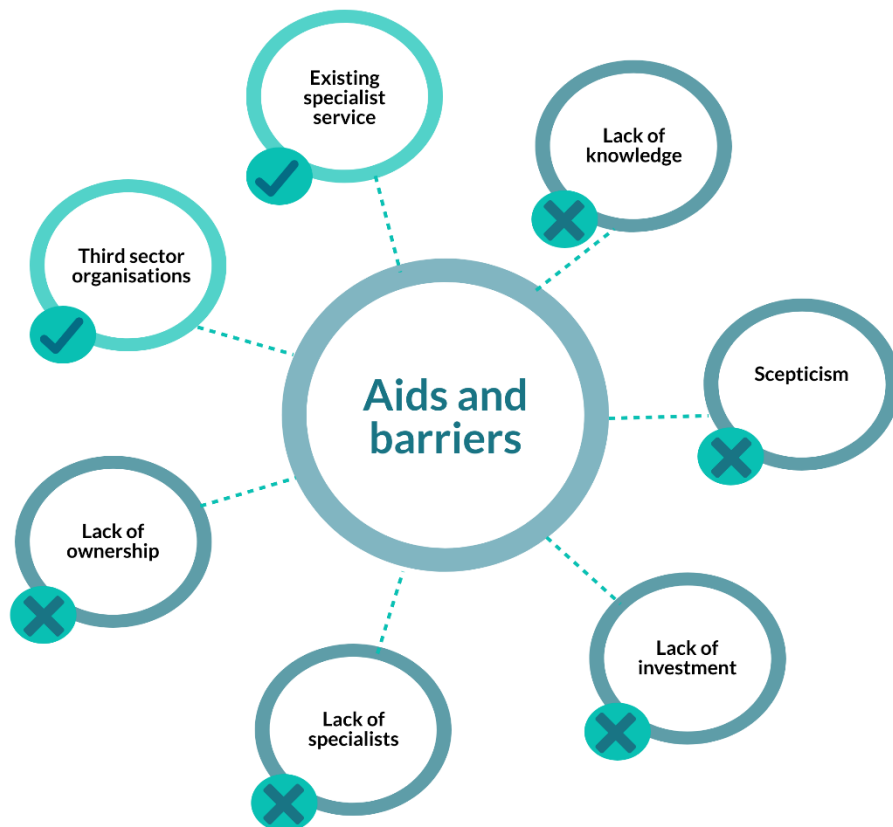


Figure 2: Identified aids and barriers to the implementation of the NICE guidelines.

### Aids to implementation

- 4.19 Although there are very limited ME/CFS services, some do exist, and these were considered a starting point or building block to develop more provision and support the implementation of the guideline. The service that stakeholders were most aware of, and which was referred to frequently, was the specialist ME/CFS nurse in Fife. There was an almost unanimous view that this post should be rolled out to other health boards: *“an enabler but massively under-resourced - need an immediate extension and similar nurses in other areas”* (Third sector ME/CFS organisation).
- 4.20 The work delivered by this postholder was considered a good example of how a small specialist service could be delivered. As well as NHS Fife the services in NHS Lothian at the Astley Ainslie in Edinburgh and in NHS Greater Glasgow and Clyde the Centre for Integrative Care in Glasgow were highlighted as potential starting points for expanding provision. Stakeholders from all three services felt that their existing services could be expanded to support more people with ME/CFS.
- 4.21 The role of third sector organisations was seen as an aid to implementation by all stakeholder types. Their potential was recognised for both the support they provided to people with ME/CFS in understanding the new guideline, and as an important bridge between clinicians and patients, *“seeing more muscle from community link workers, making people aware of what’s available in the third sector - a whole network who aren’t active in the NHS, some have useful skills”* (Clinician).

### Barriers to implementation

- 4.22 Whilst these positive supports were acknowledged, the challenges to implementation were viewed by stakeholders as more significant. These are discussed in turn.

### Lack of ownership

- 4.23 Stakeholders noted that the support a person with ME/CFS requires is provided by different teams within the health and social care system. However, the World Health Organisation (WHO) defines ME/CFS as a neurological condition. Nevertheless, clinicians, third sector organisations and individuals with ME/CFS expressed frustration that some neurologists shied away from leading on the condition.

*"[ME/CFS] is a neurological condition as defined by WHO, meaning the logical starting point is for neurologists to get involved, they're not in the most part at the moment"* (Third sector ME/CFS organisation). *"They are reluctant to embrace ME as part of their canon"* (Person with ME/CFS).

- 4.24 A few clinicians highlighted this as well, noting that, *"Neurology provides support for a lot of conditions but doesn't seem to be particularly engaged with ME"*.
- 4.25 This response and absence of ownership from some neurologists was considered a stumbling block for implementation of the guideline and further development of services.

### **Lack of knowledge**

- 4.26 Stakeholders identified a lack of training and knowledge about ME/CFS amongst GPs. This can lead to a delay or unwillingness to commit to diagnosing ME/CFS. Consequently an investment of time and resources would be required to increase the knowledge and understanding in such a pivotal role for providing support to help people to live with and manage their ME/CFS.

### **Scepticism**

- 4.27 From individual clinicians to Royal Colleges, aspects of the NICE guideline have been questioned and this has emphasised the disbelief that some clinicians share about the condition and how it should be treated and managed. This is viewed as another barrier to implementation. One person with ME/CFS said *"Royal Colleges are where most people go to continue their professional development and some don't educate on ME - some still believe in GET approach"*. Another emphasised the impact of the Royal Colleges' position *"Royal Colleges [are] not supportive of NICE guidelines so will hamper their dissemination"* (Person with ME/CFS)

### **Lack of specialists**

- 4.28 Stakeholders highlighted the limited knowledge across clinicians both in primary and secondary care. This means that, unlike other conditions, there are a lack of specialists or clinicians with an interest in ME/CFS and where there is expertise it is held within a small pool of people. So, alongside the general awareness raising amongst clinicians there was a need for more people who could fill a range of

specialist ME/CFS roles. A few stakeholders felt that specialists would “*emerge as it becomes more acceptable to express and pursue an interest in ME and as research is better funded*” (Clinician)

### **Lack of investment**

- 4.29 The lack of funding and resources created an obstacle not only in the financing of the education of key clinicians but also to the investment in services that could deliver new pathways and much-needed support to people with ME/CFS. A few stakeholders also saw this as a signal that this condition is overlooked and ME/CFS is not a priority for healthcare plans or services.

## 5. Moving forward

- 5.1 As part of the discussions, stakeholders were asked for their views on the ways in which the sectors, patients' and clinical groups could move forward the care of people with ME/CFS. Their responses built on the earlier conversations about the barriers to implementation of the NICE guideline and priority actions. These are described in this final chapter. A summary of the key discussion findings is also presented, and the chapter ends with recommendations.

### Developing services

- 5.2 Although all stakeholder types recognised the significance of the barriers that needed to be addressed to implement the NICE guideline in Scotland and develop appropriate and relevant services, when asked to consider what a service could look like, there were plenty of suggestions as to who should be part of a service and how it should operate.

### Specialist community-based service

- 5.3 The majority of stakeholders felt that there was a need for specialist services. Their proposals centred on a design that had a community-based focus with a ME/CFS practitioner at the centre who concentrated on supporting the person living with ME/CFS through the management of a care and treatment plan. That plan was then delivered by a network of different specialisms which could involve at any time: cardiology, neurology, gastroenterology, dietetics, pain management, immunology, pharmacology, occupational therapy, or physiotherapy.
- 5.4 Those that proposed this approach stressed the importance of connections to, "*avoid the silos of ologies*" between the different teams ensuring that they shared information and understood the breadth and depth of the condition and the multiple impacts it could have. In partnership with this specialist service, the majority of third sector stakeholders wanted to provide wrap around care - for instance the clinician provides medical advice and support for treatment, third sector looks at isolation, social care, benefits etc., but in tandem so care is joined up.

### **Specialist national or regional centres**

- 5.5 Whilst the specialist local service was a popular suggestion with all stakeholder types, a minority of the clinicians also identified the need for one national or several regional centres of excellence. These would carry out research and be staffed by highly trained specialist clinicians supported by other team members - occupational therapists, physiotherapists, and nurses. This centre model was compared to rehabilitation units already in existence, e.g. for brain injuries, and their role would be to provide advice and diagnostic support to local community services through virtual clinics and lead on developing and sharing good practice, trialling new approaches and encouraging consistent use of assessment tools and management approaches.

### **Join existing programmes to pilot specialist service**

- 5.6 One clinician suggested using existing approaches to design and deliver services for other conditions. They identified the Chronic Pain Speciality Network as an example. This has worked to improve access to services and improve health outcomes for those who experience chronic pain and it was developed as part of the [Modernising Patient Pathways Programme](#).

### **Build on existing mainstream services**

- 5.7 A few clinicians considered a specialist clinic approach as resource intensive and felt that the solution should be found within the existing mainstream services.
- 5.8 One approach was to look at the health and social care partnership (HSCP) or NHS board infrastructure and consider how existing services could be extended or developed, building on the strengths of their established systems and processes. This model also builds staff expertise ensuring that the care and treatment is the responsibility of all professionals and therefore they all need to be appropriately educated.
- 5.9 The other suggestion was to introduce a ME/CFS co-ordinator - a named person who had an interest in ME/CFS and dedicated time to co-ordinate and navigate through the care and specialist support that was needed by an individual at different times. In this model that person could be from a variety of backgrounds - social care, the third sector or primary care and the individual with ME/CFS and their GP would discuss and identify who that co-ordinator would be.

### **Applying the learning from the pandemic**

- 5.10 Regardless of how services are developed, stakeholders were unanimous about the huge leap in digital enablement resulting from the pandemic and that this learning had to inform service delivery. Digital/remote appointments provide a real opportunity for ME/CFS care. Pursuing a blended model would reduce or completely end the need to travel and the necessary energy budget needed to do so.
- 5.11 The majority of stakeholders also felt that the attention to, and high profile of, long COVID had helped to acknowledge that “post viral illness is a thing”. As the infrastructure and service provision develops to support people with long COVID, then the potential for synergies should be considered where management of the condition has similarities between ME/CFS.

### **Involvement and recognition of lived experience**

- 5.12 Stakeholders described the disbelief that people with ME/CFS often face when they interact with health and social care services and the huge impact this has on them and what services they go on to access. These stakeholders strongly felt that, if real progress is to be made, future services and treatment for ME/CFS needs to be patient-led. This will require involvement of people with ME/CFS in the design of services and greater recognition of that lived experience so that their voices are heard. To achieve this patient involvement, work would be needed to build the relationship and develop the trust between people with ME/CFS and clinicians.

### **Partnership working with the third sector and clinicians**

- 5.13 Stakeholders of all types recognised the potential benefits of the third sector and clinicians working together to deliver and manage the care of people with ME/CFS. They considered the third sector’s knowledge and lived experience as an ideal complement to clinical recommendations and treatment plans. They could also provide clinicians with a greater understanding of the impact of the condition on people’s lives.
- 5.14 Again, relationship-building was needed to move forward this partnership-working. Stakeholders felt that this collaboration could be encouraged and facilitated at

government level to break down barriers and the perception held by some third sector organisations that “*they were not held in high enough account to merit co-operation*”.

### Education of future and current clinicians

- 5.15 Stakeholders from the ME/CFS community described some of the experiences of accessing the health and social care services. They wanted people with ME/CFS to be able to attend an appointment with a clinician and “*be listened to and believed*”.
- 5.16 Stakeholders felt that an education programme for clinicians, starting with GPs, had to form part of the next stage for moving forward. This programme would raise awareness and understanding so that ME/CFS was believed and understood. Once the basic messages were in place the continued professional development of clinicians would provide them with knowledge of effective management so that they can deliver responsive care, adapting as the severity of ME/CFS changes.
- 5.17 One stakeholder explained “*it is the nature of the GP / clinician to want to 'get to the bottom of it' - but you have to draw the line somewhere and stop testing for everything*” (Clinician). A robust education programme would provide clinicians with the confidence to diagnose ME/CFS and identify an appropriate management and care plan.
- 5.18 An issue for people with ME/CFS and third sector organisations was how, and the extent to which, ME/CFS was taught in medical schools. They called for the better education of medical students. One stakeholder gave an example of St Andrew's University, in partnership with Dundee University, having trialled a project where medical students met patients and discussed care and management. A member of the panel had ME so that cohort of medical students would have a much better awareness and recognition of ME/CFS. Changes to what is currently taught in medical schools would ensure that the next generation of clinicians understand about ME/CFS and how to provide care and support.



## Leadership from the Scottish Government

5.19 The majority of stakeholders identified a lack of priority for supporting people with ME/CFS and delivering appropriate services. They felt that ME/CFS had been underserved for a long time and called on the Scottish Government to set out a more ambitious agenda that would improve the status quo.

5.20 There were many requests as to how this should be done and these centred on:

- Recognising the condition and challenging the disbelief and scepticism that surrounds it. This needs to include an end to providing individuals with views that are not in line with the NICE guideline the opportunities to influence and hinder action;
- Acknowledging the resistance from some Royal Colleges, which is impacting on the response from clinicians, and recognising the commitment from the Royal Colleges who do support the NICE guideline;
- Dedicating resources to invest in services that could pilot new ways of working;
- Placing clear expectations on NHS boards that people with ME/CFS need to be able to access appropriate services and invite proposals as to how they can deliver this in their board area; and
- Encouraging more research, especially around biomarkers, so that there is a better understanding about the condition.

## Summary and recommendations

5.21 There was plenty within the NICE guideline that was welcomed by all stakeholders. In particular, the recognition that it was a medical condition, significant changes in the recommended practice for GET and CBT, and the specific consideration given to severe ME/CFS and children and young people.

5.22 It was felt that applying the guidance in Scotland could be achieved by updating the SGPS. However, on a practical level, the lack of existing services made it difficult for most stakeholders to identify a platform to move things forward. Stakeholders felt that change generally started with education, awareness-raising, political buy-in and ensuring people with ME/CFS are heard.

- 5.23 The education of clinicians in primary and secondary care and within medical schools was seen as key to unlocking the knowledge, understanding and confidence to support people with ME/CFS in both current and future generations of clinicians. The role of the GP in diagnosis and then supporting care and management of the condition was considered pivotal.
- 5.24 There was recognition of the lack of services, with a few exceptions like the ME/CFS nurse in NHS Fife, and the need to develop referral pathways to access specialist provision. Stakeholders had differing views about the structure of specialist services. The majority of stakeholders who advocated for a specialist service saw a ME/CFS practitioner with links into multiple specialist teams as an approach that could be replicated across different areas. A few others considered centres of excellence as another layer to that specialist provision, and a minority of stakeholders thought that existing services could be adapted to meet the needs of people with ME/CFS.
- 5.25 There was also agreement amongst stakeholders that the learning from the pandemic should inform the shape of any service and the potential synergies with long COVID should be explored in that design. The valuable contribution of the third sector should be harnessed to enhance the clinical response to supporting and managing the care of people with ME/CFS and this would require facilitation to build those collaborations. Any service development should also be informed by the voice of people with ME/CFS.

## Recommendations

5.26 To implement the NICE guideline in Scotland, several recommendations were identified and presented below.

- The Scottish Good Practice Statement is updated to reflect the changes within the guideline.
- There is a visible commitment to supporting the key changes within the guideline, to help end the scepticism and disbelief.
- The publication of the revised SGPS is accompanied with promotional activities and awareness raising.
- Consideration is given to the most effective approaches to improve GP knowledge, confidence and understanding of ME/CFS through an appropriate education programme.
- Pilot services are funded in a selection of NHS boards to test the development of specialist services with patient involvement and third sector collaboration embedded in the design.
- The option of including ME/CFS as a specialist network within the Modernising Patient Pathway Programme is explored.
- More research into ME/CFS is actively encouraged within the academic sector.

## Appendix 1 – Results of the online stakeholder survey about ME/CFS NICE guideline

### Introduction

In addition to the interviews and group sessions described in the main report, we also invited people to comment on the NICE guideline and how it might be implemented in Scotland through a short online survey.

Whilst we were able to ensure a representative balance of clinicians, third sector representatives and people with lived experience of ME/CFS in the direct research, this survey was open to anyone – clinicians, people with ME/CFS, third sector organisations – who wanted to contribute. 12 out of the 93 that responded identified themselves as clinicians – the overwhelming majority of responses were from people with lived experience of ME/CFS.

These responses constitute a valuable reflection of lived experience and represent a considerable amount of work on the part of people living with ME/CFS. We appreciate that the energy needed to complete a response is a large investment for anyone living with ME/CFS and the volume of response is testament to how much this community wants to be heard.

Therefore we have presented the results of the survey as a separate piece of work, making clear that it is predominantly the opinions of people living with ME/CFS, or with clinical experience of treating people with ME/CFS.

## Responses

### What did we ask?

The survey posed three open questions.

1. What should the short term focus and priorities for ME/CFS be in Scotland?
2. What practical tools would be useful in shaping the Scottish guidance for implementation of NICE guidance?
3. What should a specialist service for ME/CFS look like? Who should be on a specialist team, and where should the team be located?

### Who took part?

The online survey ran at the same time as the one-to-one interviews with stakeholders and was open for a month. A total of 93 people responded. Most responses were from people living with ME/CFS or caring for someone with ME/CFS.

- 66 people with ME/CFS\*
- 13 parents or carers of people with ME/CFS.
- 12 clinicians
- 3 other respondents\*\*

*\*Two of whom were also clinicians*

*\*\*One research body, one advocate organisation and one person with Long COVID.*

### What did people say?

The themes that emerged from the online survey echoed those of the one-to-one interviews explored in the main report. Rather than repeat what would be essentially the same report we have captured the themes that emerged by:

- illustrating each of the key themes that emerged in response to the first question in the words of those with lived experience, using a selection of direct quotes from the survey findings;
- listing all the practical tools and resources people suggested might help the implementation of the NICE guideline; and
- outlining the elements of an ideal specialised service identified by people with lived experience of ME/CFS.

## Theme 1: Belief

### The basis of all care

Survey respondents noted that belief in ME/CFS needed to be the starting point for any policy or service related to the condition.

- *“The trauma of being disbelieved & undermined & ignored by hcp’s now means I struggle to communicate with hcp’s. I am still ignored. I am still belittled & gas lit. Gas lighting is a huge problem.”*
- *“The FIRST RULE is to believe us when we say that we are ill. BELIEVE us when we say that something will exacerbate our symptoms. BELIEVE us when we say that we are in pain....It is not all in our heads. We are genuinely severely ill and we need help, not hindrance. We should not have to fight for basic care and basic simple consideration.”*
- *“Unfortunately many GPs don’t understand ME or how to treat... Indeed need to get doctors generally to accept it as a true condition.”*
- *“[My suggestions] are about helping the person with ME feel supported, understood and believed which has been sadly missing from a lot of medical interaction for many many years. These are the fundamental first steps in correcting the damage that has been done to people with ME over the years and help them build a bit of faith in the medical community.”*
- *“[The priority should be] emphasising once and for all that ME/CFS is a genuine medical condition ie not psychosomatic... along with recognition that many ME patients have in the past been treated with disbelief, rejection and neglect, and that hopefully this will now cease.”*
- *“There is still in quarters a lack of belief that this is a biologically induced medical condition. Many GPs accept this but many don’t with a devastating impact on sufferers”*

- *“My GP ‘blanks’ me if I mention ME... I feel very offended and unheard that my illness is not understood, let alone recognised in my current GP practice. Nor indeed by staff in local hospitals, in my experience.”*
- *“Training of healthcare professionals is also essential as there is still a belief in some circumstances that it is all in the mind!”*

## Theme 2: Specialists

### Expertise in ME/CFS

Survey respondents stressed the need for specialist services dedicated to ME/CFS, with expert practitioners available to offer diagnosis, after-care and management.

- *“To actually provide some specialist care.  
At present (to the best of my knowledge) there is one specialist nurse in Fife who is entirely inaccessible to the majority of the population of Scotland who have this physical illness.”*
- *“GPs need to be able to support patients to manage their condition by referring to specialists who can treat symptoms.  
Currently it is extremely difficult, often impossible, to secure a referral which means treatment is largely non-existent and GPs don’t know what to do with patients.”*
- *“We do not have ME specialists in Scotland and we need them badly. We also don’t have care plans, as there are no specialists to write them.  
We need actual ME specialists who fully understand the condition, are up to date on the latest research, can support and treat people with ME, can prescribe medication, can provide supporting evidence to the DWP, housing associations, social work, etc.”*
- *“The specialist team should understand and be educated on all facets of ME. Many doctors/specialists still see ME patients as “heart sink patients.”*

*If a specialist does not have biomedical training in ME it is pointless being referred to that service. If a specialist is ill informed then they will do more harm than good"*

- *"Specialist services that we can be referred to for help rather than feeling like we have nowhere to go.*

*We are left to try and manage and figure out such a complex and terribly debilitating illness alone apart from the information we can get online from ME/CFS charities."*

- *"Partnerships – formal agreements for treatment & support needs to be overseen by a specialist ME practitioner.*

*I mean nearly a decade after being diagnosed with ME, I still have not seen a neurologist."*

- *"We need to set up specialist teams for people with ME and get many more specialist nurses for regular appointments.*

*I think I read recently that there are 33 specialist nurses for MS (which, don't get me wrong, isn't enough either) but we only have 1."*

- *"As I've no care plan (who would write one when there are no ME specialists?), if I had to go into hospital suddenly, the hospital would have no way of understanding my needs."*

- *"I can't access [medication] for ME as there are no ME specialists, and other specialists won't prescribe it as they are not ME specialists."*

- *"In an ideal world people with ME/CFS would be assigned a support nurse (similar to a breast cancer nurse) to provide emotional and practical support.*

*A named individual that you could call between appointments if you have concerns or queries."*



## Theme 3: Education

### Embedding knowledge in the workforce

Survey respondents outlined the importance of training and education to 'effect a sea-change' in attitude around ME/CFS and increase confidence in diagnosis and management.

- *“Inform medical professionals and include information about ME and NICE guideline in medical training. There is nothing in medical curriculum about ME.”*
- *“Roll out an educational programme for ALL health professionals regarding the symptoms of and appropriate support for ME/CFS patients. Include it in the training programmes of new staff but also it needs to be compulsory CPD for existing staff. This is the most important first step. At the moment knowledge is so limited by health professionals (due to lack of training), that they do not understand the challenges we face.”*
- *“Education of healthcare professionals is the most crucial component in creating a shift in culture where people are interested in treating ME.”*
- *“Mandatory education of doctors, nurses and physios on what ME is. We can't hope for proper implementation until the previous misinformation has been dealt with.”*
- *“Training, training and more training, for GPs especially, but also for hospital staff, to increase knowledge, communicate the changes and effect change in both behaviour and beliefs.”*
- *“It would be a bonus if there was education of the general public as there has been so much misinformation up to now. Not to mention education of the DWP who seem to have a very poor understanding of the condition. Hospital wards need to be aware of the extra hazards that having ME pose and stays made as bearable as possible.”*
- *“Education/awareness-raising specifically for health care providers. It needs to be part of every medical courses teaching. This is a massive task but it is vital as there is so*

*much misinformation around ME, such dangerous advice and information being given to sufferers and such a lack of understanding of ME and how it affects people.”*

- *“Wider education for those dealing with people with CFS. My own experience with an insurer and the Ombudsman did not make me feel either organisation had a culture of knowledge or understanding.”*
- *“Education of GP and primary care providers more widely. While the guideline is a landmark moment for people with ME, it will still amount to nothing if clinicians aren’t aware of it and gain a basic understanding of ME – which is currently lacking. A programme of mandatory training is needed to bring people up to speed.”*
- *“Educating primary health care providers to speed up timely diagnosis and making sure support services aren’t a postcode lottery by ensuring each health board is able to provide adequate, timely and considered care and treatment plans. Perhaps also ensuring the ME is a mandatory part of medical education.”*
- *“I also think anyone in training to become a medical professional, social worker, etc., should be taught properly about ME as part of their education. I know this is a big task, but it’s necessary as there has been so much misinformation about ME, and it has been a neglected illness for decades.”*

## Theme 4: Management

### Helping people self-manage

Feedback emphasised the importance of early advice to pace, rest and work within an individual energy budget.

- *“Make it easy for everyone to understand this condition, what pacing is, what operating within energy envelope means, and why overdoing it, especially in terms of exercise can be harmful. Point out helpful literature that already exists.”*
- *“Advice and support on pacing. No incremental increases. Through understanding of PEM/PESE.”*
- *“Support and correct advice such as convalescing and pacing.”*
- *“As time passes, pacing is vital, not led exercise.”*
- *“Giving people personalised advice about managing their symptoms – this did not happen to me. Also advise them not to use more energy than they perceive they have – they should manage their daily activities and not ‘push through’ their symptoms.”*
- *“Healthcare professionals need to prescribe rest & understand the meaning of post exertional exhaustion.”*
- *“Issuing clear diagnostic criteria for GPs including information on PEM – this should include example questions for patients or validated scoring systems such as the DePaul Symptom questionnaire to improve diagnosis. Early access to advice: developing patient accessible information on pacing which can be used while awaiting specialist rehab clinics.”*
- *“Patients must be urged to rest and pace themselves, even on good days. This needs to be laid out with examples. Forcing through and plucky spirit only leads to worsening of the illness.”*
- *“Evidence suggests that there is a greater chance of recovery or a reduction in severity of symptoms, if rest & pacing is introduced immediately. Therefore GP knowledge about appropriate patient self help is essential.”*
- *“Define proper “STOP, REST, PACE” protocols and promote support for patients to find their baseline and keep within their energy envelope.”*

## Theme 5: GET and CBT

### Changes around GET and CBT

Survey respondents highlighted the recommendations against using GET and how important it now is that this is removed from practice. They welcomed that change in CBT, now positioned as an aid in managing life with a chronic illness, not curative.

- *“Stop offering any kind of exercise therapy. Whatever you are calling it, GET or something else, if it involves increasing exercise the evidence says this needs to stop. If it’s based on the idea we are deconditioned it is harmful, cruel. It put me in a wheelchair and left me bed bound for a whole year. At which point I was abandoned by the health service as I was now too severe.”*
- *“Abolishing any previous recommendations for GET and CBT and advising a regime of activity management best described as “Pacing”.”*
- *“GET ruined my life (as it does for most ME/CFS patients, something finally acknowledged by the new guidance). This urgently needs to stop being foisted onto unsuspecting patients.”*
- *“It is vital that any member of any specialist service, including Doctors, nurses, therapists etc., have a good understanding of Post Exertional Symptom Exacerbation and understand why GET can cause damage.”*
- *“ME remains taught under Mental Health. If this isn’t rectified nothing will change. We will just remain to generate further decades of ill-informed doctors prescribing inappropriate and harmful ‘treatments’. The SGPS must be updated to reflect that GET & CBT are not treatments or a cure for ME”*
- *“There is an urgent need to communicate to all GPs, specialist nurses and any specialist services that still exist in Scotland that the evidence of effectiveness GET and CBT is of “poor” and “very poor” quality and that these interventions should not be promoted to or thrust upon patients.”*
- *“Graded exercise therapy in all its guises should be immediately banned as they are dangerous. Patients should be reminded to keep inside their energy envelope.”*

- *“I cannot tell you how many people’s lives I have been able to positively change simply by guiding them to the right resources and by giving them advice on activity management. Please stop harming patients by sending them to services that are only trained in administering GET and CBT.”*
- *“Of particular importance is an understanding of PEM/PESE. The sooner folk are made aware of this along with early diagnosis maybe fewer folk will deteriorate significantly thru ignorance, which happened to me. We need to lose the fear that ME folk have that they will be forced in to GET and CBT.”*
- *“Ensuring GET is not offered to any patient in Scotland and that clinicians are aware that the guideline explicitly states it shouldn’t be recommended. While it is still being offered in Scotland, which it currently is, there is huge risk to patients and so this needs to be acted on urgently.”*
- *“Disseminate the revised guidance to ALL clinicians who may have patients with ME: GPs, nurses, hospital doctors, physiotherapists and OTs in hospital and community. Advise Royal Colleges to inform members that GET is now contraindicated and that CBT is only advised for symptom management. This will involve updating training including CPS modules.”*

## **Practical tools**

### **Aiding the implementation of NICE in Scotland**

Survey respondents suggested a significant number of resources to help shape the implementation of the NICE guideline in Scotland, and, more widely, to use in general education about ME/CFS. These resources can be supplied on request.

## Specialist service

### A specialist service for ME/CFS

The sections below summarise the feedback from participants of the survey about what a specialised service for ME/CFS could look like, where it should sit, and who should be part of the service.

### Ideal ME/CFS Specialist Service

#### Values

- ✓ Committed: based on belief and acceptance of ME/CFS as a complex multi-system condition.
- ✓ Accessible: model to include home visits, local appointments, adapted environments and virtual clinics.
- ✓ Consistent; offering long-term support – not a ‘discharge and abandon’ model.
- ✓ Co-produced: patient-centred care built around individuals recognising that ‘one size does not fit all’.

#### Services

- ✓ Able to confirm diagnosis and perform exclusionary tests for other possible conditions.
- ✓ Would offer annual reviews to monitor progress of condition as well as ‘drop-ins’ responsive to flare-ups and changes in health.
- ✓ Hub for information and support on management of ME/CFS, with expert knowledge of energy management and pacing principles.
- ✓ Able to signpost to third sector and other key support services.

#### Location

**Local:** offered in the community to make the service accessible.

**Regional:** a fair distribution of clinics across the country, or the option to go to clinics in other health boards (perhaps online).

**National:** possible central hub (not necessarily a physical hub) of expertise that can be accessed from community provision.

## Structure

- ✓ Overseen by an ME/CFS consultant / occupational therapist / specialist nurse / GP – the “background is less important than the experience of ME and open-mindedness”. If the service was deliverable by a GP / nurse then access to a specialist consultant should be available.
- ✓ A linchpin service that can access and navigate to a range of other specialisms to support the multi-system nature of the condition.
- ✓ Specialisms mentioned in feedback include: gastroenterology, physiotherapy, cardiology, neurology, dietetics, occupational therapy, orthopaedics, rheumatology, pharmacology, immunology, toxicology, sleep specialists, pain management and endocrinology.

## Peer Support

- ✓ Partnerships with the third sector to provide peer support and mentoring.
- ✓ Services would include emotional support, insight into symptom management and coping strategies for living with a chronic condition.
- ✓ Feedback also highlighted the need for support, advice and information for family and carers of people with ME/CFS.

## Counselling

- ✓ Provision of, or access to, a counselling service or psychological input.
- ✓ This support would be to help people live with the secondary impacts of a chronic illness (depression, isolation, relationship breakdown, inability to work), not as a ‘curative’ approach.

## Practical Help

- ✓ Inclusion of, or access to, benefit advisors and support staff to help with financial and practical support.
- ✓ This could include benefits, home adaptations, access to carers and mobility assistance.
- ✓ Advocacy services to act for people living with ME/CFS when dealing with employers, benefits agencies and educational providers.



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