



Members Survey on the delivery of therapy within specialist ME/CFS services and the journey to publication of the new NICE Guideline on ME/CFS

October 2021

Introduction

In 2018 the National Institute for Health and Care Excellence (NICE) began the process of developing a new guideline on ME/CFS to replace the previous guideline published in 2007.

Shortly before the planned publication in August 2021 NICE announced that they had paused publication and provided a news article which included the following statement:

Because of issues raised during the pre-publication period with the final guideline, we need to take time to consider next steps. We will hold conversations with professional and patient stakeholder groups to do this. We need to do this so that the guideline is supported.

BACME as an organisation were not involved in the development of the guideline. BACME was registered as a stakeholder and submitted a comprehensive response to NICE following the publication of the draft guideline in November 2020. BACME felt the key issues raised in our comment submission had been addressed in the proposed final guideline and BACME did not raise any additional concerns with NICE ahead of the planned publication of the guideline.

Media reports indicated that the main areas of concern regarding the proposed new guideline were regarding the recommendations about the therapy approaches Graded Exercise Therapy (GET) and Cognitive Behaviour Therapy (CBT), the definition of which had changed from the 2007 guideline to the proposed 2021 guideline.

BACME requested to be present at the roundtable meeting organised by NICE to explore the concerns that had been raised.

BACME contacted members to give them an opportunity to inform the Board to be in a position to represent the majority view of membership. As part of this process we conducted a survey specifically focusing on the current delivery of GET and CBT in specialist ME/CFS services.

The following document provides information gathered from the survey which was presented at the roundtable meeting with NICE and representatives from other key organisations. Following the meeting, NICE announced that they were going ahead with publication of the guideline.

The survey was presented to BACME members with an introductory message which included information about the proposed new NICE guideline definition of Graded Exercise Therapy (GET):

Graded exercise therapy is defined in this guideline as therapy based on the deconditioning and exercise intolerance theories of chronic fatigue syndrome. These theories assume that ME/CFS is perpetuated by reversible physiological changes of deconditioning and avoidance of activity. These changes result in the deconditioning being maintained and an increased perception of effort, leading to further inactivity. Graded exercise therapy consists of establishing a baseline of achievable exercise or physical activity and then making fixed incremental increases in the time spent being physically active

BACME membership report

August 2021

Number of active BACME members: **179**

Number of active BACME members registered with an NHS email: **124** (69%)

Number of BACME members who have provided information on their job role: **85** (47%)

Occupational Therapists	32
Physiotherapists	16
Psychologists/Mental health practitioner	14
Doctors	8
Clinical lead	6
Managerial positions	5
Other	3
Nurses	1

BACME Board members by job role:

Chair: Consultant Nurse Paediatric and Adolescent service

Deputy Chair: Area Co-ordinator

Occupational Therapist: 5

Patient and carer representatives: 3

Research Nurse: 1

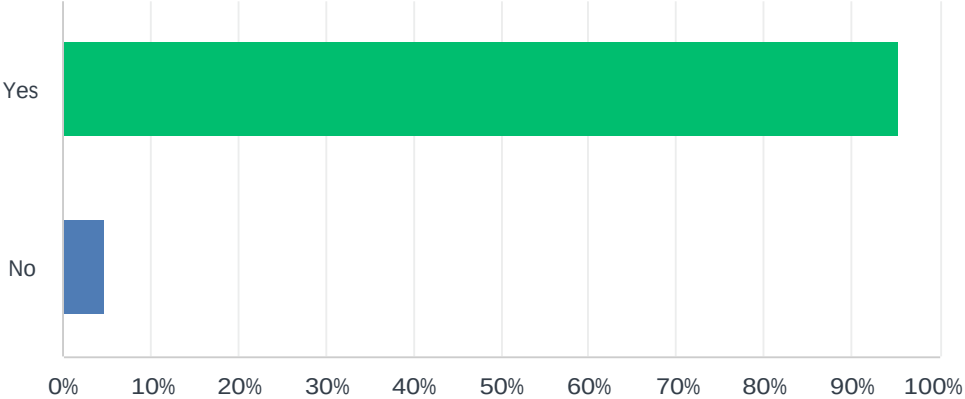
Doctor (GP): 1

Physiotherapist: 1

Clinical Psychologist: 1

Q1 Are you a professional delivering care to people with ME/CFS?

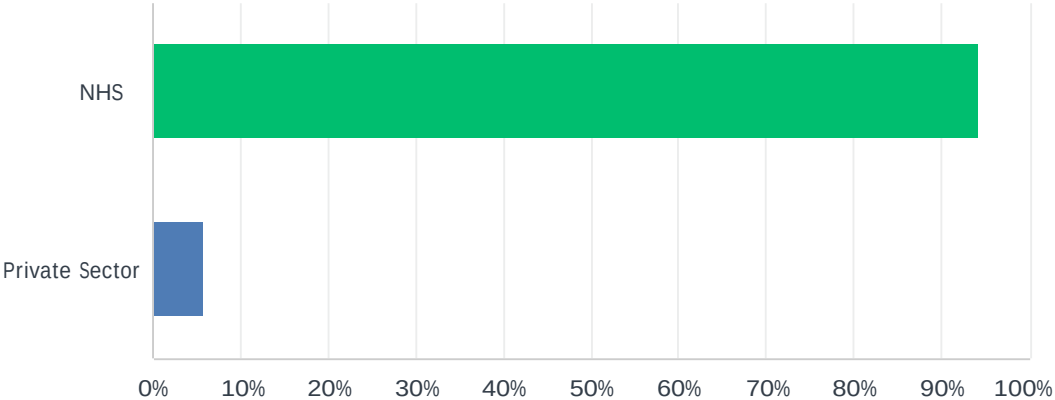
Answered: 109 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	95.41%	104
No	4.59%	5
TOTAL		109

Q2 Is your work with people with ME/CFS primarily within the...

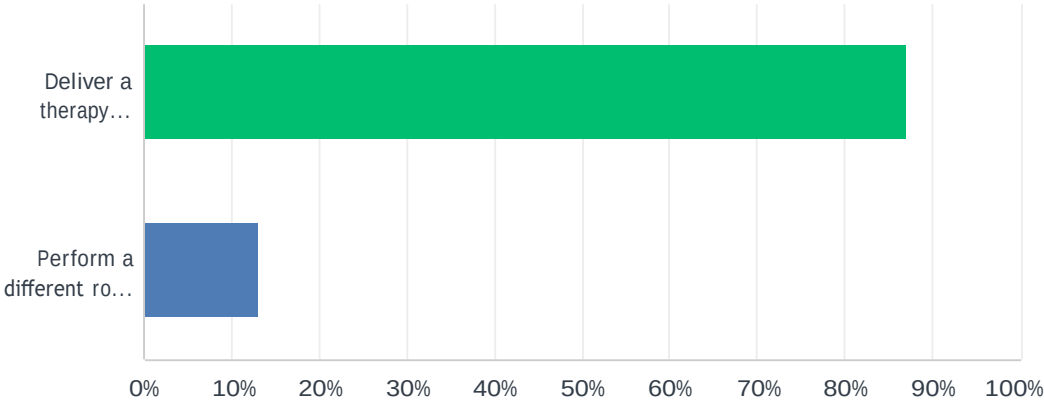
Answered: 103 Skipped: 6



ANSWER CHOICES		RESPONSES	
NHS		94.17%	97
Private Sector		5.83%	6
TOTAL			103

Q3 In your clinical role do you...

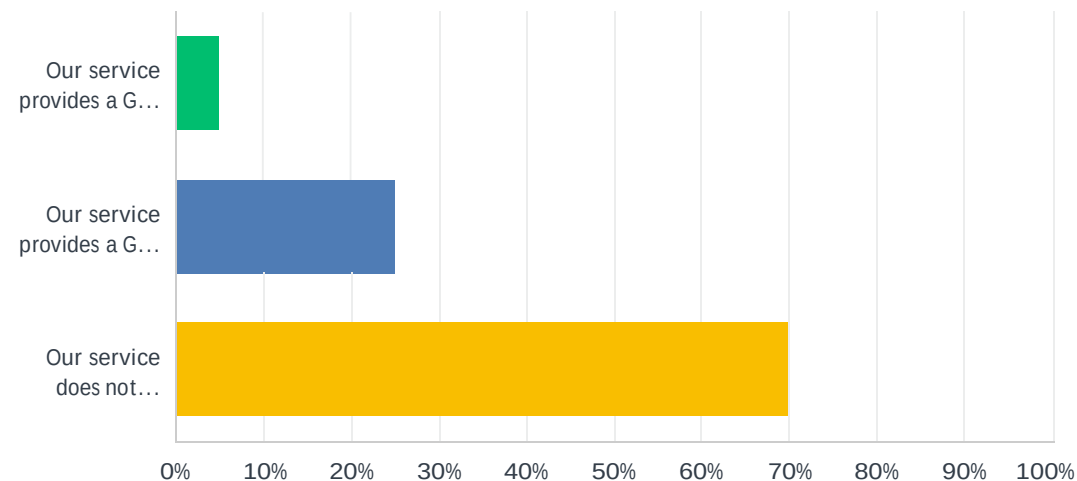
Answered: 100 Skipped: 9



ANSWER CHOICES	RESPONSES	
Deliver a therapy programme to people with ME/CFS	87.00%	87
Perform a different role in your service (e.g. only providing diagnostic assessments, providing input to an MDT, managerial position, providing specific therapeutic input such as dietetic advice)	13.00%	13
TOTAL		100

Q4 Please choose the statement that best describes your service delivery

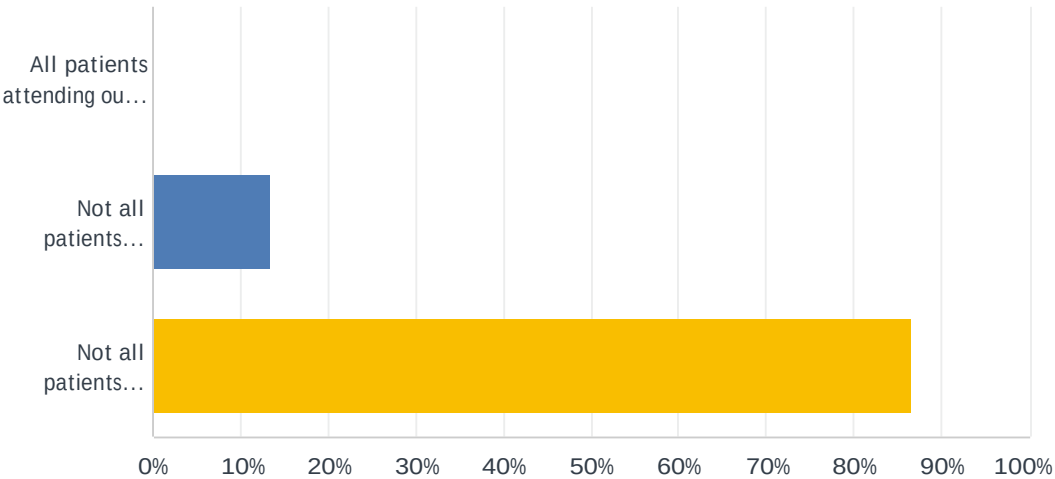
Answered: 99 Skipped: 10



ANSWER CHOICES	RESPONSES	
Our service provides a GET programme based on deconditioning and exercise intolerance theories.	5.05%	5
Our service provides a GET programme which is not based on a primary deconditioning theory for the illness	25.25%	25
Our service does not deliver a programme called GET	69.70%	69
TOTAL		99

For those respondents whose service delivers a GET programme:
Q5 Please choose which of the following 3 statements reflects the delivery of GET in your service:

Answered: 30 Skipped: 79

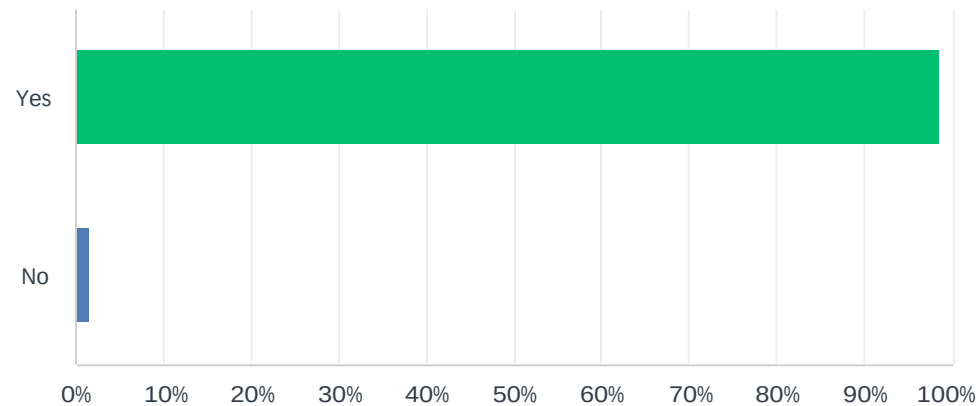


ANSWER CHOICES		RESPONSES	
All patients attending our service for a therapy programme receive a GET programme		0.00%	0
Not all patients attending our service for a therapy programme receive a GET programme and the decision regarding who attends a GET programme is made by a clinician		13.33%	4
Not all patients attending our service for a therapy programme receive a GET programme and the patient is involved in the decision about whether they attend a GET programme.		86.67%	26
TOTAL			30

For those respondents whose service does not deliver a GET programme:

Q6 Does the therapy programme delivered by your service include guidance on managing physical activity and/or exercise?

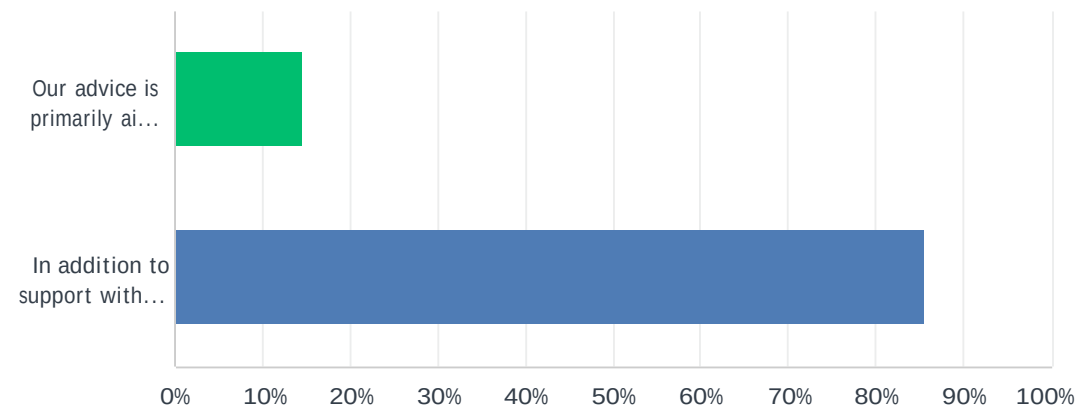
Answered: 69 Skipped: 40



ANSWER CHOICES		RESPONSES	
Yes		98.55%	68
No		1.45%	1
TOTAL			69

Q7 Please consider the guidance you provide on physical activity management and choose which of the following statements most closely represents the guidance your service provides:

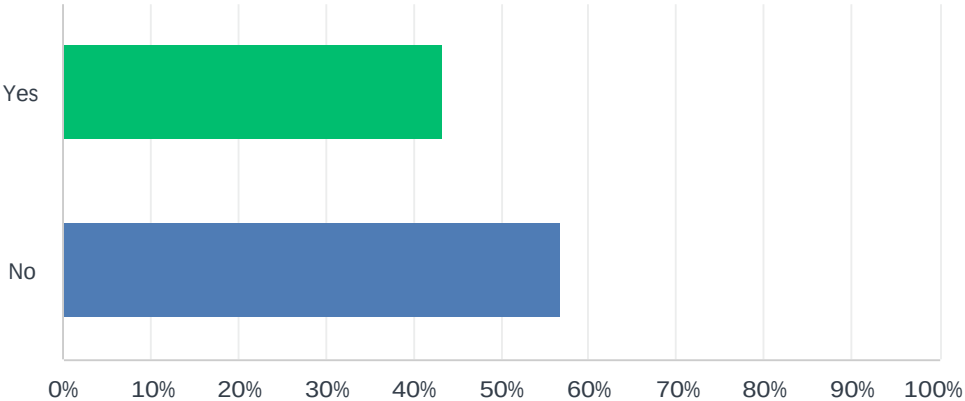
Answered: 96 Skipped: 13



ANSWER CHOICES		RESPONSES	
Our advice is primarily aimed at teaching the principles of pacing aiming for maintenance		14.58%	14
In addition to support with maintenance our service also offers advice tailored to the individual patient which includes grading up physical activity		85.42%	82
TOTAL			96

Q8 Does your service deliver a therapy programme called Cognitive Behaviour Therapy (CBT)?

Answered: 97 Skipped: 12

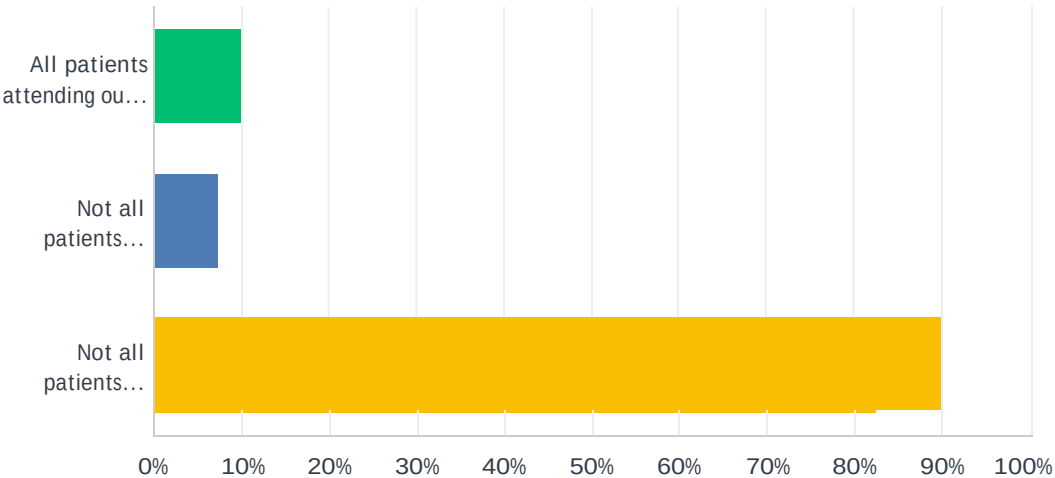


ANSWER CHOICES		RESPONSES	
Yes		43.30%	42
No		56.70%	55
TOTAL			97

For those respondents whose service delivers CBT:

Q9 Please choose which of the following 3 statements reflects the delivery of CBT in your service:

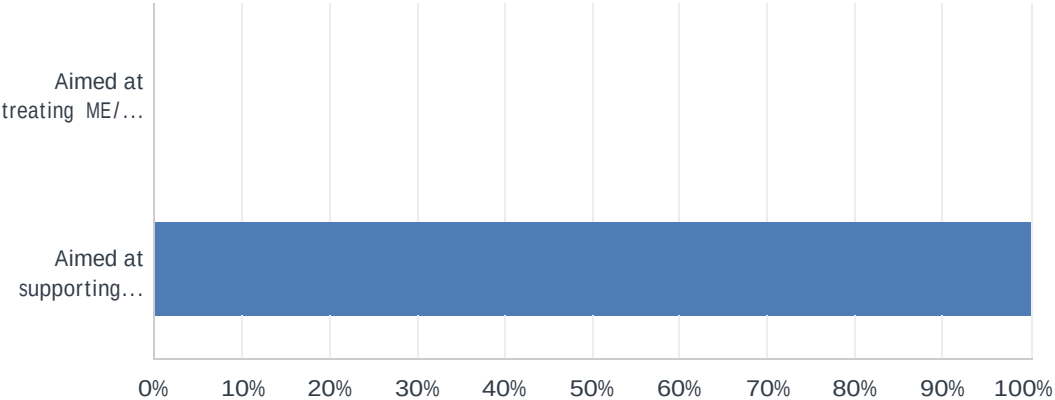
Answered: 40 Skipped: 69



ANSWER CHOICES		RESPONSES	
All patients attending our service for a therapy programme receive a CBT programme		10.00%	4
Not all patients attending our service for a therapy programme receive a CBT programme and the decision regarding who attends a CBT programme is made by a clinician		7.50%	3
Not all patients attending our service for a therapy programme receive a CBT programme and the patient is involved in the decision about whether they attend a CBT programme.		82.50%	33
TOTAL			40

Q10 Is your CBT programme...

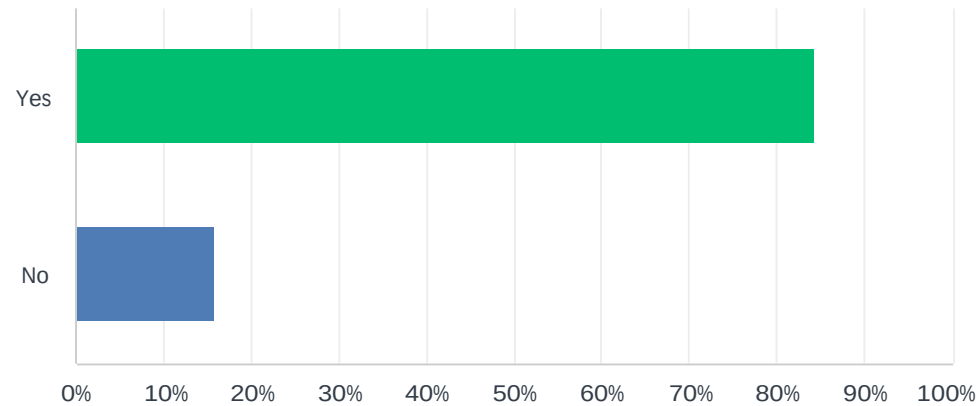
Answered: 40 Skipped: 69



ANSWER CHOICES	RESPONSES	
Aimed at treating ME/CFS based on the principle that the symptoms are largely caused by unhelpful illness beliefs	0.00%	0
Aimed at supporting someone with ME/CFS to manage their condition and address emotional factors which contribute to their symptom burden	100.00%	40
TOTAL		40

Q11 Does your service provide therapeutic programmes that are not based on GET and/or CBT (this may be in addition to GET/CBT)

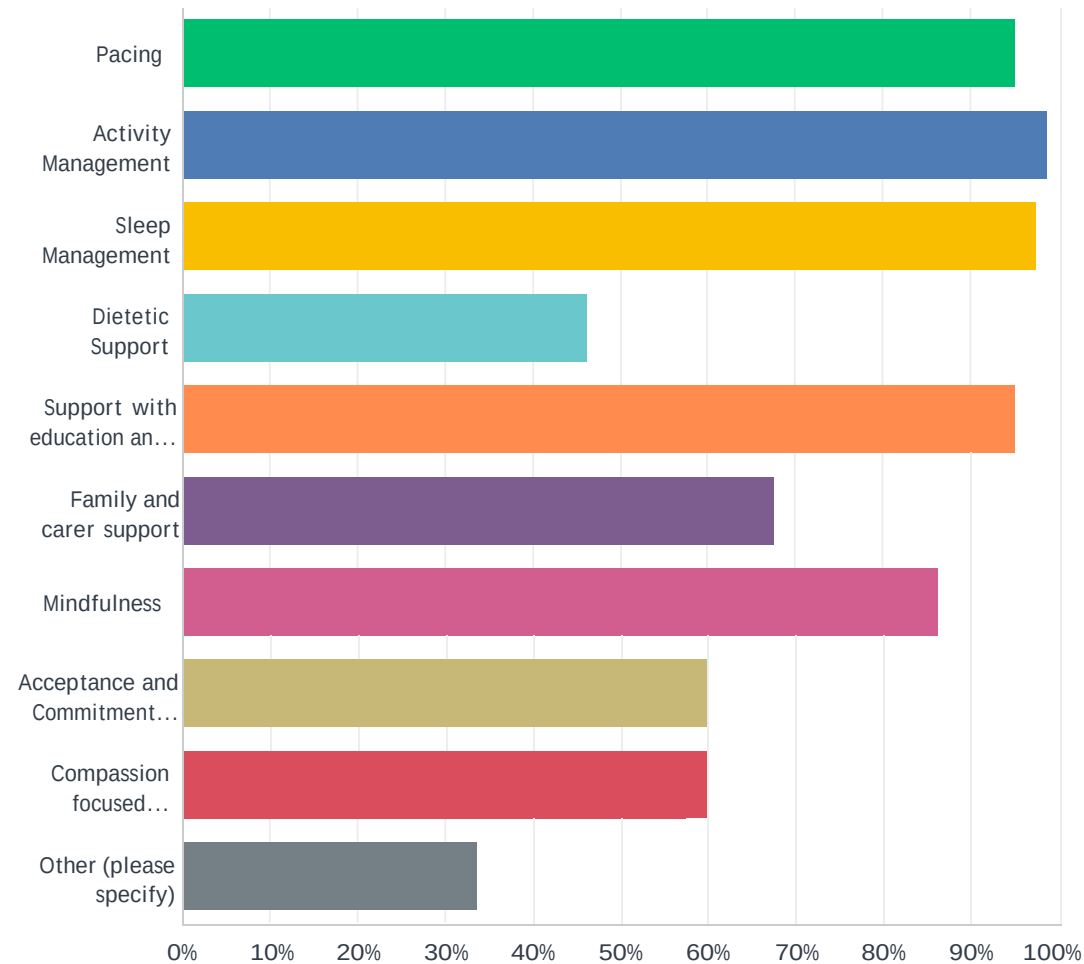
Answered: 95 Skipped: 14



ANSWER CHOICES		RESPONSES	
Yes		84.21%	80
No		15.79%	15
TOTAL			95

Q12 Please tick any additional therapeutic interventions provided by your service

Answered: 80 Skipped: 29



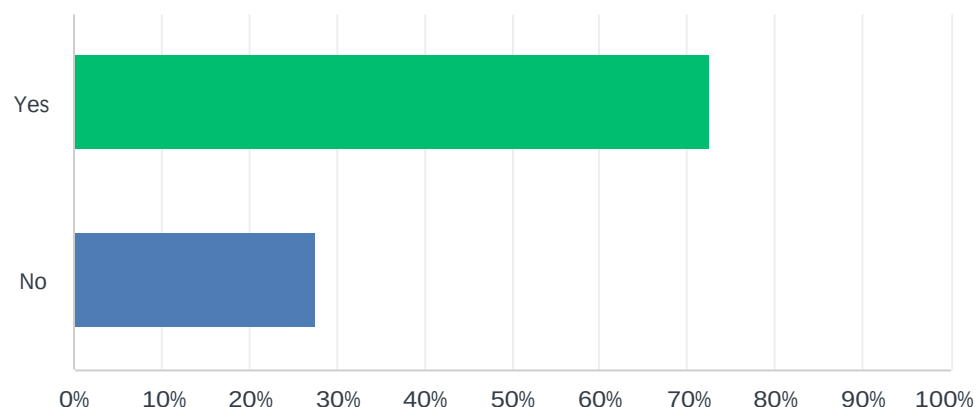
ANSWER CHOICES	RESPONSES	
Pacing	95.00%	76
Activity Management	98.75%	79
Sleep Management	97.50%	78
Dietetic Support	46.25%	37
Support with education and work issues	95.00%	76
Family and carer support	67.50%	54
Mindfulness	86.25%	69
Acceptance and Commitment therapy	60.00%	48
Compassion focused therapy	57.50%	46
Other (please specify)	33.75%	27
Total Respondents: 80		

Respondents could also submit free text answers detailing what else they provide and answers included:

- Education about ME/CFS and dysregulation
Orthostatic tolerance measures
Hypnotherapy
Sensory integration
Systemic Therapy
Psychotherapy
Qi Gong
EMDR
Narrative therapy
- OT support with aids and equipment
Heart rate monitoring
Breathing training
Memory and concentration strategies
Peer support
Solution focused techniques
Information about other organisations providing support

Q13 Would you support publication of a new NICE Guideline which states that services should not deliver a Graded Exercise Therapy (GET) programme based on a deconditioning model of the illness.

Answered: 87 Skipped: 22

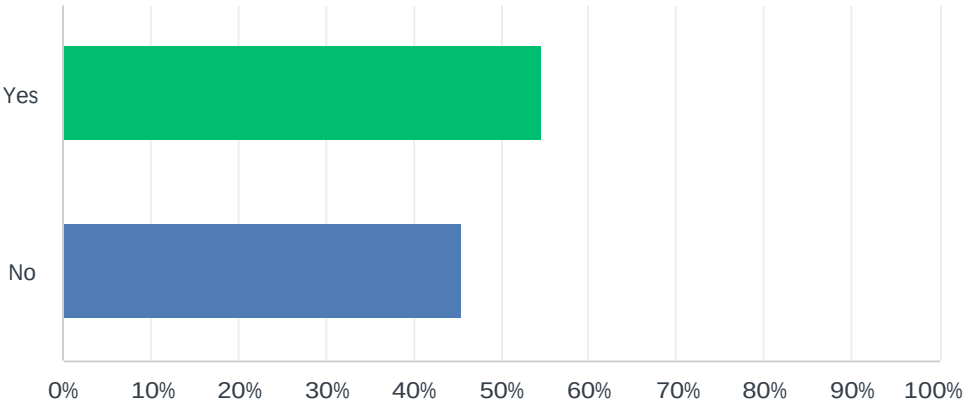


ANSWER CHOICES		RESPONSES	
Yes		72.41%	63
No		27.59%	24
TOTAL			87

Comments submitted relating to this question included opinions that GET is not based on deconditioning and that deconditioning can become part of the illness. Other comments expressed a feeling that GET is too restrictive and is not a suitable programme for people with ME/CFS. Some comments reflected on the use of a dysregulation model of understanding the illness. Many comments gave details of how grading up activities can be incorporated into individualised programmes.

Q14 Would you support publication of the new NICE Guideline which states that services should not provide CBT programmes outside the remit of aiming to support patients to manage their condition?

Answered: 88 Skipped: 21



ANSWER CHOICES		RESPONSES	
Yes		54.55%	48
No		45.45%	40
TOTAL			88

The comments that were submitted with this question showed that respondents clearly feel CBT techniques are of value as part of a package of care which is individualised and tailored to individual patient’s needs. Comments also reflected on the importance of managing mental health issues and how mental and physical health are inextricably linked and shouldn’t be considered separately. There were also comments reflecting on the relevance of who delivers a CBT programme and how good outcomes have been obtained in specialist CFS/ME services but referring patients with ME/CFS to mental health services for CBT may not be appropriate.

How your views informed the NICE guideline publication meeting

The BACME National Services Survey conducted in 2018 identified around 50 specialist NHS CFS/ME services in the UK. This survey was completed by 109 BACME members, the majority of whom are clinical staff working in NHS specialist services.

The results indicate that Graded Exercise Therapy (GET) and Cognitive Behavior Therapy (CBT) are not the primary therapy approaches currently being used in NHS services. Despite these therapies being recommended in the 2007 NICE Guideline, many clinical staff are aware of research developments revealing more about the underlying physiological processes and have listened to feedback from patients indicating that these approaches are not always suitable and hence they have moved on to look for other approaches that may help. Comments and opinions shared in the survey indicate a more holistic approach to treatment following feedback from patients. The data demonstrates that the majority of respondents are delivering guidance on grading up activity when appropriate on an individual basis, without using a GET model of delivery.

The data also demonstrates that the term GET has been interpreted in different ways and has been delivered based on different illness models.

During the NICE roundtable meeting it was acknowledged that the 2007 NICE guideline described GET rather than defining it and did not make any reference to the illness model it was aimed at treating. The description of GET in the 2007 NICE guideline included additional strategies such as general activity management and sleep management strategies. This gave scope to therapists to develop therapy programmes called GET which incorporated strategies that are often considered to be pacing strategies. It was agreed at the meeting that GET as a term has been interpreted and delivered in different ways. However, because of the definition used in various research trials, the term GET has become synonymous with a deconditioning model of the illness and an expectation that following a GET programme will lead to a full recovery. Everyone at the meeting agreed that this is an incorrect approach for people with ME/CFS.

The 2021 NICE guideline on ME/CFS has clarified the definition of GET and restricted the use of the term to therapy programmes based on a deconditioning model of the illness with fixed incremental increases in activity. BACME supported this clarification. It therefore follows that GET should not be used for people with ME/CFS and the term GET should no longer be used to describe flexible, individualised therapy programmes that are aimed at supporting people with ME/CFS to manage their condition.

BACME recognise that some people with more severe or long-term ME/CFS may lose strength and fitness as a result of the limitations imposed by their illness. This needs to be addressed with extreme care, being aware of the underlying physiological abnormalities that may result in symptom exacerbation in response to changes in activity levels and recognising that very small changes and periods of consolidation are needed. Clinicians delivering care to people with ME/CFS should have a good understanding of the post-exertional exacerbation of symptoms which can occur in order to provide appropriate advice to those patients who are looking to increase their activity levels.

Our survey results relating to the delivery of Cognitive Behaviour Therapy (CBT) demonstrate that services who offer this to people with ME/CFS are doing so in line with the recommendations in the new NICE guideline which is that it is a tool that can be used to help support patients with the management of their condition, not as a curative treatment.

Next Steps

Our survey demonstrates that services are already incorporating many different therapy approaches and provide other aspects of supportive care. It is recognised that many of the therapeutic strategies being used in specialist ME/CFS services have not had formal evaluation or published data and therefore could not be included in the NICE Guideline evidence review. Personalised and flexible therapeutic approaches cannot be studied in randomised controlled trials as these require a standardised approach where all participants follow exactly the same therapy programme. The benefit of a positive therapeutic relationship is also difficult to quantify and measure but is an important aspect of good quality healthcare.

It is important that the clinical community look for ways to effectively evaluate the services that are being delivered to ensure they are providing effective and safe treatment. It is also important to acknowledge that until a more accurate way of defining ME/CFS is found, any research on therapy approaches will be vulnerable to recruitment bias.

BACME continues to support research which aims to provide further understanding of the underlying pathological processes that generate the symptoms experienced by people with ME/CFS in the hope this will also lead to more refined therapeutic approaches.

BACME recognises the importance of providing confident support to people with ME/CFS now.

BACME recognises the need for increased investment in specialist service provision to ensure equitable access for people of all ages and with all levels of severity of the illness.

BACME will continue to look for opportunities to provide education, training, information resources and support to clinicians and services to ensure we aim for the highest quality of care for people with ME/CFS and where possible, disseminate supportive information to the patient population.

BACME will use the new NICE guideline as a foundation on which to build further clinical guidance on the delivery of care to people with ME/CFS and work to ensure that the patient story is heard and embedded in the future of ME/CFS care.