



# Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Services in Scotland: Findings from an analysis of surveys issued to NHS Boards in Autumn 2022



**HEALTH AND SOCIAL CARE**

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## 1. Abbreviations

ACRT	Active Referral Clinical Triage
AHP	Allied Health Professional
CBT	Cognitive Behavioural Therapy
CCD	Case Consensus Definition
CFS	Chronic Fatigue Syndrome
CIC	NHS Centre for Integrative Care (NHS Greater Glasgow and Clyde)
CMHT	Community Mental Health Team
COPM	Canadian Occupational Performance Measure
Cou	Counsellor
CP	Clinical Psychologist
CT	Computed Tomography (medical imaging technique)
DI	Dietician
FI	Fitness Instructor
GET	Graded Exercise Therapy
GP	General Practitioner
LTC	Long-term Conditions
MDT	Multi-disciplinary Team
ME	Myalgic Encephalomyelitis
MFI	Management of Fatigue Index
MHN	Mental Health Nurse
MRI	Magnetic resonance imaging (medical imaging technique)
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OT	Occupational Therapy
PT	Physiotherapy

SF36	Short Form (36) Health Survey
SWEMWBS	Short Warwick Edinburgh Mental Wellbeing Scale
TI	NHS Technical Instructor/Support worker
Vol	Volunteer

## 2. Executive Summary

This report analyses survey responses from ten NHS Health Boards in Scotland to understand what ME/CFS services are being provided and how services are embedding the updated National Institute for Health and Care Excellence (NICE) guidance on the diagnosis and treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). The aims of this report are to understand the barriers and opportunities to implementing the updated NICE guidelines and how NHS Boards can be best supported to create ME/CFS specific care in the future.

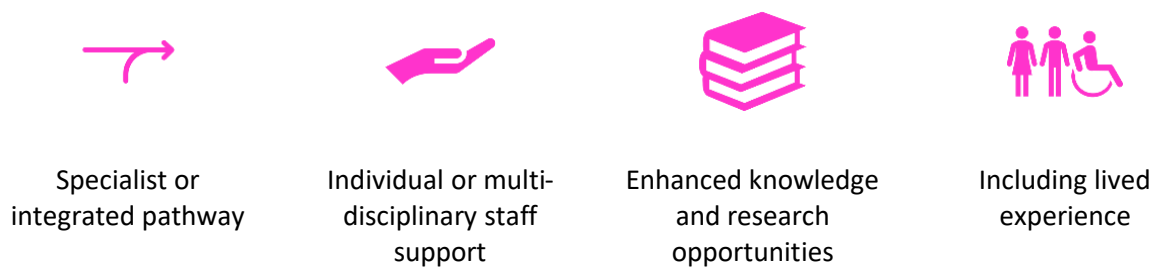
The survey analysed in this report was commissioned by the Scottish Government in response to the growing call for specialist ME/CFS services in Scotland (since 2002) and after the recent (2021) NICE ME/CFS treatment guidelines were updated. This report is to be considered alongside the publication of a stakeholder [consultation](#) review regarding the changed guidelines and the potential implications for support in Scotland.

The results showed that, overall, provision of care across the ten NHS Boards was varied from generalist to specialist support by staff trained in ME/CFS. More than half of the NHS Boards that responded to this survey did not have specific ME/CFS referral pathways, and only one had a specifically trained ME/CFS staff nurse. Many people with ME/CFS were referred onto long-term condition management pathways for other illnesses, such as Long COVID or chronic pain, as these often provided suitable support and management options for people who experience conditions with similar symptoms to ME/CFS. Most NHS Board responses highlighted that there is an awareness of the updated NICE guidelines, specifically around Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT). Despite this awareness, implementation of the updated guidelines as a whole was varied due to limited resources, lack of specific pathways or trained ME/CFS staff to support implementation, referrals of people with ME/CFS to third sector organisations or other long term condition management pathways, and increased caseloads due to the impact of COVID-19. The results of this survey highlight the willingness of NHS Boards to develop ME/CFS specific treatment and support, yet there is an acknowledgement that potential barriers will need to be addressed first.

Through the analysis of this survey data, the key perceived barriers to implementing the new NICE guidelines or developing an ME/CFS specific pathway included challenging outdated views and application of ME/CFS knowledge. Both factors would potentially impact the variation of support across Scotland. In addition, NHS Boards highlighted issues around funding and resources specific to local service delivery. The responses highlighted the value of a multi-disciplinary team for supporting people with ME/CFS and the potential benefits of integrating support into other long-term condition management pathways. However, perhaps due to the lack of one specialist ME/CFS pathway within most NHS Boards, patient feedback or outcomes were more challenging to monitor or obtain.

Four key findings were identified from the results of this survey, highlighting potential areas requiring further research or understanding.

Figure 1: Key findings identified from the results of this survey.



The results highlight a need to understand clinical, lived experience, and stakeholder perspectives on whether ME/CFS services should be delivered through a specialist pathway or support should be integrated into pathways for the management or treatment of other long-term conditions. In addition, whether this support should be delivered by an individual staff member or via a multi-disciplinary team. The results of this survey combined with the stakeholder consultation review show support for establishing further education and research opportunities in Scotland for people with ME/CFS. Finally, delivery of pathways and education opportunities should be created with consideration and involvement of those who live with and are impacted by ME/CFS to ensure that the design and development of ME/CFS care in Scotland is suited to meet the needs of those with this condition.

### 3. Introduction

Myalgic Encephalomyelitis (ME), also referred to as Chronic Fatigue Syndrome (CFS), is a [long-term, chronic condition with a range of symptoms, the most common of which is extreme tiredness](#). Other symptoms may include pain, brain fog, and sensory overwhelm as well as [sleep disturbances and post-exertional malaise after activity](#). ME/CFS is more common in women, usually developing between mid-20s to 40s, although it can affect anyone, including children. The causes of ME/CFS are largely unknown, however it has been suggested that viral or bacterial infections, immune system regulation, hormonal imbalance, or family genetics may be triggers. Due to the invisibility of this condition, ME/CFS is often considered a [hidden disability](#). Treatment is usually patient-centred depending on symptoms and can include [energy management techniques, medicine, and lifestyle changes](#).

The [2002 Scotland's Chief Medical Officer Short Life Working Group](#) made recommendations to establish ME/CFS specific services that had not yet been actualised. A further 26 recommendations were then made in 2010 by the [Scottish Health Network assessment report](#) to ensure better support for people with ME/CFS. In 2020, the [ME-CFS healthcare needs assessment: Briefing](#) (published by the Scottish Public Health Network) reemphasised the previous recommendations and acknowledged ME/CFS as a neurological condition, advising that the delivery of recommendations should take account of the Scottish Government's [Neurological Care and Support Framework](#).

In October 2021, the [National Institute for Health and Care Excellence \(NICE\) updated their clinical guidance](#) for diagnosing and managing ME/CFS based on evidence reviewed before the COVID-19 pandemic. The guidelines are aimed at health and social care professionals, commissioners, people living with ME/CFS, their carers/families, and the general public. The new guidelines provide recommendations on symptom management, specialist and multi-disciplinary care, frequency and structure of review, and care for people with severe or very severe ME/CFS as well as children and young people. The changes made in the recommendations by NICE include the removal of Graded Exercise Therapy (GET) as a suggested treatment and a repurposing of Cognitive Behavioural Therapy

(CBT) to become a support rather than cure. Across third sector ME/CFS organisations and those with lived experience, the changes have been welcomed. Many feel that previously these [therapies undermined their lived experience with this condition](#) and the updated guidance began to address the [negative and stigmatising interactions amongst those clinicians](#) who are less willing to treat ME/CFS as a recognised neurological condition. However, [some clinical and other professional groups have disputed the new NICE guidelines](#), suggesting that the new recommendations regarding GET and CBT undermine the positive impacts that these types of intervention may potentially have for people with ME/CFS.

The Scottish Government commissioned a review in December 2021, published in July 2022, outlining [stakeholders' views and priorities](#) for implementing the updated NICE guideline in Scotland as well as highlighting areas for improvement in established support pathways for people with ME/CFS. Clinicians, third sector ME/CFS organisations, and people living with ME/CFS were asked about their views on the changes made in the NICE guidelines. Among the overall positive reflections about the NICE guidelines in this review, many believed that the removal of GET was a “massive step forward” for people living with ME/CFS and that the repurposing of CBT as a support rather than cure was welcome. In addition, many endorsed the recognition of differences between severities of ME/CFS as well as children and young people living with this condition. Overall, stakeholders [“welcomed the guidance’s improved diagnostic criteria and aspirations for specialist care.”](#)

The National Clinical Director and Interim Director [wrote to NHS Boards](#) on 14 June 2022 to raise awareness of key changes in practice within the updated NICE guidelines on managing and diagnosing ME/CFS. Subsequently, the former Cabinet Secretary for Health & Social care met with MEAction on 21 September 2022 to discuss ME/CFS care in Scotland and awareness of the condition amongst clinicians. The survey analysed in this report emerged from an action point from the meeting: to map services for ME/CFS, to identify services or pathways which work well, and consider how these might be replicated.



This survey was commissioned on 3 October 2022 and a Scottish Parliamentary debate, held on 3 February 2023, noted the intention to publish this analysis.

This report analyses survey responses from ten NHS Health Boards in Scotland to understand how services are embedding the updated NICE ME/CFS treatment and support guidelines. In particular, this report seeks to understand:

- current service provision,
- awareness of the updated NICE guidelines and how they have been implemented so far,
- barriers and opportunities to implementing the guidelines,
- where support is needed to embed the updated guidelines.

## 4. Methodology

A scoping, qualitative survey was issued to Medical Directors in 14 territorial NHS Boards on 3 October 2022. The deadline for returns was extended to 30 November 2022 to maximise the response rate. Eleven responses were returned from ten NHS Boards. However, NHS Dumfries and Galloway Allied Health Professionals and the Clinical Health Psychology Service filled out two separate responses; so, in some instances, when referring to the overall position of this NHS Board, these two responses were combined. Responses from the ten participating NHS Boards are set out below in order to map health service provision across Scotland as at Autumn 2022.

NHS Boards were asked questions about local services available for people with ME/CFS in their area, implementation of the NICE guidelines, future plans for providing ME/CFS services, and any additional information they would like to share. The full questionnaire can be found in [Appendix One](#).

Scottish Government social researchers analysed the survey responses and authored this report. The free-text responses were analysed using a qualitative thematic approach in Microsoft Excel. Excel was chosen as preferred method due to the manageable number of responses received. The information was coded to match emerging themes and then grouped together for the discussion of results, below.

### 4.1 Limitations

The returns provided by NHS Boards who participated in this survey provide a snapshot of services for people with ME/CFS that were in place or planned as at Autumn 2022. The analysis therefore does not capture any developments in services or support that have occurred since October 2022.

As it was optional to take part in this survey, the results do not provide a complete picture of the support and services offered to people with ME/CFS throughout Scotland. Some NHS Boards, for example NHS Lothian, did not respond despite having a specific ME/CFS support pathway (as reflected in a [mapping of ME/CFS](#)

[services](#) in the UK by the British Association of Clinicians in ME/CFS). In addition, as referenced in the results section below, not all NHS Health Boards that responded to this survey answered all questions.

It must also be noted that responses or non-responses may have been impacted by the resources available to complete the survey given the ongoing and consistent nature of the pressure and demand facing NHS services in 2022.

## 5. Results

This section summarises the results of the survey based on the responses of ten NHS Health Boards. Where appropriate, the two responses from NHS Dumfries and Galloway are considered separately.

### 5.1 NHS Board pathway from referral to support by service

Overall, ME/CFS support services were delivered in a variety of ways: by generalist services within primary and secondary care, specialist staff with ME/CFS training, services that provided support for long-term conditions with similar symptoms (such as Long COVID or chronic pain), or third sector organisations.

Table 1 shows, in alphabetical order, where NHS Boards receive their ME/CFS referrals from. Table 2 shows what primary support is offered to people with ME/CFS by each NHS Board. Table 3 shows what secondary support is offered by NHS Boards if there is no specialist service for ME/CFS or similar long-term condition management service available.

Table 1: Where NHS Boards receive their ME/CFS referrals from

NHS Board	Referrals from
NHS Borders	No response
NHS Dumfries and Galloway (Allied Health Professionals)	General and specialist community rehabilitation
NHS Dumfries and Galloway (Clinical Health Psychologists)	General Practitioner (GP), Secondary Care Nursing, Secondary Care Medical, Dietician, Health Visitor, Neurology, Pain Clinic, Physiotherapy, Occupation Therapy, Psychiatry, Community Mental Health Team.
NHS Fife	GPs and Secondary Care Consultants
NHS Forth Valley	GPs
NHS Greater Glasgow and Clyde	GPs and Secondary Care Consultants
NHS Lanarkshire	No response
NHS Orkney	No response
NHS Shetland	"usual route"
NHS Tayside	No response
NHS Western Isles	GP

Table 2: What primary support is offered to people with ME/CFS by each NHS Board

NHS Board	ME/CFS primary support offered
NHS Borders	No specialist or related ME/CFS service
NHS Dumfries and Galloway (Allied Health Professionals)	No specialist or related ME/CFS service
NHS Dumfries and Galloway (Clinical Health Psychologists)	Clinical Health Psychology Service (only when ME/CFS is a major factor in a person's psychological distress)
NHS Fife	Clinical Nurse Specialist Service in ME/CFS (primary care)
NHS Forth Valley	No specialist or related ME/CFS service
NHS Greater Glasgow and Clyde	NHS Centre for Integrative Care (CIC) <sup>1</sup>
NHS Lanarkshire	No specialist or related ME/CFS service
NHS Orkney	Funded Physiotherapist for Long COVID/ME patients (capacity limited)
NHS Shetland	No specialist or related ME/CFS service
NHS Tayside	No specialist or related ME/CFS service
NHS Western Isles	No specialist or related ME/CFS service

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<sup>1</sup> Establishing an Occupational Therapist within the CIC that will support patients with ME/CFS in the future.

Table 3: What secondary support is offered by NHS Boards if there is no specialist service for ME/CFS or similar long-term condition management service available

NHS Board	ME/CFS secondary support offered
NHS Borders	Most appropriate clinical services (Physiotherapy, Occupational Therapy, Pain Management Service, GPs with special interest in ME/CFS) and third sector support (Live Borders for physical and mental wellbeing)
NHS Dumfries and Galloway (Allied Health Professionals)	Regional general and specialist Community Rehabilitation, Occupational Therapy, Physiotherapy, Nursing, Dietetics, Psychology Services, and third sector services such as Active Communities and Leisure Facilities (although not specific ME/CFS services)
NHS Dumfries and Galloway (Clinical Health Psychologists)	Occupational Therapy, Physiotherapy, Silvercloud, Pain Clinic, Health & Wellbeing Team, Social Work, Community Mental Health Team, Psychiatry
NHS Fife	Third sector agencies (Action for ME, ME Association, Pain Association Scotland) and a range of clinical services based on individual need: Psychology, Neurology, Pain Clinic, Gastroenterology, Psychiatry, Medicine, Physiotherapy, Social Work, Occupational Therapy
NHS Forth Valley	Primary Care and Secondary Care (specific areas such as Paediatrics and Physiotherapy)

NHS Greater Glasgow and Clyde	In-house CIC programmes <sup>2</sup> , live Active, Online yoga, Orthotics, Westmarc Wheelchair Services, Community Rehabilitation, Chaplaincy Listening Service, Community Connectors – Social Prescription, Musculo-skeletal Physiotherapists, Occupational Health, Online resources (ALISS, Moving into Balance, IMPARTS), Andrew Weil Centre for Integrative Medicine, third sector (Alliance, Citizens Advice, Cycling for Disabled, Macmillan Cancer Support)
NHS Lanarkshire	Primary Care (Occupational Therapists) and Secondary Care (specialist referrals to Paediatrics), COVID Rehabilitation Pathway, Community Stroke and Neurological Pathway, Community Brain Injury Pathway (Allied Health Professional and Psychology staff), Rheumatology Occupational Therapy, and Physiotherapy
NHS Orkney	Communication between physiotherapist and physicians
NHS Shetland	Support from GPs, Allied Nurse Practitioners, Physiotherapy, Community Mental Health Team (Psychologists), Occupational Therapists, and third sector “Mind your Head” for mental health support
NHS Tayside	Secondary Care Services (Rheumatology, Neurology, Respiratory, Psychiatry, and Paediatrics)
NHS Western Isles	Support of symptoms from Primary Care (GP, Physiotherapy, Occupational Therapy, Specialised Respiratory Assessment and Management service), online resources from the NHS Western Isles Central Coordinator, and third sector organisations such as Pain Association

The above tables show that only one responding service had a specific ME/CFS pathway for patients in their health board (*NHS Fife*) and three other boards cited staff trained in ME/CFS support as the primary service offered to people with

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<sup>2</sup> Supported Self-Management/Psychoeducation Group Programmes, Physio Movement based education programmes, Individual therapies, Holistic Day Service, Complimentary Therapy, Acupuncture



ME/CFS (*NHS Dumfries and Galloway, NHS Greater Glasgow and Clyde, NHS Orkney*). All other NHS Boards who responded to the survey reported that ME/CFS patients were managed through primary or secondary care, third sector organisations, or received support that was integrated with other long-term condition management pathways. Some practitioners in these pathways were reported to be trained in treating and managing symptoms similar to the approaches advocated in the new ME/CFS clinical guidance.

The responses show that people with ME/CFS are identified through Case Consensus Definition (CCD) or Canadian diagnostic criteria (*NHS Fife*), symptomatic assessments (bloods and further investigation as required) (*NHS Borders*), NICE NG206 guidelines (*NHS Shetland*), by a senior doctor through Active Referral Clinical Triage (ACRT) (*NHS Greater Glasgow and Clyde*), GP (*NHS Western Isles*), or other primary care services (*NHS Lanarkshire*). One NHS Board highlighted that ME/CFS may co-exist with other long-term conditions and co-morbidities making referrals complex. Thus, ME/CFS may emerge as a main concern after assessing multiple symptoms and ruling out other conditions (*NHS Greater Glasgow and Clyde, NHS Tayside, and NHS Lanarkshire*). NHS Shetland responded that not all referrals for people with ME/CFS are accepted and other times they need to be referred to NHS Grampian. Four NHS Boards did not mention whether people with ME/CFS were self-referring for support or were referred from other healthcare areas or services (*NHS Borders, NHS Lanarkshire, NHS Orkney, NHS Tayside*).

## 5.2 How support is being delivered

Table 4 shows the nine NHS Boards that gave details about how support was being delivered. Some NHS Boards provided a significant range of options in terms of mode of delivery, while others provided a more limited range of options.

Table 4: How support is being delivered by NHS Boards

NHS Board	Face to Face	Phone	Email	Video	Web Forum	Web Delivery
NHS Borders	X	X		X		
NHS Dumfries and Galloway	X	X	X	X		X
NHS Fife	X	X	X	X	X	

NHS Forth Valley	X	X				
NHS Greater Glasgow and Clyde	X	X	X	X		
NHS Lanarkshire	X	X		X		X
NHS Orkney	X					
NHS Shetland	X	X		X		
NHS Tayside	No response to question					
NHS Western Isles	X	X		X	X	X

The responses showed that all NHS Boards who responded to this question (n=9, 100%) provided face-to-face support. Remote support through phone (n=8, 89%) and video (n=7, 78%) were the next most common delivery modes. A third of NHS Boards that responded said that they provided support via email (n=3, 33%) and/or via web delivery (n=3, 33%). Web forum was the least common mode (n=2, 22%).

### 5.3 Who is delivering support

Table 5 shows which staff members support people with ME/CFS for each NHS Health Board. The results show that Occupational Therapists, Physiotherapists and Nurses comprised the roles most commonly providing support, followed by doctors (including GPs) and Clinical Psychologists. A multi-disciplinary approach was evident in some NHS Boards with a range of practitioners providing support, while other NHS Boards involved a narrower range of staff.

Table 5: Which staff member is supporting people with ME/CFS<sup>3</sup>

	OT	PT	Nur	Doc	CP	Di	MHN	Cou	TI	FI	Vol	Other
NHS Borders	X	X	X	X	X					X		
NHS Dumfries and Galloway	X	X	X	X	X				X			* #
NHS Fife			X								X	
NHS Forth Valley	X	X	X	X								*
NHS Greater Glasgow and Clyde	X	X	X	X								~
NHS Lanarkshire	X	X	X	X	X	X	X	X	X	X	X	*
NHS Orkney		X										

<sup>3</sup> Abbreviations: OT (Occupational Therapist), PT (Physiotherapy), Nur (Nurse), Doc (Doctor), CP (Clinical Psychology), Di (Dietician), MHN (Mental Health Nurse), Cou (Counsellor), TI (NHS Technical Instructor/Support Worker), FI (Fitness Instructor (Local Authority/Move More etc), Vol (Volunteer/Buddy/Peer Support), Other. Full list of abbreviations can be found at the beginning of this report.

NHS Shetland	X	X	X		X		X	X				
NHS Tayside												*
NHS Western Isles	X	X	X	X	X	X	X					*

*Response to other:*

\* Any services requested by primary care can be accessed

~ Art Therapist (trainee students), Complementary Therapist, Acupuncturist (Clinical Nurse Specialist), Bowen Therapist (Doctor), Counselling Psychologist (trainee students), Music Therapy (occasional trainee student)

# Counselling Psychologist & Specialist Psychological Therapist

#### 5.4 Awareness and implementation of NICE guideline changes

NHS Boards were asked about their awareness and implementation of the changes to the NICE guidelines regarding ME/CFS management, specifically around the advice on GET and CBT.

Tables 6 and 7 show the majority of the eight NHS Boards who responded to this question were very aware of updated NICE guidelines on GET (n=6, 75%) and CBT (n=5, 63%), or at least moderately aware of guidelines on GET (n=7, 88%) and CBT (n=8, 100%).

Table 6: How aware NHS Boards are about the NICE guideline changes about Graded Exercise Therapy (GET)

	GET				
	Not aware	Slightly aware	Somewhat aware	Moderately aware	Very aware
NHS Borders					X
NHS Dumfries and Galloway				X <sup>4</sup>	X
NHS Fife					X
NHS Forth Valley					X
NHS Greater Glasgow and Clyde					X
NHS Lanarkshire				X	
NHS Orkney	No response				
NHS Shetland					X
NHS Tayside		X			
NHS Western Isles	No response				

<sup>4</sup> There were differences between the two NHS Dumfries and Galloway responses: For the purposes of this report, the results written above have used the highest level of awareness – very aware - from the Clinical Psychology response.

Table 7: How aware NHS Boards are about the NICE guideline changes about Cognitive Behavioural Therapy (CBT)

	CBT				
	Not aware	Slightly aware	Somewhat aware	Moderately aware	Very aware
NHS Borders				X	
NHS Dumfries and Galloway			X		X
NHS Fife					X
NHS Forth Valley					X
NHS Greater Glasgow and Clyde					X
NHS Lanarkshire				X	
NHS Orkney	No response				
NHS Shetland					X
NHS Tayside				X	
NHS Western Isles	No response				

Despite the awareness of the guidance changes reported across the majority of the NHS Boards who responded, formal implementation of the wider ME/CFS guidelines was varied.

NHS Fife, which has a dedicated service for adults with ME/CFS, reported that they had implemented the changes to their services, continue to train staff, and liaise with secondary, community, and other NHS Boards seeking advice. However, this was not the case for children and young people as there is no dedicated ME/CFS service for this group, who are referred to a general care pathway instead.

NHS Greater Glasgow and Clyde, which supports symptoms of ME/CFS through their Centre for Integrative Care (CIC), responded that it supported ME/CFS patients through pacing rather than GET and that CBT was often included in individual

treatment plans as a form of person-centred support rather than a cure. Despite not having a specific ME/CFS service, training was provided for Allied Health Professionals and Physiotherapists (Band 5), who have become a specialist resource for other health care professionals interacting or treating people with ME/CFS. This includes the support offered to people with ME/CFS through the long-term condition management programmes offered by CIC. This Board also reported utilising patient and carer feedback to inform person-centred care programmes, such as the Holistic Day Service Programme.

NHS Lanarkshire reported that it incorporated the updated guidelines into other long-term condition management services where symptoms may overlap (such as a Long COVID patient workbook, a Fibromyalgia pathway and generic fatigue management programme). This NHS Board also highlighted that there was awareness training around the guidelines for the primary care Occupational Therapy team.

NHS Borders and NHS Dumfries and Galloway (AHPs) responded that staff engaging with ME/CFS patients were aware of the guideline changes and will continue to monitor the way in which support is given. However, NHS Dumfries and Galloway highlighted that awareness and communication of guideline changes varied across the region and that this is something an area of focus for them.

Some NHS Boards responded that there was a lack of implementation because there was not a specific service within which they can implement changes, and that some NHS Boards reported primary or secondary care referring individuals to third sector or community options. In addition, lack of dedicated funding, no training or service delivery capacity, and increased caseloads of long-term condition management due to the impact of COVID-19 were cited as barriers to implementing the guidelines. Two NHS Boards reported minimal progress with implementing the NICE guidelines, however this may be reflective of both Boards lacking a specific referral pathway for people with ME/CFS.

## 5.5 Barriers and opportunities to implementing updated NICE guidelines

Table 8 shows the grouped themes across the seven NHS Boards who provided responses when asked about potential barriers and opportunities around implementing the new NICE guidelines.

Table 8: Emerging themes from responses about the barriers and opportunities around implementing updated NICE guidelines

Barriers	Opportunities
Financial and resource constraints	Improving treatment and symptom management through specific ME/CFS resources
Challenging 'traditional' views about ME/CFS management and treatment	Improving outcomes for ME/CFS patients and for patients with other long-term conditions
Application of the guidelines in Scotland might be slow to develop	Education of staff (increased awareness about ME/CFS through training and development, ability to recognise symptoms early)
General lack of knowledge around ME/CFS and recognising symptoms early	Utilising MDT staff to support ME/CFS patients and treatment management
Existing patient barriers to accessing support – lifestyle, stigma, lack of awareness to report symptoms	Patient engagement (raising awareness of symptoms and empowerment through self-management of their condition)
	Strengthen and create links to ME/CFS and long-term condition support pathways and stakeholders (for example, third sector organisations and public health strategies)

Half of the NHS Boards that responded reflected that opportunities in the new NICE guidelines would be contingent on increased funding and resources increasing. Four NHS Boards chose not to respond to the questions about barriers and opportunities.

## 5.6 Plans for specialist ME/CFS services

When asked if they had plans to develop specialist ME/CFS services in the future, out of the 11 responses, two NHS Boards said that they already had services in place, one NHS Board said that they had plans to link in with Long COVID support pathways, five said that they did not have plans to develop specialist services for ME/CFS in their area, and three NHS Boards chose not to respond to this question<sup>5</sup>.

NHS Fife and NHS Greater Glasgow and Clyde responded that they already have services in place, however staff in these NHS Boards delivering support are not part of an ME/CFS specific service. The services for patients with ME/CFS in NHS Fife are led by a nurse in a community setting who also treats other long-term conditions. However, NHS Fife also highlighted that this was a single-person post with limited capacity, with support needing to be expanded to other MDT members to “reduce waiting times and better meet demands.” NHS Greater Glasgow and Clyde services to ME/CFS patients are delivered through the Centre for Integrative Care (CIC) and Allied Health Professional (AHP) services. CIC staff include Associate Specialists, Specialist Doctors, Clinical Nurse Specialists, Complementary Therapists, Administrative Staff, Secretaries, and a number of students on placement. AHP staff include Physiotherapists (Bands 5 and 6), Occupational Therapy, and a generic Health Care Support Worker. This NHS Board also responded that having a team delivering service specific care to ME/CFS would “provide the opportunity to ensure robust, measured implementation of the guidelines, provide education to other AHPs working with CFS/ME patients within generic services and provide targeted care for this patient group.”

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<sup>5</sup> NHS Dumfries and Galloway reported two different responses to this question. The Allied Health Professionals reported that they had plans to develop a specialist service by linking in with other long term condition management pathways and the Clinical Health Professionals did not provide a response (although they currently do provide psychological support for people with ME/CFS).



NHS Dumfries and Galloway has plans to extend the support offered by the Allied Health Professionals to develop a ME/CFS service by linking support with Long COVID services, GP, Occupational Therapy and Psychology staff. In order to do this, they hope to develop the wider MDT and specialist service model in the area, and include user involvement in the development of this service (through strengthening links with local networks, voluntary groups, and buddy/mentor programmes).

NHS Lanarkshire's response did not indicate that they planned to develop a specific ME/CFS service, but they referenced financial and resource challenges, and waiting lists, as barriers for new service developments, coupled with continued stigma around ME/CFS that impacts service user engagement for improved services.

### 5.7 Potential benefits of combined long-term condition pathways

All ten NHS Boards who responded to this survey identified 'significant' synergies between ME/CFS and Long COVID pathways. As considered above, some NHS Boards reflected that implementing the NICE guidelines would also provide an opportunity to improve outcomes for patients with other long-term conditions.

NHS Fife identified that shared expertise could improve research, clinical care, and self-management for both conditions, and could reduce service demand. NHS Borders identified that a Long COVID Clinical Lead will allow opportunities to review the pathways and management approach for multiple long-term conditions, including ME/CFS, which could contribute to improved patient outcomes and service development. NHS Shetland conceptualised a shift from an acute, reactive, crisis intervention model, to a supportive service and self-management approach for long-term conditions more broadly actualised through establishing peer support and community options. NHS Greater Glasgow and Clyde highlighted opportunities for learning and potentially integrating assessments and treatment approaches for Long COVID and ME/CFS into physiotherapeutic practices within an individualised treatment and management pathway. NHS Tayside noted that a Long COVID pathway would share common opportunities and types of intervention with a ME/CFS pathway.

## 5.8 Provision of outcome data/patient feedback

NHS Boards were asked about whether they were provided with feedback from patients or outcome data to help them understand the impact or experiences of people with ME/CFS using their services. The results in Table 9 show that only three NHS Boards (*NHS Fife, NHS Greater Glasgow and Clyde, NHS Lanarkshire*) reported capturing outcome data or patient feedback. Outcome measures comprised of satisfaction surveys in addition to a range of clinical outcome surveys/tools. The low use of outcome data/patient feedback may be linked to the fact that very few NHS Boards who responded use specific ME/CFS services to support patients.

Table 9: NHS Boards that capture outcome data and/or patient feedback

	<b>Types of Outcome Data/Patient Feedback</b>
NHS Fife	<p>Patient opinion website reports, service led surveys, patient satisfaction surveys, open suggestions from patients both individually and through local support groups, national charity agencies, colleagues, and professionals.</p> <p>Clinical outcomes measured using selective forms applicable to case management.</p>
NHS Greater Glasgow and Clyde	<p>Centre for Integrative Care (CIC) conducts audits to assess outcome measures (using Patient Reported Outcome Measures (PROMS), MYMOP2, WEMWEBS, and FSS).</p> <p>Patient and carer feedback through the CIC and the Friends of Centre for Integrative Care (not all are ME/CFS patients).</p> <p>The Allied Health Professional service do not yet use outcome measures specific to ME/CFS, PROMS are used for 'Moving Into Balance' classes that are accessed by patients with a range of conditions, which is not specific to ME/CFS.</p>
NHS Lanarkshire	<p>Canadian Occupational Performance Measure (COPM) and Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS) collected by Primary care OT for ME/CFS patients.</p>

	<p>Some patient feedback received via Care Opinion.</p> <p>Physiotherapy use MFI (Management of Fatigue Index) and SF36 (Short Form (36) Health Survey)</p>
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## 5.9 Additional reflections from NHS Boards

Six NHS Boards shared the same feedback in relation to future directions, demonstrating a shared desire to improve research and resource to understand and assess a range of clinical features and symptoms associated with ME/CFS:

*“Nationally, NHS Scotland should be looking to be a world leader and actively researching emerging theories of ME/CFS - the links to hypermobility, spine issues, autoimmunity, dysautonomia, cerebral blood flow etc. NHS Scotland does not have a single upright cross-sectional scanner (CT or MRI), a vital tool for assessing stress on the upper spinal cord and likely neurological dysfunction.”*

Additionally, NHS Greater Glasgow and Clyde highlighted a range of interventions and service developments that they are piloting or planning to support people with ME/CFS. Support includes:

- The Lightning Process within ME/CFS and Long COVID Unit,
- Shared learning and working through induction of AHPs from Neurological Outpatients Department and Pain Services,
- Class focused on pacing and new guidelines around movement as a bridge between physio and community services,
- Occupational Therapy support to provide holistic (mental and physical health) non-pharmacological interventions that optimise function and enhance quality of life.

## 6. Discussion

Overall, provision of support across the ten NHS Boards that responded to this survey was varied from generalist to specialist support by staff trained in ME/CFS. More than half of these NHS Boards did not have specific ME/CFS referral pathways, and only one had a specifically trained ME/CFS staff nurse. Many people with ME/CFS were referred onto long-term condition management pathways for other illnesses, such as Long COVID or chronic pain, as these often provided suitable support and management options for people who experience conditions with similar symptoms to ME/CFS.

Most NHS Board responses highlighted that there is an awareness of the updated NICE guidelines, specifically around GET and CBT. Despite this awareness, implementation of the guidelines was varied due to limited resources, lack of specific pathways or trained ME/CFS staff to support implementation. Additionally, implementation was varied due to the referral of people with ME/CFS to third sector organisations or other long term condition management pathways, and increased caseloads due to the impact of COVID-19.

The results of this survey highlight a willingness from NHS Boards to develop ME/CFS specialised treatment and support, yet there is an acknowledgement that this might not be realised due to the potential barriers. Below are some of the specific themes that relate to the barriers and opportunities of developing ME/CFS specific pathways in Scotland summarised from the results of this survey.

### 6.1 Views that do not align with NICE guidelines

Outdated views impacting the uptake of Scottish guidance around ME/CFS support was found to be a barrier. Some NHS Boards highlighted that the barriers to implementation of the NICE guidelines were related to views about treating ME/CFS that did not reflect its status as a neurological condition (lack of knowledge development and education opportunities, discrediting treatment options, potential for patients not engaging due to stigma, or acknowledging the impact that ME/CFS can have on everyday life). As reported in the [stakeholder consultation review](#),

clinicians felt that the changes in guidelines left some confusion about what were appropriate treatment options for people with ME/CFS, which may be due to the referenced 'traditional' views of this condition. This perspective was reflected in the response of one NHS Board that participated in the current survey, suggesting that such outdated views may result in a lack of support to set up services.

NHS Boards in this survey also expressed a concern that the uptake of the new guidelines across Scotland might be slow and lead to some confusion about appropriate treatment due to variation. Worries around communication of guidelines across Scotland was also emphasised in the stakeholder consultation review, which highlighted that some clinicians may continue to recommend support that does not reflect current NICE guidelines while there is not an established infrastructure of ME/CFS care. The review also highlighted that pressure on time and resources might result in varied uptake of new guidance across Scotland, a concern which was raised similarly throughout the survey responses discussed in this report.

Despite these barriers, some NHS Boards believed that the changes to NICE guidelines would challenge previous perceptions and result in positive opportunities for Scotland's future ME/CFS support pathways. The opportunities mentioned included improvement of treatment and symptom management, improved outcomes for patients with long-term conditions more generally, education of staff around awareness of this condition, collaboration and increased coordination from MDT staff, increased patient engagement and feedback through reduction of stigma, and strengthened links to third sector ME/CFS/long-term condition management organisations or pathways. These opportunities were echoed in the [stakeholder consultation review](#), where people were pleased with the potential to validate and recognise the condition as neurological rather than psychosomatic, increase education and training, and develop specialist services for people with ME/CFS. It was suggested that views which do not reflect the NICE guidelines may be a potential barrier for patients, which may dissolve with the increased positive attention and uptake of specialist support for this neurological condition.

## 6.2 Multi-disciplinary care and knowledge sharing

Support for ME/CFS in Scotland was provided by a range of staff members across multiple disciplines and organisations, which reflects the complexity of this condition where symptoms may require the knowledge and support from a multi-disciplinary team. [The stakeholder consultation review](#) highlighted that lack of capacity has a wider impact on care due to limited resources, waiting times, and increased caseloads. In addition to the benefits of multi-disciplinary support available, knowledge sharing across areas was highlighted in the analysis of this survey as a potential opportunity gained from implementing the NICE guideline changes to ensure that people with ME/CFS are receiving well-rounded expert care. This view is echoed in the stakeholder consultation review, where the work of the specialist nurse in Fife, the services in NHS Greater Glasgow and Clyde and NHS Lothian, and third sector organisations are considered to be good examples of ME/CFS support and care. Responses in the [stakeholder consultation review](#) showed an encouragement for peer practice-based learning and utilising existing systems to access a variety of support materials, echoing the responses from some NHS Boards involved in this survey.

The shared reflection provided by NHS Boards shows encouraging support for education and research in ME/CFS across Scotland to develop a better understanding of support and treatment options among current and future clinical staff. The [stakeholder consultation review](#) echoes this desire through their suggestion to build a “robust education programme” so that clinicians can confidently “diagnose ME/CFS and identify an appropriate management and care plan” as well as including this in the curriculum for the next generations coming out of medical schools.

## 6.3 Incorporating lived experience and patient feedback

As many people with ME/CFS are treated by multi-disciplinary teams or outsourced third sector organisations, it may also be a challenge to gather and incorporate patient feedback from one source where a specific pathway or centre does not exist. Only three NHS Boards reported measuring outcomes or gathering feedback from

patients. NHS Greater Glasgow and Clyde reported using patient feedback to inform patient-centred care approaches, highlighting the benefits of patient-led care in managing their condition. This may be reflective of the fact that not all NHS Boards have specific ME/CFS pathways, support may only exist through staff with limited time to gather feedback, or people with ME/CFS are treated through multiple routes (meaning gathering feedback via one local service becomes challenging). The responses to this survey and the stakeholder consultation review consultation highlighted that patient empowerment, engagement, and de-stigmatising ME/CFS were potential opportunities from implementing the NICE guidelines, which may be better supported by the incorporation of lived experience and strengthening patient feedback opportunities.

#### 6.4 Integrated pathways for long-term conditions

Some NHS Boards supported the approach to utilise pathways for other long-term conditions to support people with ME/CFS, especially long-term conditions where symptoms overlap. It became evident through the responses that, in some NHS Boards, people with ME/CFS are already being supported through these other pathways where there is no specific ME/CFS service. The potential to connect ME/CFS support to an established long-term condition management or other mainstream service, as highlighted in this survey analysis, was also supported by the consultation review.

#### 6.5 Future intentions for ME/CFS services

Seven of the NHS Boards did not provide a response to the question about future intentions to create a specialist service for people with ME/CFS, which may be linked to the responses about barriers around implementation or specific support. This suggests the need for further engagement with NHS Boards to discuss how ME/CFS services and pathways can be developed further.

## 7. Key Findings and Conclusion

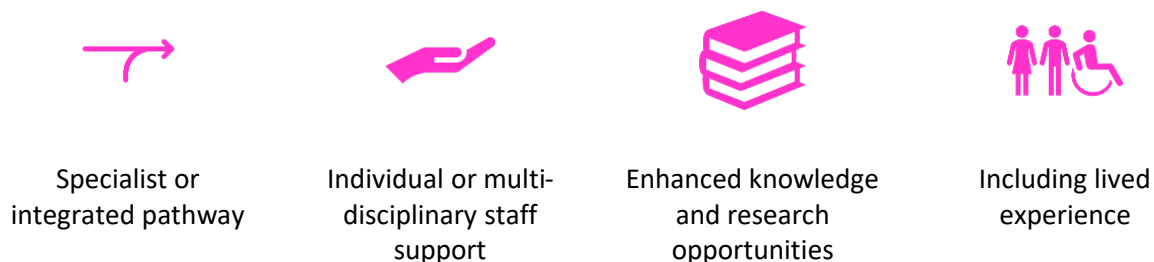
The objective of this report is to understand current ME/CFS service provision, the awareness and implementation of the updated NICE guidelines, barriers and opportunities to their implementation, and where further support is needed. The key barriers to implementing the NICE guidelines were around resources, challenging views that do not align with NICE guidelines, and concerns about how the new guidelines would be implemented consistently across Scotland. Despite these barriers, the NHS Boards that participated in this survey anticipated that the new guidelines would provide improved knowledge to support people with ME/CFS and empower people with ME/CFS about living with and managing the condition: potentially challenging some of the barriers stemming from outdated views of this condition.

In addition, NHS Boards highlighted that the new guidelines would provide improved outcomes for other long-term condition management as well as strengthen links with third sector organisations and public health strategies: potentially providing a collaborative approach to ensure a consistent and equitable implementation of ME/CFS support across Scotland. The responses to this survey and the previous stakeholder consultation review suggest that enhancing or establishing ME/CFS care in Scotland requires knowledge sharing among staff and people with ME/CFS to ensure that a care pathway is informed from both a clinical and lived experience perspective. This would have the potential to dispel outdated views that may shape the care received for this condition and create a guide for best practice to reference across Scotland.

Based on the results of this survey and taking into consideration the consultation review, this concluding section highlights four key findings from this survey that require further investigation (Figure 2) to identify the most effective services or pathways for providing ME/CFS care.



Figure 2: Four key findings from the results of this survey



Further investigation is required to fully understand whether specialist provision for ME/CFS is the most effective service approach compared with integration of ME/CFS support into other long-term condition management pathways. The results of this survey highlight that long-term condition pathways of support are already being used for people with ME/CFS where no specialist service or specific ME/CFS pathway exists. It would be key to understand whether this type of integrated support pathway should be developed further or whether establishing a stand-alone specialist ME/CFS support service or specific pathway would be more preferable for local services. This work would require engagement and consultation with NHS Boards, as well as patient representatives, to understand local preferences and transfer learning to a national level.

Linked to the question of whether specialist or integrated pathways are preferred, responses to this survey show that some people with ME/CFS receive support through individual staff and others through multi-disciplinary care. In some cases, where there is one specialised nurse or practitioner available to people with ME/CFS, there are still subsequent referrals to other staff members or third sector organisations who can provide support for specific symptoms or long-term condition management. NHS Boards who responded to this survey reflected on the significant benefits for patients and staff if ME/CFS was integrated formally into these pathways or a multi-disciplinary team was made available to provide care, although this may be reflective of the lack of a ME/CFS specialist service. The support for MDTs builds on the results of the [stakeholder review](#), where stakeholders indicated a preference

that ME/CFS support should be delivered through a specialist community-based service which includes a “network of different specialisms.” Further investigation is required to ascertain whether strengthening existing multi-disciplinary approaches utilised by some NHS Boards or training staff to provide ME/CFS specialist care would be the best way to provide support. Equally, as provision of services is dependent on staff availability, funding, and training opportunities, it would be key to understand whether these two types of support, specialist staff or MDTs, differ depending on local resources. For some NHS Boards, financial and resourcing issues emerged as a barrier to the implementation of the NICE guidelines as well as establishing a specific ME/CFS support pathway. Where barriers around establishing ME/CFS specific support may exist for financial or resourcing reasons, the potential to utilise existing long-term management pathways may be a viable alternative to specialist services. Further insight is required from NHS Boards to ascertain the benefits or limitations of specialist or integrated pathways for ME/CFS service development.

NHS Boards in this survey have indicated a desire to build education and research programmes for current and future clinical staff, which would decrease views and stigma surrounding ME/CFS that do not accord with current NICE guidelines, increase awareness, and potentially [increase the intent to train in ME/CFS as a speciality](#). The [stakeholder review](#) also suggests forming a specialist national or regional centre for research and care by clinicians to increase understanding about the management and treatment of ME/CFS.

Due to MDTs and long-term condition pathways providing the majority of support in Scotland at present, it may not be possible for individual services to gather comprehensive patient feedback about their experiences, yet responses to this survey highlighted how patient and carer feedback have informed programmes of support. [The stakeholder review](#) not only provided a means by which to gather a wide range of lived experience but also emphasised the importance of feedback surveys, highlighting that they are essential in the development of pathways and reviewing care for patients. In this context, commissioning further engagement to gather feedback from patients across Scotland would be the best method to capture

views on the most effective pathway and delivery of support from a patient perspective in the future.

Given resource constraints and funding pressures highlighted in this survey of NHS Boards, the implementation of these key findings may be dependent on an increase in the availability of resources at local and national levels.

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## 9. Appendices

### 9.1 Appendix One: Questionnaire

*The below is the questionnaire sent out to all NHS Health Boards in Scotland.*

1. Health board area?

2. What support is being provided to people with ME/ CFS in your area?

You may wish to comment on:

- General and specialist services
- Primary and secondary care
- Services for children and young people, and adults
- Services for those with mild, moderate or severe symptoms
- Therapeutic interventions

3. How is support being delivered?

4. What staff or volunteers provide support to people with ME/ CFS in your local area?

5. How are individuals in need of support identified?

6. To which services are people with ME/ CFS referred to?

7 i). How would you describe your awareness of the key changes within the NICE guideline on Graded Exercise Therapy?

(ii). How would you describe your awareness of the key changes within the NICE guideline on Cognitive Behavioural Therapy?

8. To what extent has your area started to implement the updated guideline?

You may wish to comment on particular aspects of the updated guideline, for example:

- Training for health and social care staff
- Access to ME/ CFS specialist teams

- Provision of care for people with severe ME/ CFS
- Availability of experts in secondary care to provide guidance to primary care
- Referring children and young people with suspected ME/ CFS
- Reviews of funding and capacity

9(i). Are you provided with outcome data or patient feedback from services to understand the impact or experiences of people with ME/ CFS?

(ii). If yes,

What types of outcome data or patient feedback do services provide to you?

10(i). Do you have plans for a specialist ME/ CFS service in your area?

(ii). If yes,

Where will the specialist the team be located, and who will be in this team?

11. What barriers do you anticipate in implementing the updated guideline?

12. What opportunities do you anticipate in implementing the updated guideline?

13. What are the potential synergies between a specialist ME/ CFS service and pathways for other long-term conditions, for example, Long COVID pathways?

14. Do you have any additional comments on current ME/ CFS services or future plans that you would like to share?



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