YOUR EXPERIENCE OF ME SERVICES

Survey report by #MEAction UK

October 2019

Authors: Sian Leary, Janet Sylvester,
Emma Shorter and Espe Moreno
With contributions from Rebecca
Knowles and Denise Spreag

Contents

Executive Summary

Background

This report analyses a survey conducted by #MEAction UK in response to a call for evidence from the National Institute for Health and Care Excellence (NICE) in August 2019. This report is intended to respond to that and provide further evidence to NICE as they update their guidelines on myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS).

The survey investigated key aspects all three areas of the call for evidence from NICE:

1. Management strategies that are adopted while someone is being assessed for a diagnosis of ME/CFS
2. Methods of monitoring and/or reviewing people with a diagnosis of ME/CFS
3. Evidence on the experience of people who have had interventions for ME/CFS

Methodology and Sample

The survey was conducted between 24th September and 7th October, 2019. An online methodology was used in order to meet the deadline for evidence set by NICE. Distribution was via social media and email to #MEAction's UK contact lists.

A total of 1,906 questionnaires were completed and the results are based on 1,886 who completed valid questionnaires and had a diagnosis of CFS/ME, ME/CFS, ME or CFS. The combined term ME/CFS was used in the survey as this reflects the NICE guidelines terminology used.

Management Strategies whilst being assessed for ME

Healthcare professional's initial advice had a significant effect on patient outcomes:

- 23.9% of respondents were told to increase their activity levels. 90% of these respondents reported that they deteriorated having followed this advice
- By comparison, of the 21.6% of respondents who had been told to decrease their activity and rest, 36.8% improved and only 9% had deteriorated

94.4% of respondents reported that, in hindsight, the most helpful advice they could have been given when first presenting with symptoms of ME was to decrease activities and rest whilst ill.

Services

Just over a quarter of respondents (28.6%) had not been to an ME clinic, describing a lack of available support, negative attitudes from healthcare professionals, and bad experiences from accessing recommended treatments, mainly graded exercise therapy, elsewhere.

Of the 71.4% of respondents who attended a clinic, satisfaction levels were low:

- 25.5% of clinic attendees were very satisfied/satisfied with the services
- The majority of attendees (52.7%) were very unsatisfied/unsatisfied with services.

Respondents were most likely to say that the service in clinics were a mix of appropriate/not appropriate (33.5%). Just over 40% said either most of the services or all of the services provided were not appropriate, compared with 22.9% saying most of the services or all of the services provided were appropriate.

Multidisciplinary teams

As NICE will be making recommendations on the composition of multidisciplinary teams providing services for people with ME, the survey asked for respondents views. The three most commonly chosen professions were consultants, specialist nurses and occupational therapists.

Experience of attending a clinic

Attending a clinic had a positive impact on 16.3% of respondents, but 35.6% said their health had worsened. The main consequence was that the clinic had no impact: almost half (48.1%) of respondents reported being neither better nor worse after attending the clinic. For children and young people however the results were worse, with just over a majority (51%) reporting they deteriorated having attended a paediatric clinic.

37.3% of respondents felt that the clinic they attended should be closed and a new one rebuilt with patient input. 45% felt that their clinic should adapt to provide different services. A minority of 17.7% felt their clinic should continue to provide current services.

The three most commonly cited reasons for suggesting that clinics adapt or close were:

- That they were based on a psychological approach
- They offered graded exercise therapy which was seen to be inappropriate and often led to deterioration
- A lack of understanding from healthcare professionals

43.6% of respondents said they had been pressured to undergo a certain treatment and 48% said they had not been pressured. However these figures were quite different when just paediatric specialist services were evaluated, with 65.2% of responses from or on behalf of a child or young person saying they had been pressured to undergo certain treatments, compared to 26.1% who had not been pressured.

Cognitive Behavioural Therapy

The 41.1% of respondents who attended a specialist service and received CBT reported receiving the following advice as part of this therapy:

- Over half (51.9%) of respondents who received CBT were told that deconditioning was leading to some or all of their symptoms
- Over two thirds (68.7%) of respondents reported that it was suggested that if they were able to change how they thought about their symptoms their severity would decrease
- Over three quarters (79.5%) said that they were advised on strategies to manage their illness.

Whatever was on offer, the results were ineffective, with 63.3% replying that the CBT they received was not helpful, 27.9% replying that it was somewhat helpful, and just 6.2% saying it was helpful.

Activity Management

79.2% respondents had been given advice on how to manage activity levels whilst at their clinic.

- The most common advice that respondents had been given was to find a sustainable level of daily activities and increase activities week by week (52.6%). Only 10% of respondents who had received advice said this would have been helpful with hindsight.
- A third (33.7%) had been told to adapt/decrease their activities to a sustainable level, with hindsight 62.9% said this advice would have been useful.
- Just 2.8% had been told to rest, however 26.7% of those given advice thought this would have been most helpful in hindsight.
- 10.8% of respondents had been told that exercise would help them recover and they should immediately start on a programme of increasing exercise. In hindsight, only 0.4% of respondents said this would have been helpful.

Analysis of the results for respondents who had visited paediatric services showed that children and young people were more likely than average to report rest being the most helpful advice on activity management, at 34.8% compared to 26.7% overall.

Of the respondents who had been given activity management advice, three-quarters of the 64.3% who were told to increase their activities said that with hindsight the most helpful advice would have been to halt any planned increase if symptoms worsened and that they might not be able to increase beyond a certain point.

Conclusions

The conclusions from the research, based on the key areas of NICE's call for evidence:

Management strategies during assessment for diagnosis:
- Results showed that healthcare professionals are commonly providing advice to maintain or increase activity during this period. Almost 9 out of 10 respondents deteriorated having followed this advice, compared to less than 1 in 10 who were told to rest.

Methods of monitoring and/or reviewing:
- Results identified that there was a failure of services to provide ongoing support or follow up which left respondents feeling abandoned and without help.
- Respondents thought that services should be led by a consultant, with support from professionals trained in the causes and impact of ME.

People's experience of interventions for ME/CFS:
- The experience of respondents showed that many ME services are providing unsuitable advice and treatments that often have a negative impact on patients' health.
- CBT was not helpful to a majority of respondents.
- Advice received on activity management and increasing activity was contrary to what respondents reported would have been most helpful in hindsight.
- Respondents were commonly pressured to undergo treatments.
- Overall, respondents wanted current services either to adapt or to be entirely rebuilt with patient input, confirming that current services are failing to meet the needs of patients.

At #MEAction UK we conclude that urgent change is required, as current services are not fit for purpose.

Read the entire report or full conclusions section to find out more.

Background and Objectives

The National Institute for Health and Care Excellence (NICE) issued a call for evidence on 30th August 2019 as part of the process of updating their ME guidelines. They set an initial deadline of 5th October 2019, which was then extended to 16th October 2019.

The call for evidence covered three areas that NICE felt were lacking in evidence:

- Management strategies that are adopted while someone is being assessed for a diagnosis of ME/CFS
- Methods of monitoring and/or reviewing people with a diagnosis of ME/CFS
- Evidence on the experience of people who have had interventions for ME/CFS

In January 2019 the Forward-ME Group, of which #MEAction UK is a member, carried out a survey specifically looking at the impact of the two main recommended treatments in the 2007 NICE CFS/ME guidelines (CG53), cognitive behavioural therapy and graded exercise therapy. The aim of the survey was to supply NICE with up to date patient data as they rewrite the guideline. This survey has been analysed and officially submitted as part of the current call for evidence.

#MEAction UK identified the potential for further patient data to enhance NICE's guideline development.

Considering there is a lack of evidence in these areas, #MEAction UK felt it imperative to add further evidence, working to create a balance between the professional judgement being used to write these guidelines and the expertise by experience of people with ME - especially where the wisdom of these two evidence sources contradicts.

To this end, #MEAction UK conducted a short survey covering these topics; the results of this are presented below.

Methodology

The survey was conducted online, with the questionnaire available between 24th September and 7th October, 2019. An online methodology was used in order to meet the deadline for evidence set by NICE: time constraints did not allow for paper based surveys to be sent out.

#MEAction distributed the questionnaire via social media and email to its contact list. Responses were anonymous and respondents were allowed to fill in the survey more than once if they had attended more than one ME service. The survey used the combined term ME/CFS as this is what NICE uses.

A total of 1,906 respondents completed the survey by the deadline. 6 responses were then removed from the data set as duplicates, where identical responses had been submitted, leaving a total of 1,900 responses for analysis.

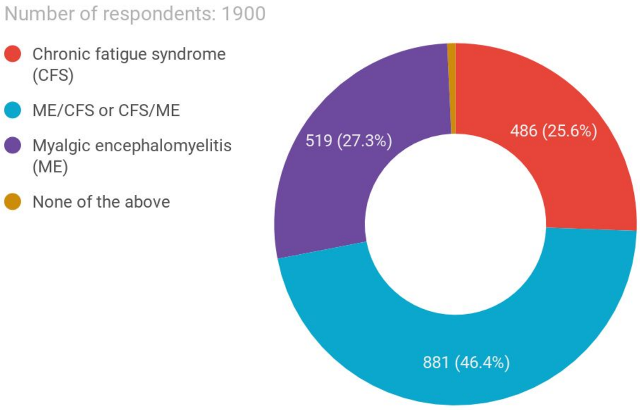
The report on the results uses charts to summarise the main quantitative findings from the survey. Open-ended comments have been analysed using thematic codes based on the main areas of comment and summaries of this analysis is provided in the report, using quotes from respondents to illustrate the main issues raised.

Profile of respondents

The initial question asked the 1900 respondents about their diagnosis of respondents.

- 46.4% (881) had a diagnosis of CFS/ME or ME/CFS
- 27.3% (519) had a diagnosis of myalgic encephalomyelitis (ME)
- 25.6% (486) had a diagnosis of chronic fatigue syndrome
- 0.7% (14) responded with 'None of the above'

Fig. 1. Diagnosis of respondents



The 14 respondents who did not have a diagnosis or CFS/ME, ME/CFS, ME or CFS were excluded from the remainder of the survey.

Of those with the above diagnoses, 99.3% responded that they experienced post-exertional malaise, defined as "a worsening of symptoms after minimal physical, cognitive or emotional exertion which can be delayed 24-72 hours or more".

Results

Management strategies whilst being assessed for a diagnosis of ME

The 1886 respondents with a relevant diagnosis were eligible to take part in this section.

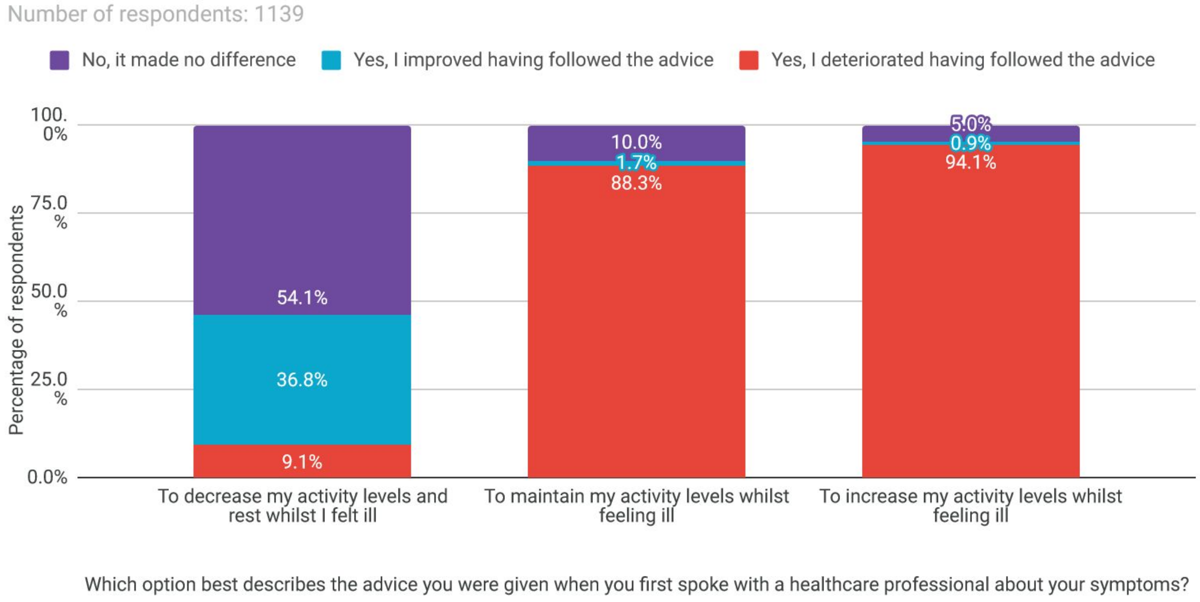
Respondents were asked, “Which option best describes the advice you were given when you first spoke with a healthcare professional about your symptoms?”

Of the 1882 respondents who answered this question:

- 39.1% (735) were not given any advice.
- 21.6% (406) were told to decrease activity levels and rest whilst they felt ill
- 15.5% (291) were told to maintain activity levels whilst feeling ill
- 23.9% (450) were told to increase activity levels whilst feeling ill

They were then asked: “Do you think following the advice you were given when you first spoke with a healthcare professional about your symptoms impacted your illness?”

Fig.2. Impact of initial advice from a healthcare professional when first presenting with the symptoms of ME/CFS



Of those who were told to decrease their activity levels and rest when they first spoke to a healthcare professional about their ME symptoms:

- 9.1% reported that they deteriorated
- 36.8% reported that they improved

- 54.1% reported that it made no difference

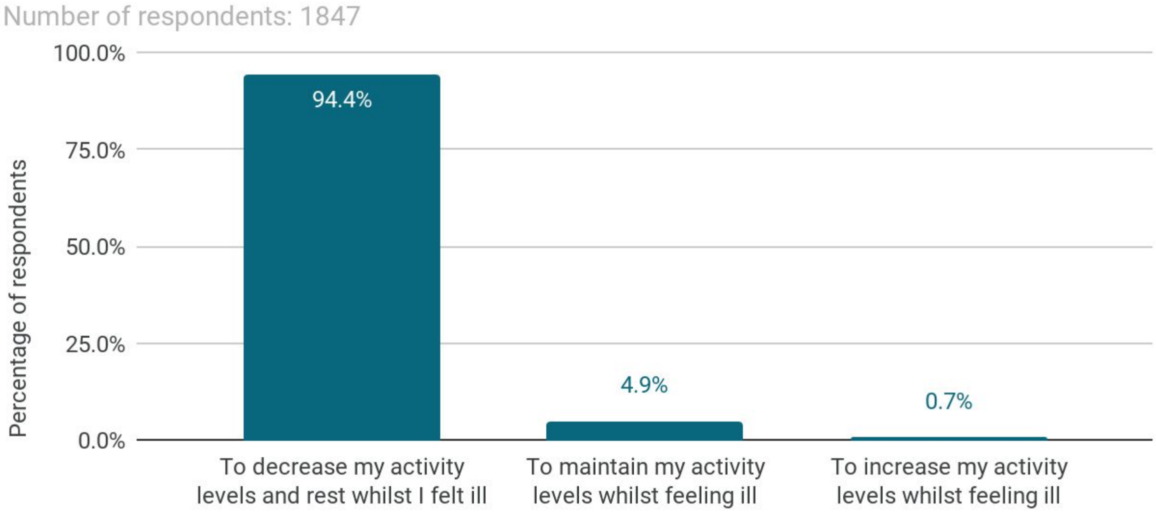
Of those who were told to maintain their activity levels when they first spoke to a healthcare professional about their ME symptoms:
- 88.3% reported that they deteriorated
- 1.7% reported that they improved
- 10% reported that it made no difference

Of those who were told to increase their activity levels when they first spoke to a healthcare professional about their ME symptoms:
- 94.1% reported that they deteriorated
- 0.9% reported that they improved
- 5% reported that it made no difference

In order to explore what advice respondents felt would have been most helpful when initially presenting with the symptoms of ME, they were asked: “In hindsight, which option best describes the advice you would have found most helpful when first speaking with a healthcare professional about your symptoms?”

- 94.4% of respondents reported that, in hindsight, the most helpful advice would have been to decrease activity levels and rest whilst feeling ill
- 4.9% reported that maintaining activity levels would have been the most helpful advice
- 0.7% reported that increasing activity levels would have been the most helpful advice

Fig. 3. In hindsight, which option best describes the advice you would have found most helpful when first speaking with a health care professional about your symptoms?



“I know that if I had been told immediately by my GP to rest, when I was mild, I would have dropped out of university then and stabilised and I would not be in this position now - where I cannot speak much, cannot move unaided and cannot even sit up or eat by myself. It has done me so much harm.”

Services

Of the 1886 responses received, 71.4% reported that they had attended a clinic, and 28.6% reported that they had not.

The experiences of the 1347 respondents who had attended a clinic are described in the section ‘Services attended’.

Had not attended a service

We asked the 539 respondents who had not attended a clinic if they had any comments. 328 respondents provided comments, with the key themes being:

- Lack of available support (299 mentions)
- Experience of health care professionals (210 mentions)
- Advice/Interventions (215 mentions)
- General negative comment about advice/services (81 mentions)

Each of these themes is explored in the following sections.

Lack of Available Support (299 mentions)

Of the 299 comments about the lack of support available, the key issues were:

- General lack of support, or no support (125 mentions)
- No clinic/services available in their area (64 mentions)
- Diagnosed a long time ago, and that there was often no support/clinic available then (46 mentions)
- Difficulty getting a diagnosis (26 mentions)
- Healthcare professional refused to or did not refer them, the clinic refused them, or they were not given funding to go to the clinic (23 mentions)
- Clinic being inaccessible (15 mentions)

“I have lost 16 years of my life with no help or advice. This disease is a living death sentence.”

“There is no provision of any help for those who are bedridden with ME or housebound and too ill to attend a clinic.”

Experience of Healthcare Professionals (210 mentions)

210 respondents commented on their experience of healthcare professionals. The key themes were:

- Lack of advice or support offered by their GP (90 mentions). For most this was a negative experience, and they felt their GP was unsupportive and lacked understanding (68 mentions). For a smaller number this was a more positive interaction with GPs who were supportive, but unable to offer advice (22 mentions).

"I have had no help at all. GP made it clear she did not believe me, said I should develop a philosophical attitude and offered no help."

"He was supportive but left me to research the disease myself. "

- Experiencing disbelief or dismissive comments from healthcare professionals (including GPs), with many being told that their symptoms were 'just' anxiety or depression (52 mentions)

"My current GP has stated she doesn't recognise ME. I've had raised eyebrows and been ignored if I've tried to tell other practice GPs and nursing staff that I've ME and how this impacts on my health."

- Healthcare professionals (excluding GPs) being unsupportive, lacking knowledge and being unable to give advice (68 comments).

"Once the diagnosis of 'CFS' was added to my notes, pretty much every GP and consultant I saw automatically assumed I was a hypochondriac"

"I feel I was fobbed off by doctors as they didn't know much about it."

Advice/Interventions (215 mentions)

215 people commented on the advice or interventions they received, or the advice or intervention they wished they had received with hindsight.
The key themes were:

- Exercise (graded exercise therapy GET, increasing activity levels), being a negative experience/experience deterioration or a desire that they had not followed this advice from healthcare professionals (62 mentions).

"Due to deteriorating more severely after medically advised early increase in exercise, I became permanently bed bound... my whole life quality is sub human."

- Self education- respondents had to educate themselves on how to manage their condition, through resources like charities and other voluntary organisations, online forums and their own professional and/or personal experience (49 mentions).
- Pacing or managing activity and rest in a positive way, either as something they found useful or something that they wish they had been told earlier/could receive (39 mentions).

- CBT/psychology- a negative experience or mention of CBT/psychology, not finding this intervention useful, or mentioned that they did not want (29 mentions).

"CBT made no difference to the fatigue/PEM but left me feeling a bit of a failure as the psychologists view was that "this cure works" so the fact that it hadn't was down to me."

- Rest- either that they found it helpful, or wish they had been told to rest earlier (23 mentions).
- Antidepressants- being prescribed for ME symptoms by health care professionals, and the experiencing of negative side effects (13 mentions) .

General Negative Comments (81 mentions)
Finally, 81 negative comments were made about the current advice and support available to people with ME in the UK.

"Doctors should be more educated and willing to listen to the plight of ME/CFS patients.... This condition is devastating to both the sufferer and their family. More help and support is crucial to help cope with not just the debilitating symptoms, but support for the loss of identity, as bit by bit quality of life changes beyond all recognition."

See Appendix 3 for the full list of comments from respondents who had not attended a specialist ME clinic.

Services attended

The 1347 respondents who had attended an ME clinic were asked to select the clinic they had attended. Of a total 69 services listed in our survey, 68 had been attended by respondents.

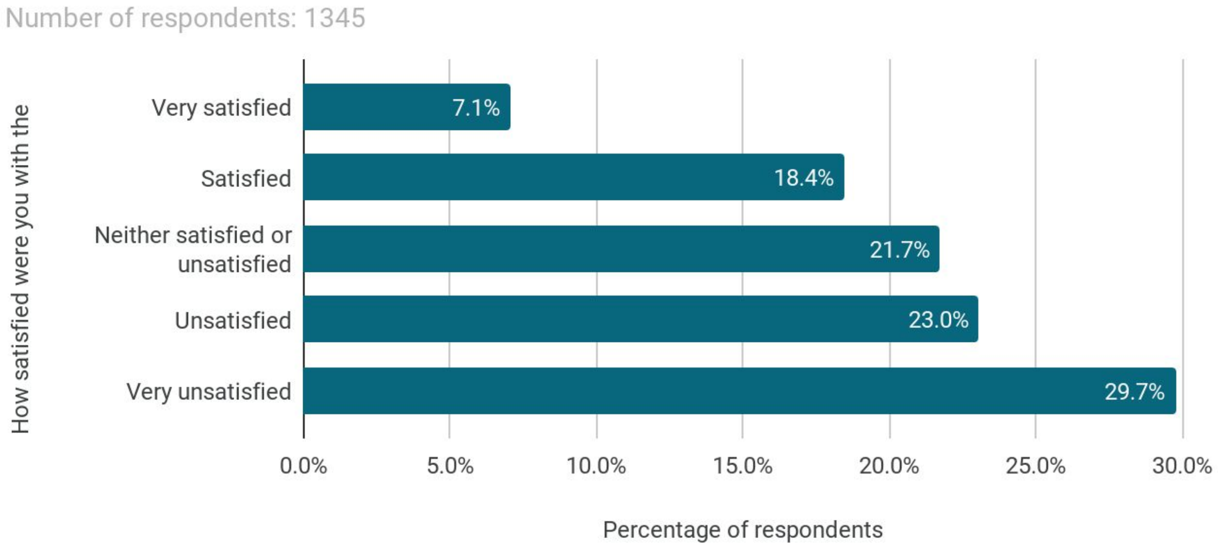
The top ten clinics attended by 28 or more respondents were:
- Bristol CFS/ME Service for Adults
- Sheffield CFS/ME Service for South Yorkshire and North Derbyshire
- Norfolk and Suffolk ME/CFS Service
- Liverpool CFS/ME Management Services
- Leeds and West Yorkshire CFS/ME Service
- Bath Specialist Paediatric CFS/ME Treatment Service
- Surrey - South West London and Surrey Chronic Fatigue Service
- Oxfordshire CFS/ME Service
- Essex Chronic Fatigue Service
- Edinburgh - Lothian CFS/ME Service

See Appendix 1 for a full chart of services attended. The year in which respondents had most recently attended their clinic is also shown in Appendix 1.

Satisfaction and views on appropriateness of services

When asked “how satisfied were you with the services, for example any treatments or courses, provided by the clinic?”, the most common responses were very unsatisfied (29.7%) and unsatisfied (23%), meaning a majority (52.7%) were unsatisfied with services. 21.7% responded that they were neither satisfied or unsatisfied, 18.4% responded that they were satisfied, and 7.1% responded that they were very satisfied, equalling a total of 25.5% who were satisfied overall.

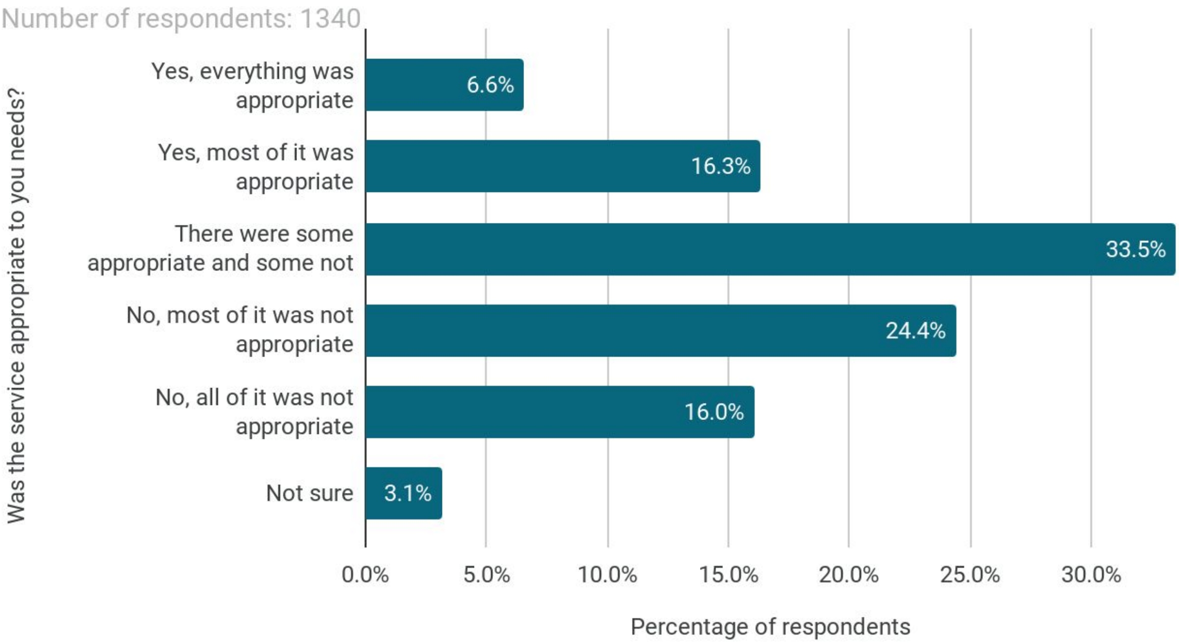
Fig. 4. How satisfied were you with the services, for example any treatments or courses, provided by the clinic?



Respondents were asked how appropriate they felt the services provided were, including any treatments or courses. The most common answer was the neutral response that there were some appropriate and some not appropriate aspects (33.5%). In total, 40.4% responded negatively, saying either most of the service (24.4%) or all of the service (16%) were not appropriate. Less than a quarter (22.6%) responded positively, saying either most of the service (16.3%) or all of the service (6.6%) was appropriate. 3.1% responded that they were not sure.

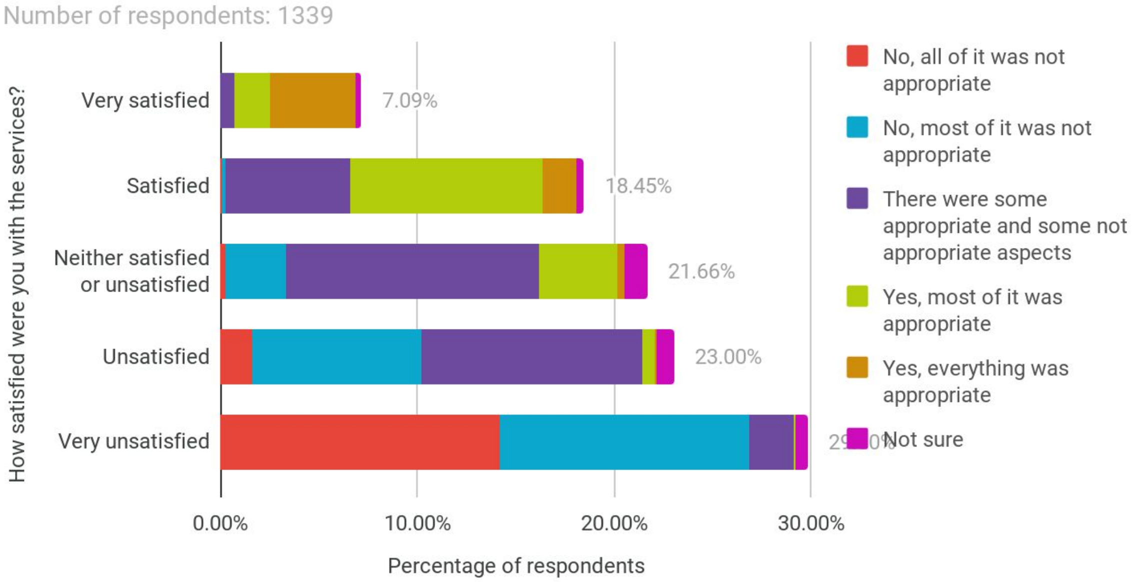
“I had to fill in an activity sheet at the beginning which had a week of time split up into hourly blocks - this was difficult to complete as I could barely sustain any activity for more than a few minutes and was mostly resting. They seemed to assume that everyone would have a 'boom and bust' activity pattern and the advice given (which was supposed to be based on my own activity chart) was clearly generic.”

Fig. 5. Appropriateness of services



The chart below compares how satisfied respondents were with how appropriate they reported the service provided to be. This demonstrates a clear correlation between finding some or all of the service not appropriate and being unsatisfied with them.

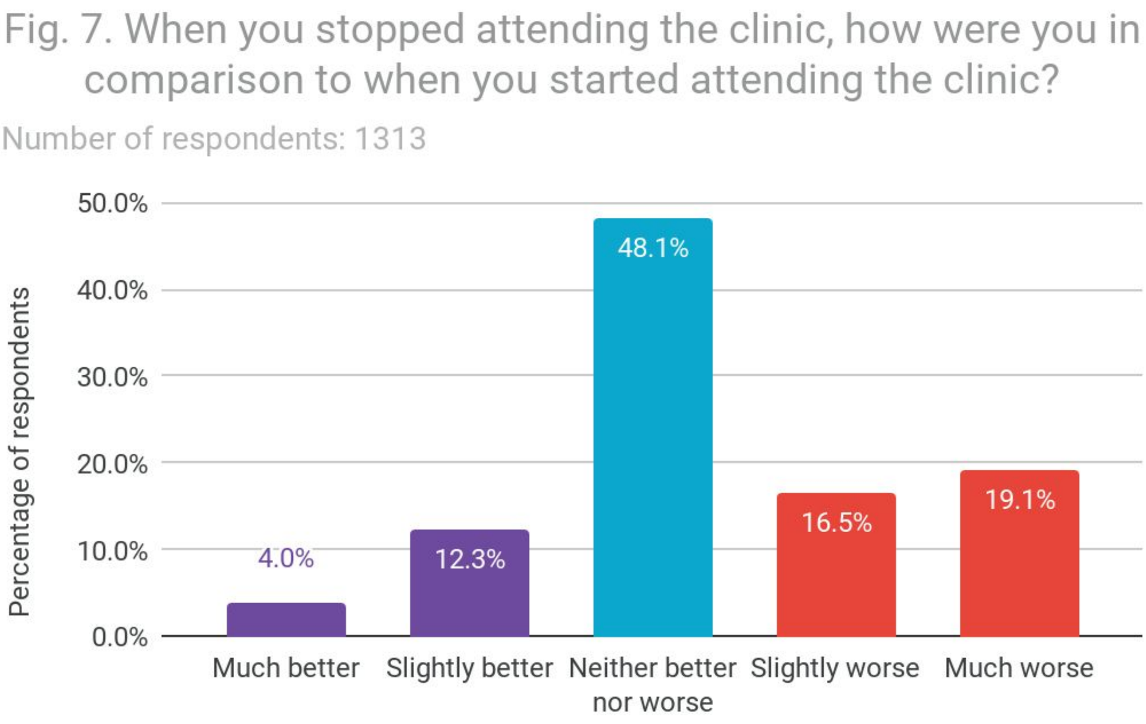
Fig. 6. Comparing satisfaction with appropriateness of ME/CFS services



Impact of attending a clinic

To understand the impact of ME clinics on the health of people with ME, respondents were asked how they were when they stopped attending the clinic in comparison to when they started attending the clinic.

Almost half of respondents said they were neither better nor worse (48.1%) after attending an ME service. Over a third (35.6%) responded that they were slightly or much worse (16.5% and 19.1% respectively) compared to a total of 16.3% who responded that they were slightly or much better (12.3% and 4% respectively).



See Appendix 1 for a breakdown of impact by service attended.

“They thought I would be 100% if I followed the course. I am the same 10 years later. I have no support and GPs know nothing about my condition.”

“I did everything the 'experts' told me to do, deteriorated badly, and was discharged from the clinic because I wasn't improving.”

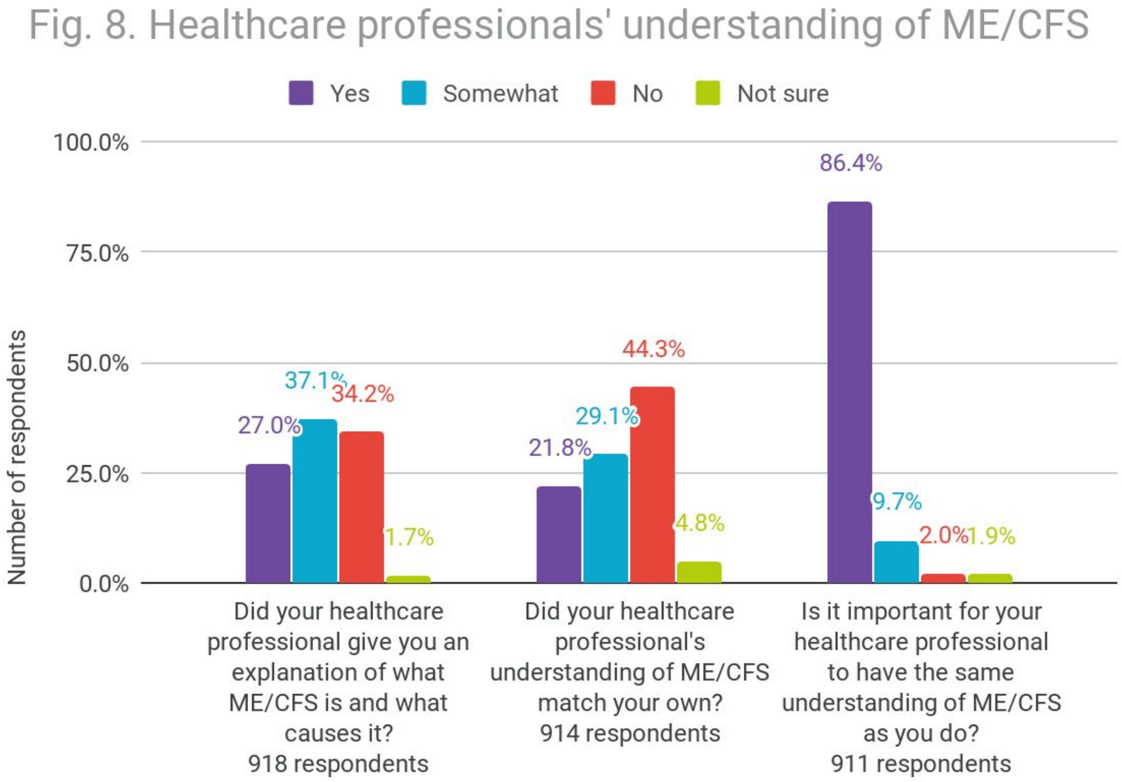
Healthcare professionals’ understanding of ME

Respondents were asked a series of 3 questions relating to healthcare professionals’ understanding of ME. These were:

1. Did your healthcare professional give you an explanation of what ME/CFS is and what causes it?
2. Did your healthcare professional’s understanding of ME/CFS match your own?
3. Is it important for your healthcare professional to have the same understanding of ME/CFS as you do?

Answer options were yes, somewhat, no and not sure.

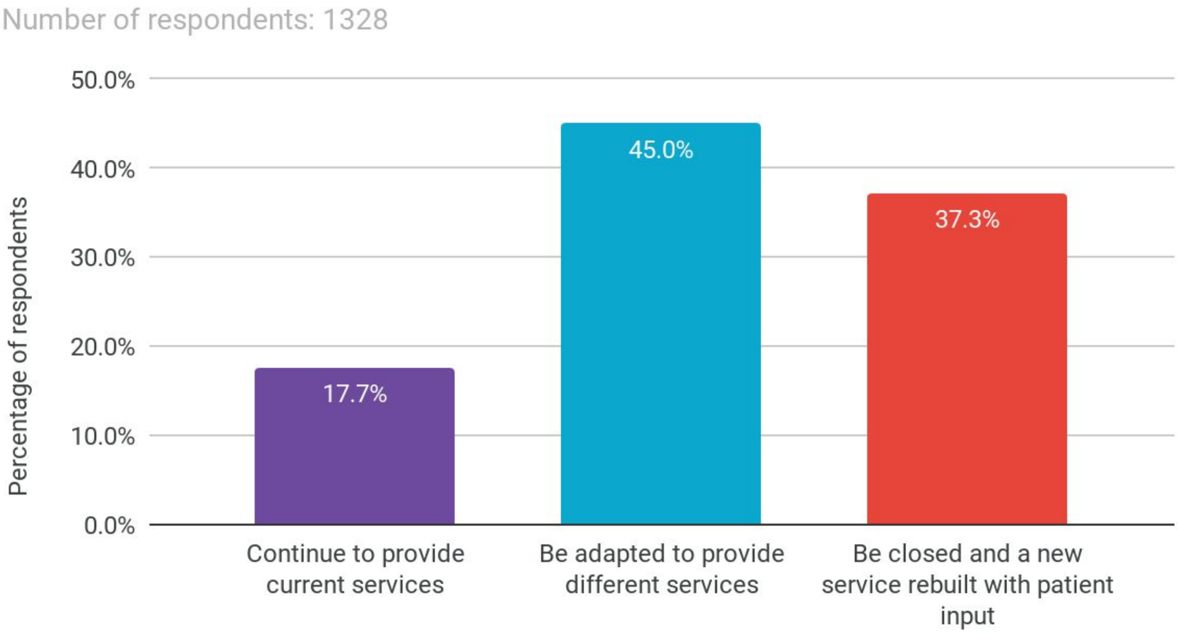
- 27% of respondents said that their healthcare professional had given them an explanation of what ME is and what causes it. In contrast, over a third (34.2%) said they had not been given an explanation and a further 37.1% said they had been given somewhat of an explanation.
- There appears to be a mismatch between the health professionals and patients’ understanding of ME: only 21.8% of respondents said that their healthcare professional’s understanding of ME matched their own, with 29.1% saying it somewhat matched, and 44.3% that it did not match.
- It is clearly important to people with ME that there is a common understanding of ME between respondents and their healthcare professional, with 86.4% answering yes, 9.7% answering somewhat and only 2% answering no.



Views on the future of UK clinics

In order to assess respondents' views on the future of the clinic they attended, we asked them what they thought should happen to the clinic based on their experience there. Over 80% of respondents said that that change was needed, with 45% responding that the clinic they attended should be adapted to provide different services, and 37.3% responding that the clinic they attended should be closed and a new service rebuilt with patient input. Only 17.7% felt that the clinic should continue to provide current services.

Fig. 9. Based on your experience at the clinic, should it:



> *"It needs to change, whether this means starting from scratch or adapting. I was given 3 appointments with an OT who was sympathetic but didn't really offer any advice. And no treatment options at all."*

We broke this down for each service. Shown below is respondents' views for all NHS clinics that had 25 or more responses. As is evident, responses varied significantly depending on the service attended.

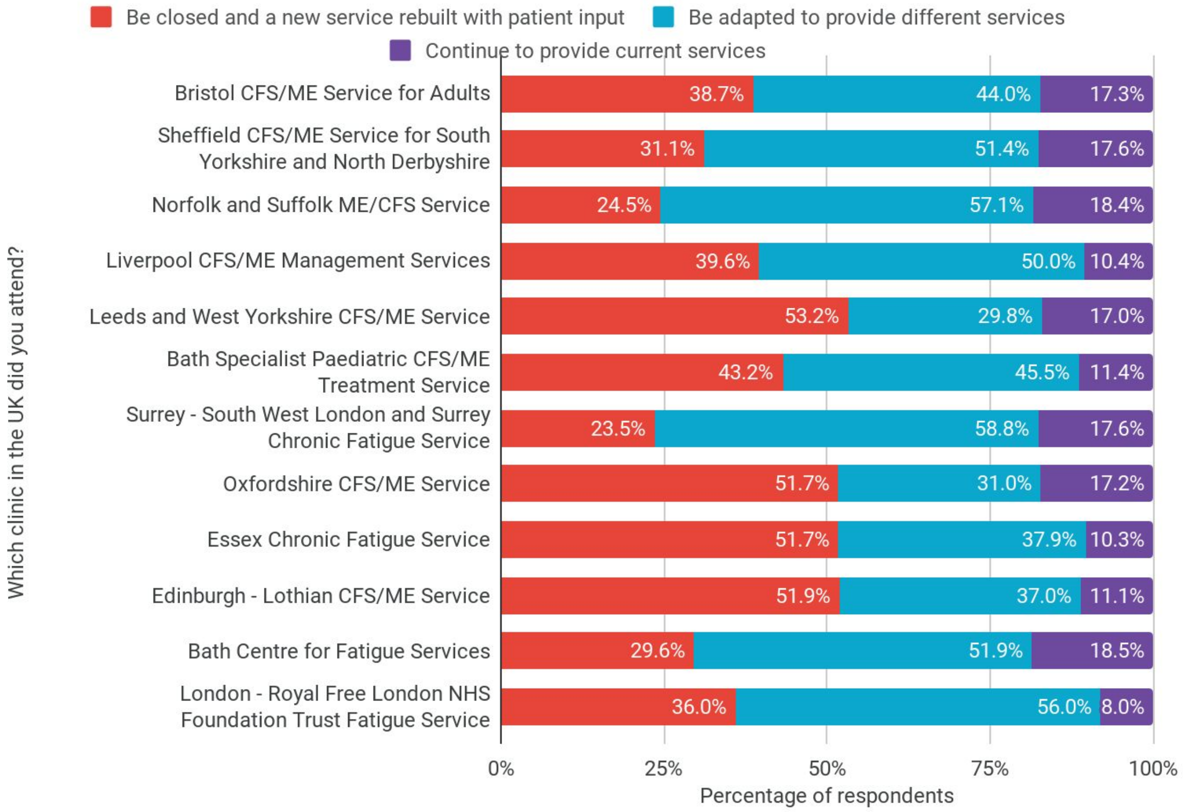


Fig. 10. Respondents' views on the future of clinics - showing data from all clinics that had 25 or more responses

Number of respondents: 748

For a full breakdown of views on all clinics see Appendix 1.

Comments on the future of UK clinics

Comments on the future of the clinics they attended were made by 1,104 respondents.

The main comments related to generally negative comments about clinics, but analysis has identified the following specific reasons for suggesting that clinics should close or be adapted:

- Psychological approach/approach based on false illness beliefs/deconditioning/biopsychosocial model (154 mentions)
- Clinic offers graded exercise therapy/condition worsened due to GET (141) mentions)
- Negative comments on staff/lack of understanding (116 mentions)
- Limited support available (115 mentions)
- Given bad/poor information/advice/treatment (81 mentions)
- Clinic offers CBT based on belief it will help with symptoms of ME (64 mentions)
- Severe ME - clinic not accessible/no support (50 mentions)

- Lack of accessible support generally (39 mentions)

Comments from respondents who wanted their clinic to continue were generally positive (81 mentions), with specific aspects highlighted:

- Positive comments on staff sympathetic/understanding/supportive (31 mentions)
- Given good/effective advice/information/treatment (12 mentions)

Other issues mentioned were:

- Pacing as effective approach/ clinics not able to support pacing effectively (51 mentions)
- Negative impact of NICE guidelines on support at clinic (28 mentions)

Finally, there were a large number of comments on how services should be developed (146 mentions), specifically identifying the need for patient involvement in designing services (42 mentions).

General negative comments (187 mentions)

Overall negative comments highlighted the range of issues respondents faced with the service offered at some clinics:

"Not fit for purpose, understaffed, no care for those who are housebound, no understanding of severe ME/CFS, no acceptance overexertion causes deterioration, no understanding of cognitive difficulties - I was told in a clinic letter they were due to loss of confidence!"

"The venue was up stairs, the staff were uninformed and the content was not relevant. Group sessions with other sufferers only provided confirmation of lack of care available, no one was helped by this process."

Psychologically based (154 mentions)

Respondents reported that clinics based their services on a psychological model of ME, citing approaches based on false illness beliefs, deconditioning and biopsychosocial model.

"Completely psychological explanation despite me already having been assessed by Cahms and no psychological issues found. They do not understand CFS/ME and wanted me to increase exercise by 25% every week. They know nothing about biomedical research or PEM."

"Hull is run by the Psychological Department they think it has a psychological base and therefore are not interested in biomedical research or approach. I was told in the first session that if we were going to work together, I would have to accept that there was an emotional element to the cause of my illness. The counsellor admitted she had no experience of ME/CFS and expected me to be able to get to the appointment and then talk for an hour, and just kept asking what I was going to do about it, and then went off sick herself."

“Clinic run by a psychologist and physio, it was tailored to ME being a psychological condition.”

Graded Exercise Therapy negative (141 mentions)

The impact of being told to do graded exercise therapy and the harm caused to respondents by following this advice was a key issue, particularly for those who wanted clinics closed or adapted.

“They still run prescribe graded exercise therapy. I felt compelled to push through my limits to drive to attend the clinic which was a distance away, stay all day without a rest period and push through to increase my exercise amounts even though I felt unwell. The group setting was OK but there was then the compulsion to 'keep up'.“

“Because it only provided and prescribed CBT and GET as ‘treatment interventions’ neither of which helped me with my symptoms and in fact made them worse; that the clinic is/was run by two people […] who continue to maintain that GET and CBT are helpful and effective ‘treatments’ contrary to current international research.”

Negative comments on staff (116 mentions)

Comments on staff ranged from those who had found staff unsympathetic and rude, to those who felt that staff simply did not understand ME and therefore were unable to provide support.

“The first appointment I had with the specialist they were astonishingly rude and told me that I was lazy and slept too much and that there was nothing wrong with me.“

“Even though I found a few aspects of the service helpful on the whole they showed little understanding of how best to help or manage the condition and no understanding regarding the limitation of ME around attending session or the knock on effect of doing so.”

Limited support available (115 mentions)

Comments on the limited support available included issues with the infrequency of appointments and limited number of sessions available.

“My appointments are every 3 months, which is not enough to help with the pacing recommended.“

“They are a very small team, with little funding. They do the best they can and they offer one on one help but you have a limited number of appointments which is not helpful for a chronic condition that ebbs and flows. The education on the illness is limited to one or two sessions and an information pack. This is compared to the private treatment I sought where I saw the lady once a week for at least a year which is generally what you need when managing such a condition.”

There were specific issues with lack of support once the sessions were completed.

“I don’t personally feel that I was given enough help and information to cope with my condition when I was discharged. There was a six month follow up but as I hadn’t improved and there was no more help available I felt rather abandoned.”

“The course was very basic and only 6 weeks long, there was a 6 month follow up session which I was unable to attend and then I was discharged from the service with no further help nor guidance and without being asked."

Poor information/advice (81 mentions)
There was a range of comments about inappropriate advice, with many highlighting information relating to treating ME as a psychological disease or based on the GET or CBT models of treatment (or both).

“The course was much too late. I had already been ill for 2 years and learnt it myself. It also didn’t cover how bad a relapse could be. It didn’t cover supplements and has no follow up help or advice available other than the course.“

“All clinic attendees are given free copies of Chalder/Burgess published books on Chronic Fatigue at first appointment, therefore primed in expected response to ‘treatment’ which is basically just psychotherapy with activity diaries.“

“Sometimes advice given was incredibly unhelpful and the only real options were CBT, GET, or sitting and talking about what you did in the last week.”

Comments also highlighted that supportive staff were often handing out information that was outdated or inappropriate.

“The team were knowledgeable and nice but aspects if the advice given I didn't feel were appropriate, particularly surrounding GET.”

CBT- Negative comments (64 mentions)
Criticisms of CBT related mainly to the therapy being used as a ‘treatment’ for ME rather than it having a negative impact on health.

“Their general recommendations seem to also be CBT or GET, and they'll never be able to treat us properly if they keep recommending outdated treatment methods.”

“The treatment is based on CBT and GET which has been debunked as inappropriate for people with ME.”

“I was offered CBT which did help me accept my illness a little better but this was misleading in the sense that I was told to keep exercising and that I would eventually recover. I did that and I'm STILL not recovered. And now I can't tolerate ANY type of exercise at all.”

Severe ME (50 mentions)
Comments from respondents with severe ME showed how they were excluded from getting support at some clinics as they were too unwell to attend.

“As a severe sufferer they reviewed things but could offer no further support. I had one appointment a letter summarising symptoms and have been left to manage. There is no provision for online support and help for those of us too poorly to attend the groups/residential.”

"The course was 2.5 hours in length which was completely inaccessible for me, given that I have 1-2 useable hours in the day including eating, getting ready and transport that meant I could only attend 1 hour of the course and not every week because it was just too much for my body.”

Other comments showed that a few clinics tried to accommodate people with severe ME highlighting the significant difference in the services offered to patients.

"I was unable to attend they came to me. Good support but v little advice and stayed too long. Should have referred me to a neurologist given my symptoms then I think. Eventually I was made to feel bad for needing ongoing support and discharged even tho I have v severe m.e.“

Lack of accessible support (39 mentions)
Having to physically attend the clinic was an issue both in terms of access to the building and being well enough to attend in person. Comments showed that some clinics did not offer alternatives to attending in person.

“The venue was up stairs, the staff were uninformed and the content was not relevant. Group sessions with other sufferers only provided confirmation of lack of care available, no one was helped by this process.”

“Makes everything worse going. Telephone support would be ideal.“

“I often wasn’t well enough to attend so I feel that home visits or video calls would initially have been helpful.”

Travelling to the clinic for appointments was a major problem for some respondents who were either too unwell to travel or felt that the travel left them too ill to take part in the sessions.

“I was discharged for not being well enough to travel. I attended 2 appointments, which were both PowerPoint presentations and received no advice, support or care.”

“Some subjects the clinic covered were good, such as pacing. It was just hard to get to the clinic every week as it was about 3 hours altogether, including travel, so for anyone that has severe ME it was a set back just to get there.“

General Positive comments (81 mentions)

Respondents who wanted the clinic to continue to provide its current services were able to identify a range of positive aspects of the clinic.

“The service is very informative and provides a safe environment to share experiences with others who have the same diagnosis.”

“They have been excellent. They visit at home and have kept us on even when we should have been discharged as my partner is so severe.”

“I got my diagnosis there and they taught me about pacing and some useful limitations, but understanding the science of it and finding ways to meaningfully improve has all been done through my own research.”

Positive comments on staff (31 mentions)

Respondents who wanted the service to be adapted or continued were able to identify key staff who had been helpful.

“The OT was amazing. Consultations by phone to avoid travelling. Sound advice.”

“I have found my ME nurse really helpful however I feel further support/treatment options would be beneficial as well as a closer link to GP & consultants.”

It was clear, however, from other comments that positive attitudes from staff were not able to address the fundamental issue of the support that was offered to patients.

“Staff were lovely, but overall the clinics are rushed and not very flexible, which is something it needs to be when dealing with patients with fluctuating symptoms.”

“Lovely well meaning people but basic group presentations and three hour trip exhausting all of what I already had researched myself with a graded exercise recommendation which doesn’t help makes it worse.”

Pacing (51 mentions)

Most comments on pacing were positive, although some respondents with a positive experience of pacing felt that the clinic should offer more advice.

“Some subjects the clinic covered where good, such as pacing.”

“The Clinic was mostly focused on giving advice about pacing and not much else.”

Not all those that had been advised on pacing felt that the advice was helpful.

“I was given a DVD about pacing and symptoms which was helpful in some ways but I was given no help from a ‘person’ and pacing only works if you are given state aid otherwise how can you work and pace. Also it is impossible to pace properly without carers, help with housework, shopping, preparing food etc which we are not offered.“

NICE Guidelines (28 mentions)
NICE guidelines were mentioned by respondents as a reason for saying their clinic should be closed or adapted, with the impact of current guidelines restricting staff being mentioned..

“The staff were caring and obviously mean well. If the new NICE guidelines were less harmful/more helpful I am sure they would deliver them well. It is poor guidelines which cause the problems!”

“Long term patients seem to have more knowledge of the illness and current staff are limited to what they can recommend due to outdated NICE guidelines.”

Developing services (146 mentions)
One of the key areas suggested in developing new clinics was involving patients in the development of services.

“Patient input and understanding of broader spectrum of patients and their needs would be beneficial alongside a more up to date approach on the understanding of some people are affected more than others with the malaise caused after the simplest of tasks.”

“As one of the millions who have cfs/me. I think that it’s of utmost importance that we have a say and input into the treatment we are offered. But I also strongly believe that more can be achieved by not saying we're faking the illness as a dr wouldn't say that to an individual with cancer but I have had it said to me countless times.”

Suggestions for developing clinics included the need to base treatment on the latest research.

“ I would like treatment based on the latest biomedical research and based on a multi-disciplinary team including a neurologist as ME is a neurological disease (WHO).”

“The advice and treatments offered should accord with up to date international research findings for ME/CFS and the WHO definition of ME/CFS.”

There were also comments on the need for clinics to include a range of healthcare professionals.

“Physiotherapy is important as well as OT and seeing consultant, but have to wait too long between appointments.”

“They need a Doctor that has some understanding of this illness and is up to date on the current research. They also need a physiotherapist who understands this illness and won't pressure patients into GET.”

Comments also highlighted that clinics should be able to help people with severe ME, reflect comments shown earlier that clinics are not always offering appropriate support for people with severe ME.

"I feel there needs to be a bit more variation in approach as I really struggled with the suggestions. I also feel it's very much geared to more mild forms and they really need to have help for people at the more severe end."

There were a range of suggestions for services that clinics should offer:

“Clinic should offer check ups, reviews, physio, counselling and OT services in my opinion.”

Extending access to services was also seen as critical in helping people with ME to cope with the illness.

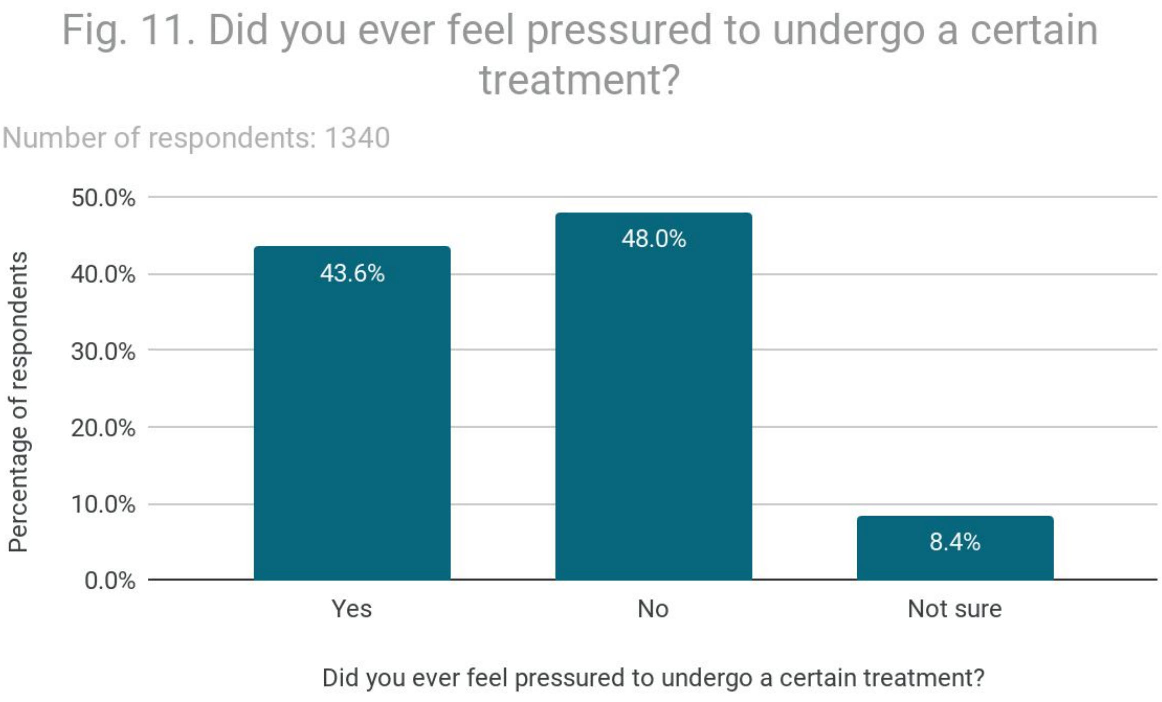
“Needs to have continuous advise services not just a course then stop and left to fend for ourselves.”

“It could do follow up appointments instead of discharging once diagnosed and also listen to your symptoms more.”

See Appendix 5 for the full list of comments explaining respondents’ views on the future of UK clinics.

Pressure to undergo treatments

43.6% of respondents said they had been pressured to undergo a certain treatment, 48% said they had not been pressured, and 8.4% said they were not sure.



A full breakdown by service of whether respondents felt pressured to undergo certain treatments is available in Appendix 1.

“The clinic advised exercise, pressured me repeatedly to take antidepressants and offered no hope or useful advice.”

“The pressure I felt to comply with treatment (GET) was subtle - I wasn't harassed into it but as I trusted the staff treating me I wanted to do my best to follow the programme even though I was clearly struggling. I was made to feel that failure to improve following this approach was down to a flaw in my personality- i.e. being too anxious and analytical- I realise now it was simply because I was too ill for GET and the struggle to succeed at it was very damaging- physically and emotionally/ psychologically. I am still severely ill 5 years later.”

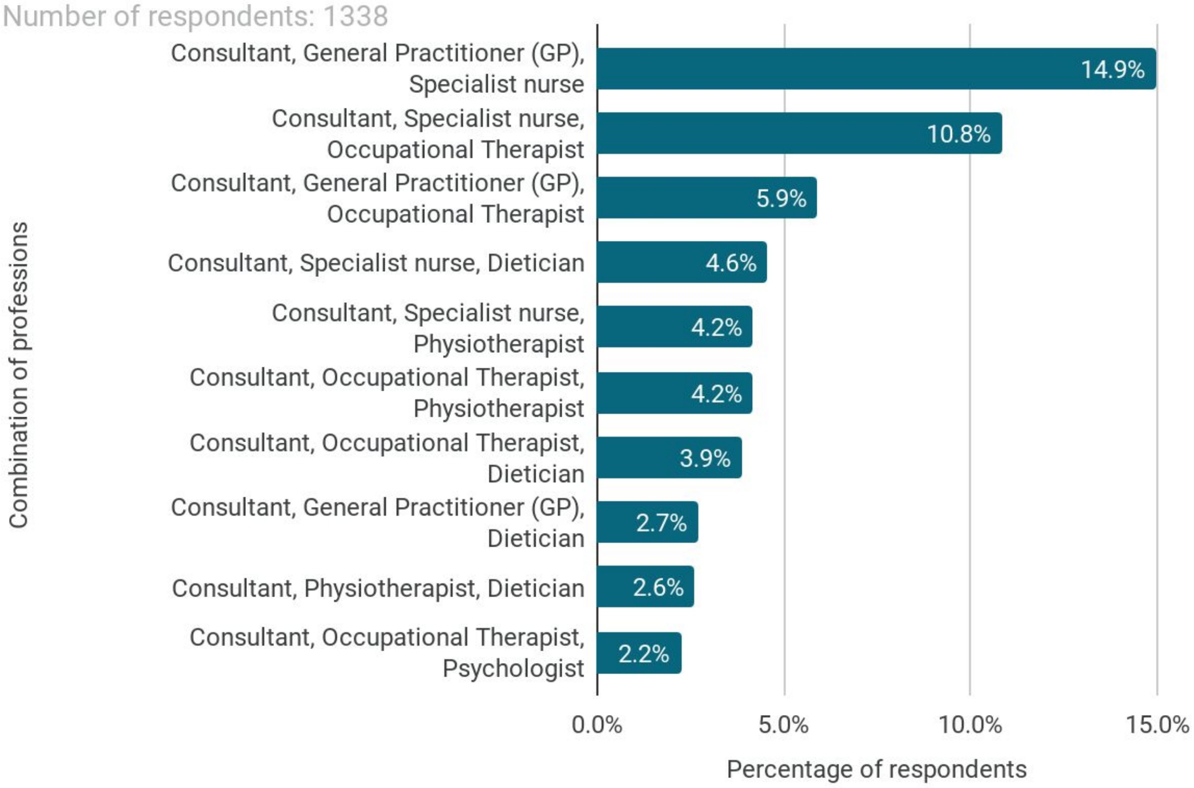
Preferred composition of multidisciplinary team

Respondents were asked to choose their top 3 professionals to be in a multidisciplinary team delivering services for people with ME. Precoded choices were consultant, general practitioner (GP), specialist nurse, occupational therapist, psychologist, physiotherapist and other. Respondents who chose other were given the option of specifying this.

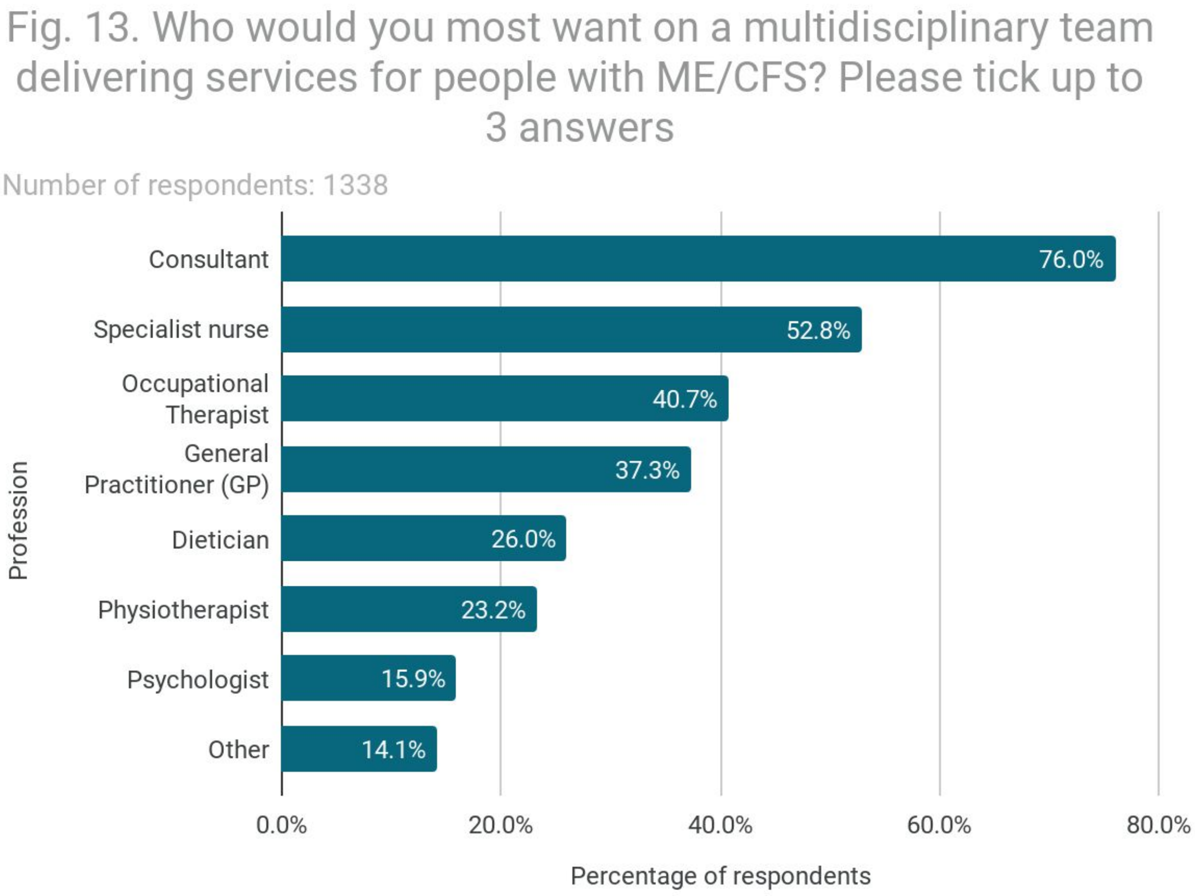
Overall there were 198 total different combinations, mainly from people specifying a variety of 'other' options. Of the 1338 responses, 750 picked one of the 10 combinations in the bar chart below. The most common combination of professionals respondents wanted in a multidisciplinary team delivering services for people with ME were:

1. Consultant, General Practitioner (GP) and Specialist Nurse (14.9%)
2. Consultant, Specialist Nurse, and Occupational Therapist (10.8%)
3. Consultant, General Practitioner (GP) and Occupational Therapist (5.9%)

Fig. 12. Top 10 combinations of professionals that respondents wanted on a multi disciplinary team delivering services for people with ME/CFS



Of the 1338 responses, consultant was the most common choice, with 76% choosing this as one of their top 3. Specialist nurse came in second at 52.8% of responses. Occupational therapist was the third most common choice at 40.7% of respondents.



Out of the 1338 total number of responses, 189 people chose other, with 48 leaving no comment. Of the 141 that left comments, there were 46 mentions of wanting to see someone with knowledge of or who specialises in ME, with no specific opinion on what role they should be in.

"A specialist who is up-to-date with all current ideas and developments with regard to ME/CFS."

"I think this could be flexible, the important part is that the staff are knowledgeable, interested and want to be there."

There were 34 mentions of the specific sort of consultant people would like to see on the team, the most common being neurologist at 18 mentions. 16 responses mentioned a desire for access to alternative medicine, and 14 mentioned having someone with lived experience of ME on the team.

See Appendix 4 for further categories of mentions that received less than 10 responses each and the full list of comments made under 'other'.

Experience of cognitive behavioural therapy (CBT)

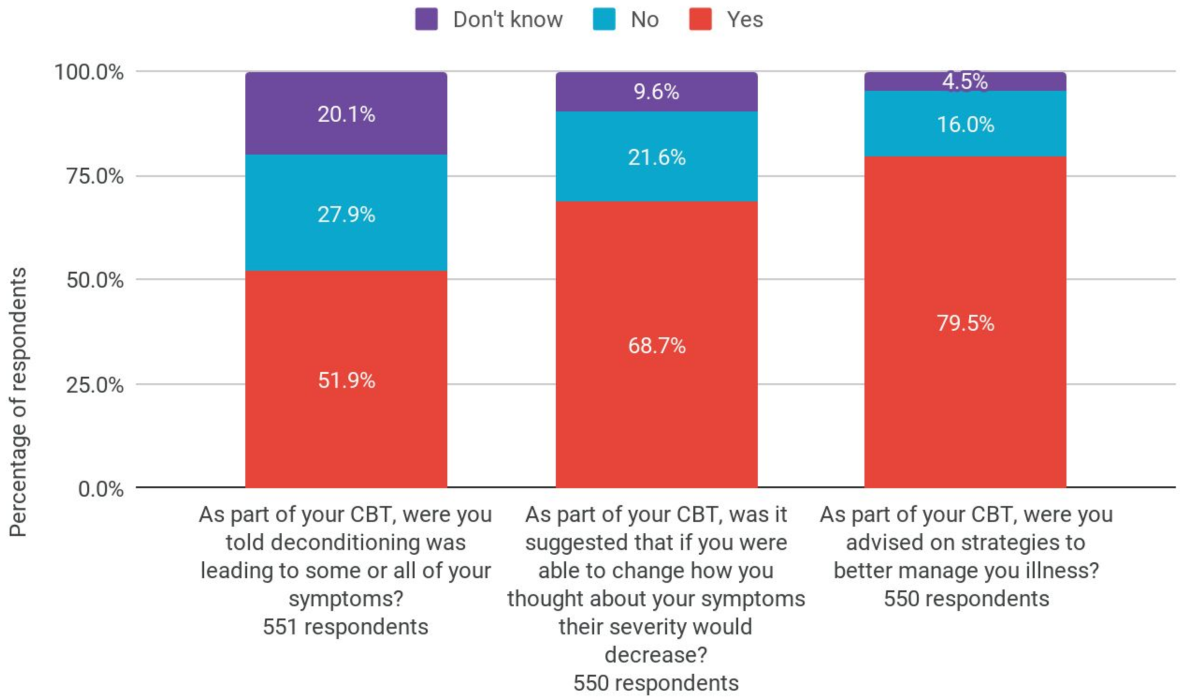
Of the 1264 respondents who answered the section on CBT, 41.1% had received CBT at the clinic they attended.

A majority of respondents who had received CBT (51.9%) were told that deconditioning was causing some or all of their symptoms, compared to 27.9% who were not, and 20.1% who responded they didn't know.

Most respondents (68.7%) also had it suggested that if they were able to change how they thought about their symptoms their severity would decrease. 21.6% were not told this, and 9.6% responded 'don't know'.

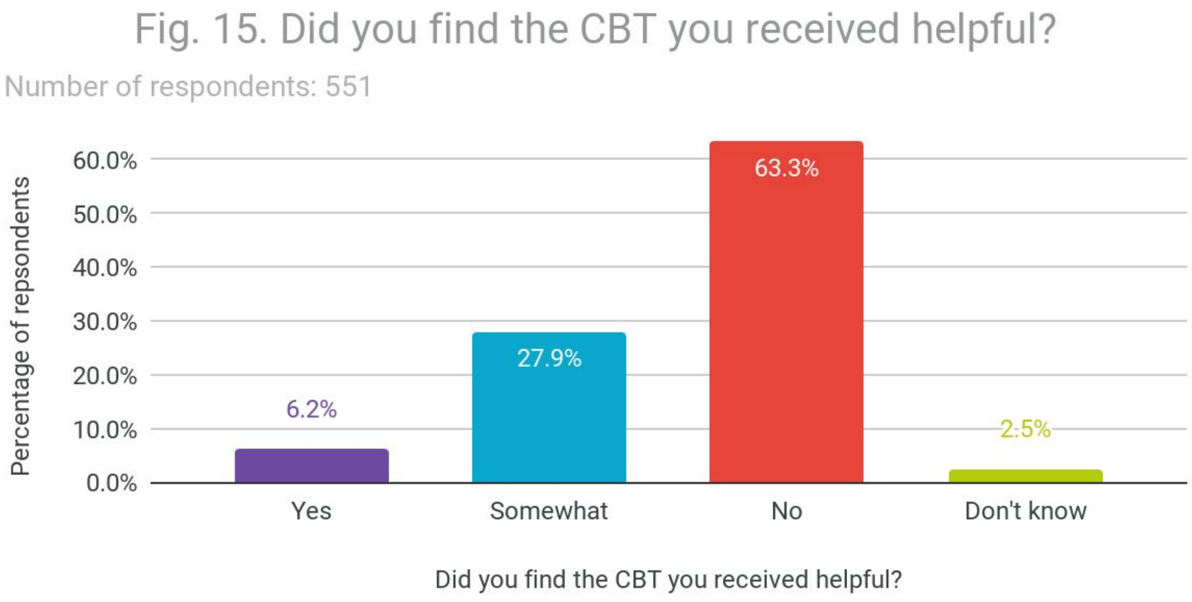
A final question explored what was involved in the CBT respondents received at UK ME clinics: "As part of your CBT, were you advised on strategies to better manage your illness?". 79.5% replied yes, 16% replied no, and 4.5% replied don't know.

Fig. 14. Cognitive Behavioural Therapy - What is involved



"CBT encouraged me to stop thinking of myself as having ME and a serious illness. They said everyone felt tired sometimes and did not accept ME"

The survey then asked whether respondents found the CBT they received helpful. A very small minority of 6.2% said yes, just over a quarter responded somewhat (27.9%), and almost two thirds responded no (63.3%). A final 2.5% responded 'Don't know'.



A full breakdown of the helpfulness of CBT by service can be found in Appendix 1.

"At no time was I given a proper programme of treatment involving medical staff. I was told that CBT would either completely resolve the ME or would significantly improve it. It has done NEITHER!"

"When I became severely ill I was pretty much ignored and I felt like a failure or that had I implemented CBT or something else correctly I would not have got worse. There was no support from specialists after I became severely ill. I now live in a care home and have had severe ME for 20 years."

Advice on activity management

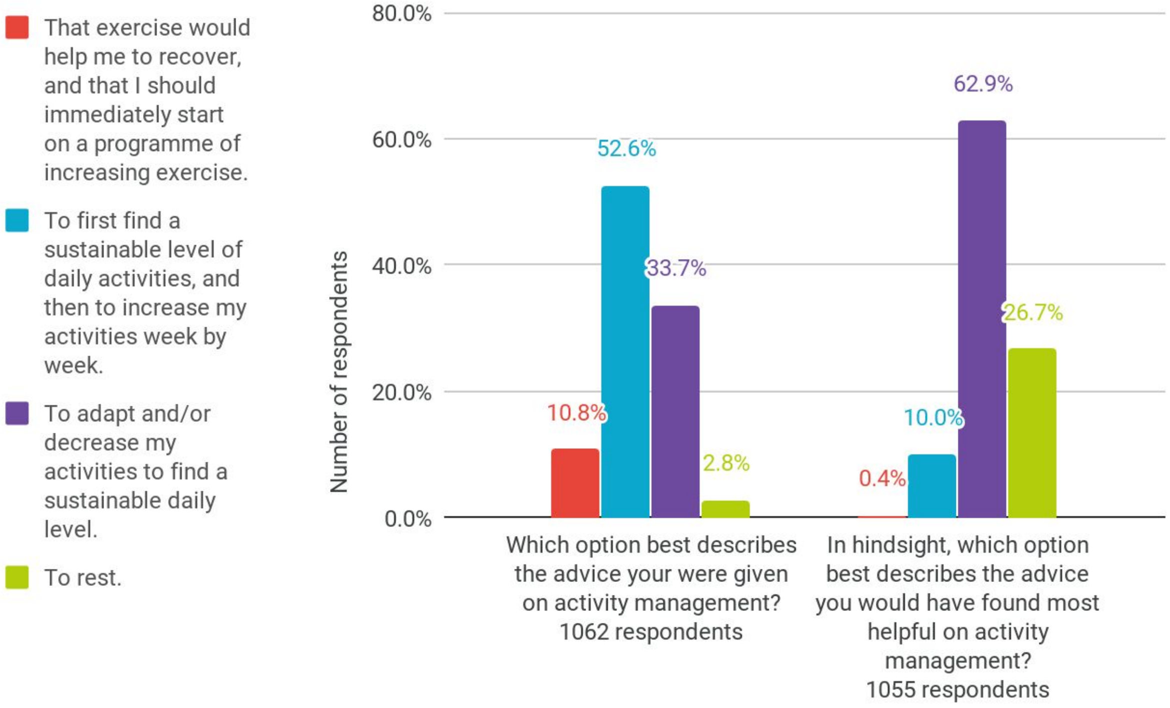
79.2% (1067) of respondents were given advice on how to manage activity levels whilst at their clinic. This cohort were then asked about their experience and what advice would have been most helpful in hindsight. 20.8% (280) of respondents said they had not been given advice on activity management at the clinic they attended. These respondents were routed to the questions on what advice would have been the most helpful in hindsight.

Advice on activity management

The next chart shows a comparison between the advice on activity management respondents received with the advice they now report would have been most helpful.

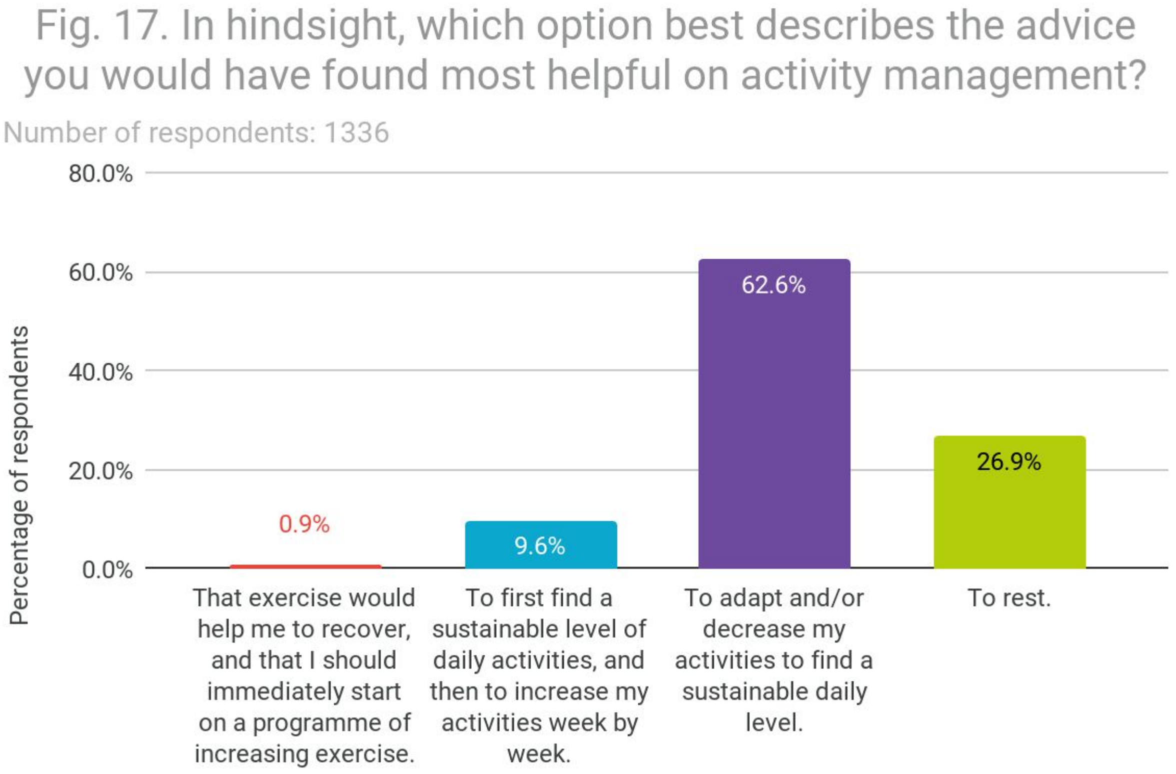
- 10.8% were told that exercise would help them recover, and that they should immediately start on an exercise programme. Just 0.4% of respondents reported that this would have been the most helpful advice.
- 52.6% were told to first find a sustainable level of daily activities, and then to increase their activities week by week. 10% reported that this would have been the most helpful advice.
- 33.7% were told to adapt and/or decrease their daily activities to find a sustainable daily level. A majority of 62.9% reported this would have been the most helpful advice.
- Finally just 2.8% were told to rest, however over a quarter of respondents (26.7%) reported that this would have been the most helpful advice

Fig. 16. Advice given on activity management compared to advice that would have been most helpful in hindsight



> *“I was never given time to find my proper base level before being encouraged to increase my activity levels. It is impossible to know where to go if you don't know where you're starting from!”*

Overall, over 60% of all respondents reported that, in hindsight, the advice on activity management they would have found most helpful would have been to adapt and/or decrease their activities to a sustainable daily level.



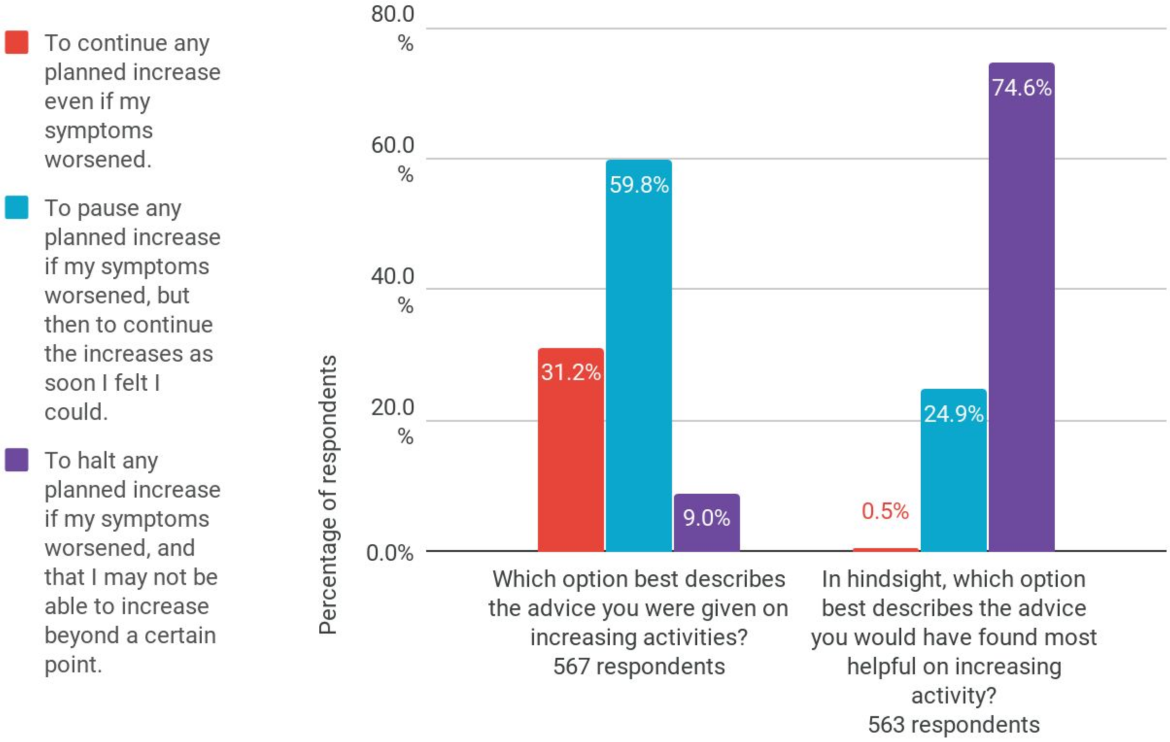
A full breakdown of the activity management advice received at each service can be found in Appendix 1.

Advice on increasing activity

The chart below compares the advice on increasing activity respondents received with the advice they report would have been most helpful.

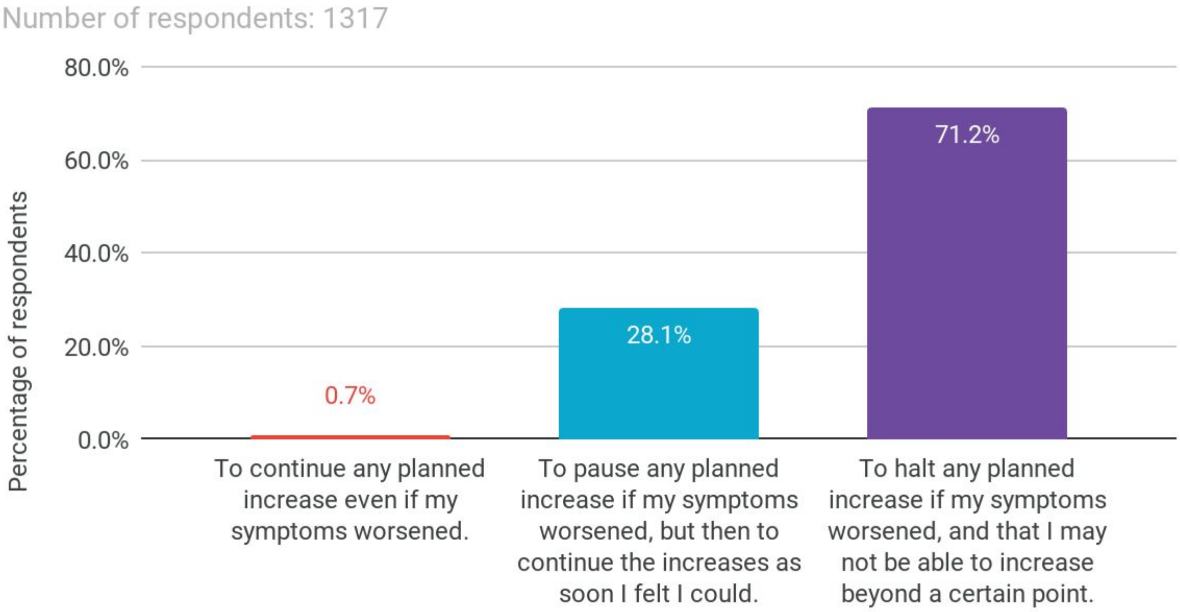
- 31.2% were told to continue any planned increases even if their symptoms worsened. Just 0.6% of respondents who were given any advice on increasing activity reported that this would have been the most helpful advice.
- 59.8% were told to pause any planned increases if their symptoms worsened, but then to continue the increases as soon they felt the could, compared to 24.8% who reported that this would have been the most helpful advice.
- 9% were told to halt any planned increases if their symptoms worsened, and that they may not be able to increase beyond a certain point, compared to the large majority of 74.6% of respondents who reported that this would have been the most helpful advice.

Fig. 18. Advice given on increasing activity compared to advice that would have been most helpful in hindsight



Overall, 71.2% of all respondents reported that, in hindsight, the most helpful advice on increasing activity would have been to halt any planned increase if their symptoms worsened and that they may not be able to increase beyond a certain point.

Fig. 19. In hindsight, which option best describes the advice you would have found most helpful on increasing activity?



Final comments

Respondents were asked whether they had any final comments before submitting their response. 797 answers were recorded for this question.

A range of themes have been identified in the responses, some relating to questions the survey had asked and others to topics beyond the scope of this survey; most were still related to treatment, and experience of ME services.

Overall, there were 582 mentions of negative experiences, compared to 95 mentions of positive experiences, with some responses mentioning both.

Key themes identified are:

- Experience and impact of services (391 mentions)
- Experiences with healthcare professionals (382 mentions)
- Activity management and graded exercise therapy (127 mentions)
- Cognitive behavioural therapy (78 mentions)
- Stigma, a psychological approach and blame (103 mentions)
- Difficulty accessing diagnosis and referrals (62 mentions)
- Lack of follow up and early discharge from treatments/services (60 mentions)
- Being left alone with no treatments, advice, care or support (130 mentions)
- Severe ME/CFS (49 mentions)
- Other treatments (65 mentions)

Each of these themes is explored in more detail below.

Experience and impact of services (391 mentions)
391 mentions related to the experience respondents had of services, the impact attending had on their health, and the provision of inappropriate services.

184 respondents included general negative mentions of the clinic they attended, compared to 49 respondents who reported positively on the clinic they attended.

“I feel badly let down and angry that this service made my illness worse and contributed to me eventually having to stop working.”

“Just that the advice and information given was often muddled and/or contradictory and very unhelpful overall. For example, there didn't seem to be an understanding that even basic activities of daily living could be too much (as most were for me) so that it was actually impossible to 'find a sustainable baseline' in the way they expected but it was just assumed this would be a quick and simple and all the emphasis was on increasing activity.”

“Great service in terms of being well understood by physiotherapist with good advice given on finding a baseline before implementing any increase of activity. Therapist made me realise I do too much considering my diagnosis. This kind of therapist is hard to find having experienced different services in different parts of the UK.”

82 respondents mentioned that after attending the clinic their health was worse. 3 respondents mentioned a positive impact on their health.

“I was able to manage my illness for over 30 years without needing intensive care before I was involved in this service. Taking their advice ruined my life and that of my family.”

“I should not have been dismissed, belittled and pushed beyond my boundaries. As a result I developed new symptoms with speech, swallowing and mobility.”

73 comments discussed services not meeting their needs, be this through location and travel times being prohibitive, not being well enough to attend and no home visits or telephone appointments available, appointments being rescheduled at the last minute, services closing down or not being available in their area, or not being allowed to bring anyone with them.

“The service isn't fit for purpose if it can't be flexible over being too unwell to attend (I had phoned to cancel beforehand with explanations.”

Experience with healthcare professionals (382 mentions)
382 respondents mentioned their experience with 1 or more healthcare professionals.

There were 45 mentions of positive experiences with healthcare professionals, of which 19 were related to the respondent’s GP.

“It’s clear to me that services to people with ME vary considerably. I feel incredibly fortunate in having an incredibly supportive and knowledgeable specialist in the team at Truro and a brilliant GP, but I dread either of those two professionals moving on from their posts.”

Respondents described 273 negative experiences with healthcare professionals, with 92 of these relating to GPs.

“I've never felt so belittled as by the Dr I saw there, I was in floods of tears after she spoke to me and she just got up and opened the door.”

“I found that when speaking to other professionals they either thought I was lying or misdirected me.”

“Professionals knowledge and understanding of CFS/ME in my experience is very poor and impacts significantly on my condition and any outcomes. I have had a consultant tell me

CFS/ME did not exist and a GP sit and stroke his imaginary beard while telling me they could not explain my symptoms."

"I have had CFS/ME for 17 years now and I still don't feel we are believed/understood by healthcare professionals, they still use the same plan fits all approach and that is the worst approach as we all differ so much. I wasn't diagnosed for 4 years and in that time was told over and over to push myself, increase my activity and push through the pain/fatigue etc. I was given CBT and graded exercise over and over even though I kept telling them it was making me worse."

64 respondents mentioned a need for better education and training of healthcare professionals.

"Educate more GPs and hospital staff about ME as most do not believe in this illness or no nothing about it, it's very frustrating to have an illness that isn't being taken seriously."

"Health care professionals need up to date training on ME/CFS. (...) Those who are meant to be helping us are causing us the most harm."

Activity management and graded exercise therapy (127 mentions)
Respondents made 110 mentions of graded exercise or advice to increase activity levels- of which 107 were negative. 17 respondents mentioned being told to maintain or decrease activity levels.

"Following GET/CBT caused a huge decline from relatively mildly affected to housebound/bedbased. I have not recovered from that."

"6 years to get diagnosed, then when I did the clinic made me even worse , pushed me far beyond my body's capabilities with the promise that I would recover from my deconditioning in their words."

"I was made to believe I had to keep pushing through. I did this for further 7/8years and believe I'm so much more worse for it. Its soul destroying."

Cognitive behavioural therapy (78 mentions)
There were 63 negative and 15 positive mentions of CBT.

"I was given CBT and graded exercise over and over even though I kept telling them it was making me worse. Now every year that passes I get worse and worse, new symptoms arise, pain is worse and so is both the physical and mental fatigue."

"CBT encouraged me to stop thinking of myself as having ME and a serious illness. They said everyone felt tired sometimes and did not accept ME."

“Graded Exercise Therapy & Cognitive Behavioral Therapy should be banned, at best it's problematic, outdated and full of lies and at worst severely dangerous leaving patients with little to no quality of life or function.”

“CBT doesn't work if the cognitive symptoms of ME are severe on a particular day, because the symptoms make it impossible to implement. Graded Exercise Therapy makes things worse. Real action and treatment is needed, not trying to fob patients off with CBT and GET as a magic fix, and then blaming the patients when they don't work, or sectioning them when they won't undertake the "treatment", as was the case with one patient who died."

“Cbt helped me come to terms with having M.E. I'm not sure it helped with much else.”

Stigma, psychological approach, deconditioning, false illness beliefs, and blame (103 mentions)

There were 103 mentions of the stigma respondents experienced, including the use of a psychological approach, negative mentions of being told about deconditioning and false illness beliefs, as well as blame being attached to the respondent for their illness or not recovering.

“Last week I visited my gp with severe head pain, she was sympathetic till I said I had m.e, she threw her pen down, rolled her eyes and said I had too much time on my hands to dream up symptoms.”

“The guilt associated with being told ‘if you do more you’ll get better’ is enormous. I was bed bound and in a terrible way... the energy required to get to appointments on the few occasions I could manage would set me back months. Then I’d feel guilty that I tried to go something I knew I couldn’t do when my energy might have been better used laughing or enjoying my family.”

Difficulty accessing diagnosis and referrals (62 mentions)

62 respondents spoke of difficulty being diagnosed, experienced misdiagnosis or years between onset and diagnosis. Respondents also mentioned believing that had they known and been given accurate advice earlier on, they wouldn’t be as severely affected as they are now.

“When I first got ill no one would even entertain a diagnosis as there was no local help available. This meant my symptoms kept getting worse while I tried to keep working. I have continued to deteriorate despite finally being able to be referred to the local service and had I had decent advice on rest during the initial stages I believe I may not have been as disabled by it as I am now.
I really feel that where ME/CFS is suspected that a stronger emphasis on early diagnosis and treatment is a must.”

Lack of follow up and early discharge from treatments/services (60 mentions)

There were 60 mentions of lack of follow up or early discharge from treatment, including discharge due to deterioration, or discharge when the illness or life circumstances made it impossible to attend appointments as regularly as required by the service.

"The physiotherapist told me that almost all her patients recover which I found surprising as I had been told and read that there is no cure and as soon as it became clear I was not getting better I was discharged rather abruptly."

"Once the course ended that was effectively the end of the support offered"

Being left alone with no treatments, advice, care or support (130 mentions)
130 respondents described being left on their own with no appropriate treatments or advice, no support, and family often acting as carers.

"I'm currently left to my own devices and no longer under any NHS care. Simply forgotten about and left to rot."

"From diagnosis I haven't felt supported. Feel as though I have been left to manage this horrendous, debilitating and fluctuating illness by myself. I have had no advice or support regards to working and sickness and the stress caused by trying to adapt and manage every aspect of life has further exacerbated my symptoms. I've had no real support with regards to which medications to relieve symptoms and feel that GPs do not understand/believe this condition. Something has to change to support the thousands of sufferers in this country alone!!"

"Since 2009 I have not received ANY informed expert advice or support with my ME and have encountered disbelief and hostility."

Severe ME/CFS (49 mentions)
49 respondents mentioned being or becoming severely affected, or concern about provisions for the severely affected.

"The advice and materials given are not suitable for someone with severe ME/CFS and the clinic did not know how best to help someone with my severity of condition- resulting in discharge after worsening symptoms"

"When I became severely ill I was pretty much ignored and I felt like a failure or that had I implemented CBT or something else correctly I would not have got worse. There was no support from specialists after I became severely ill. I now live in a care home and have had severe ME for 20 years."

Other treatments (65 mentions)
65 mentions of other management or treatment approaches were recorded, including pacing, B12 supplementation or injections, Vitamin D, medication for POTS and other comorbid conditions, pain medication, meditation and nutrition. These were often unavailable at clinics.

See Appendix 6 for all comments submitted for this question.

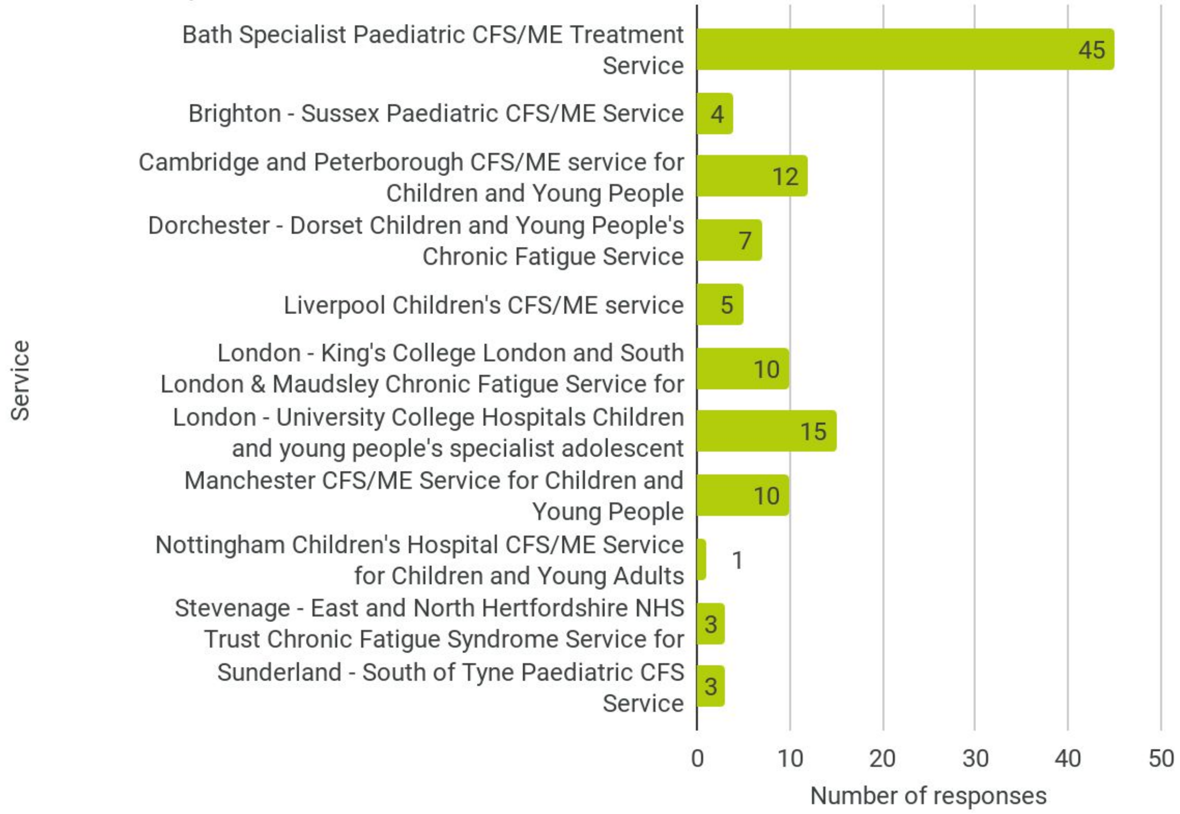
Specialist paediatric services

115 responses related to specialist paediatric services; whilst this is a fairly low number we considered it important to analyse separately responses relating to these services. The results for paediatric services have been compared with the overall survey results described in the previous sections of the report.

Results in this section summarise key findings where there were more than 100 respondents.

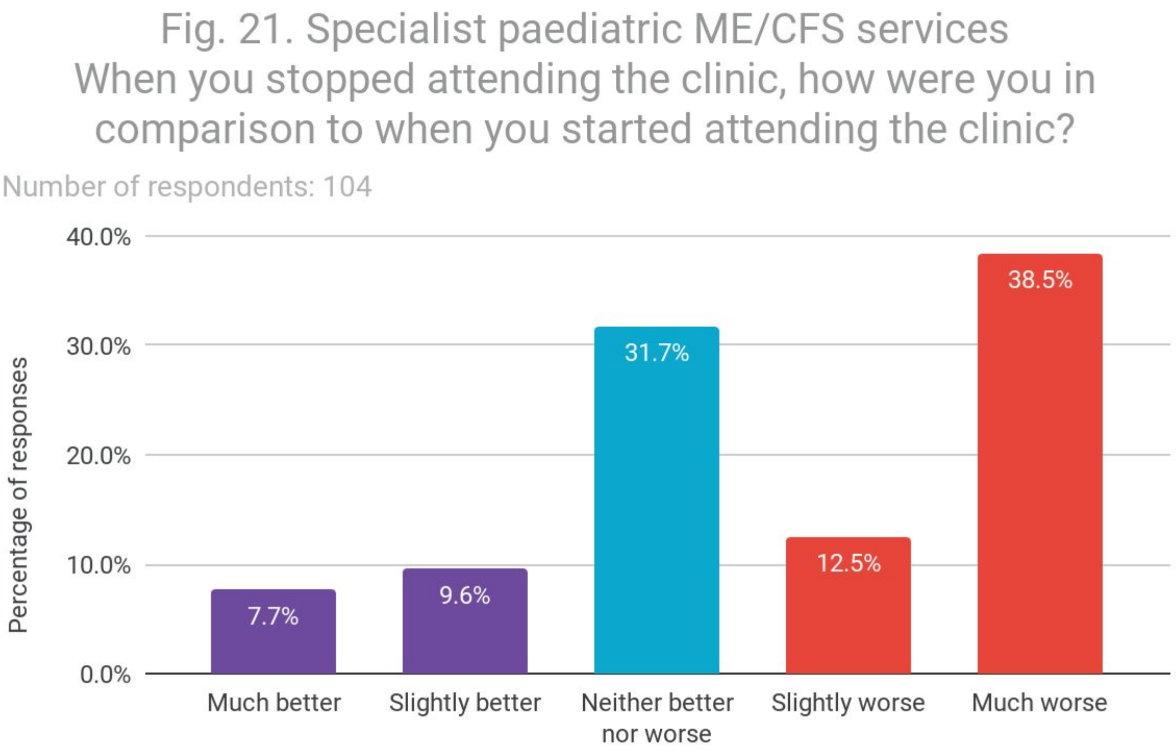
Services attended

The chart below shows the number of respondents for each specialist paediatric service in the UK. The most commonly attended service was Bath Specialist Paediatric CFS/ME Treatment Service.



Impact of services

A higher proportion of respondents reported they were worse (51%) after attending a specialist paediatric service than the overall figure for all the services (35.6% - fig. 7). 31.7% reported they were neither better nor worse and a total of 17.3% that they were better.



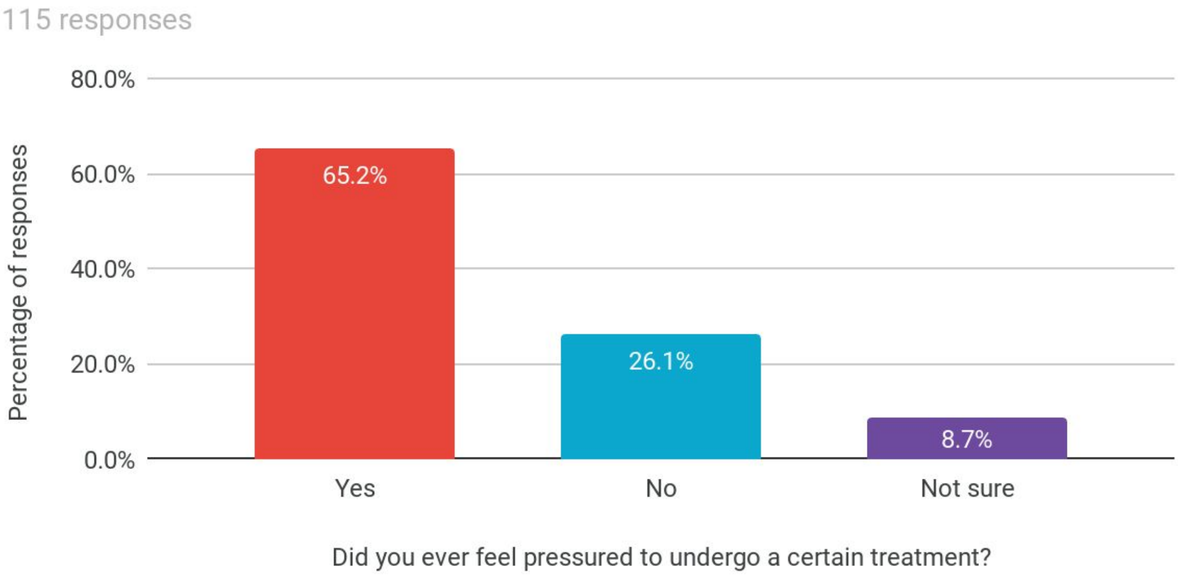
“Physio made my daughter worse. Shaking and causing PEM. So much conflicting advice. The professionals don’t even know what to do. How are we supposed to know?”

“Consultants in this department accused my mum of FII [fabricated or induced illness] because she didn’t agree with treatment. She had to go to my doctor, as she was so worried about me, to get me to stop doing GET as it was making me worse and it was getting very close to my exams.”

Pressure to undergo specific treatments

65.2% of specialist paediatric services respondents had been pressured to undergo specific treatments, compared to 43.6% of respondents overall (fig. 11). 26.6% of paediatric respondents said they had not been pressured to undergo specific treatments compared to 48% overall. A similar percentage (paediatric: 8.7%; overall: 8.4%) responded ‘don’t know’.

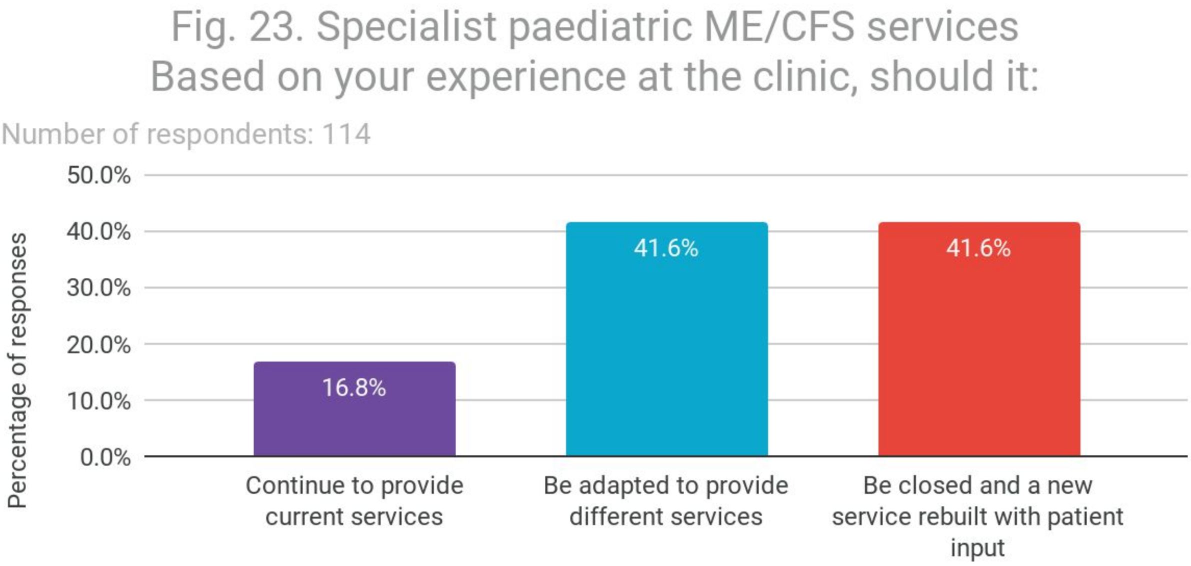
Fig. 22. Specialist paediatric ME/CFS services
Did you ever feel pressured to undergo a certain treatment?



"She went from being able to walk short distances to being unable to walk, sit up or hold her head up. She was shouted at and told she was lazy and forced to do intense physio including hydrotherapy. She was made to get out of bed at 7am and not allowed to return until 7pm. The advice and care she received was so harmful and neglectful. 5yrs later she still hasn't recovered, she [is] a full time wheelchair user, tube fed and missed 5 yrs of schooling. Something MUST change. We are under a different hospital now, the care is not harmful but also isn't helpful or supportive. There is nowhere for us to turn to for help."

Views on the future of specialist paediatric services

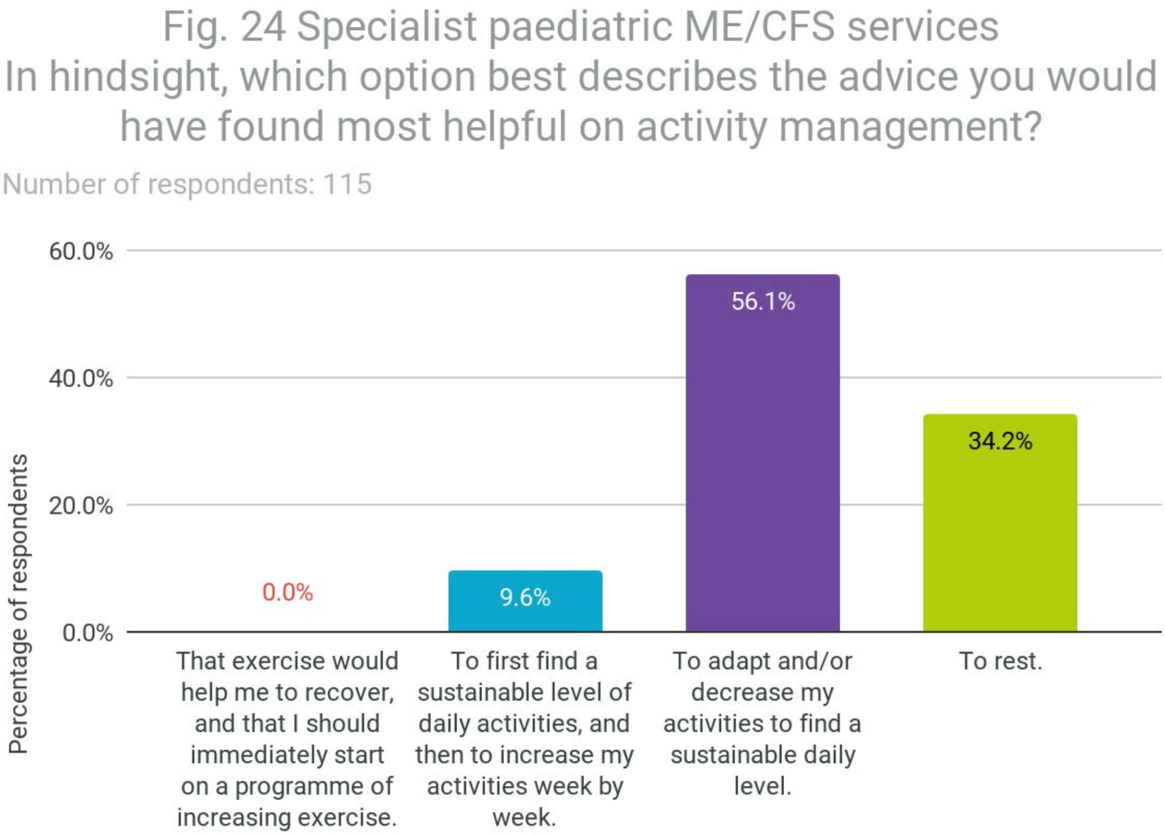
Responses relating to specialist paediatric services showed a higher proportion wanting the service to be closed and a new one rebuilt with patient input (42.1%), compared to 37.3% for all services (fig. 9). A lower proportion responded that the service they attended should be adapted to provide different services, 41.2% for paediatric services compared to 45% overall. A similar percentage reported that the service they attended should continue to provide current services: 16.7% for paediatric services compared to 17.7% overall.



Breakdown by clinic for all services is shown in Appendix 1.

Activity management

A higher proportion (34.8%) of responses relating to paediatric services reported that, in hindsight, rest would have been the most helpful advice on activity management, compared to 26.9% overall (fig. 17). A majority of 55.7% reported advice to adapt and/or decrease their activity would have been the most helpful advice, compared to 62.6% overall.



Conclusions

The conclusions have been structured around the three areas NICE outlined in their call for evidence.

Management strategies whilst being assessed for a diagnosis of ME

The findings described in this report expose a gulf between the advice given to respondents and what, with hindsight, they would have found most helpful.

Strikingly, when first speaking to a healthcare professional about their symptoms, almost 10 times as many respondents reported deterioration having followed advice to maintain or increase their activities than those who were advised to rest. 94.4% of respondents reported that, in hindsight, the most helpful advice would have been to rest - a figure that cannot be taken lightly.

Methods of monitoring and/or reviewing people with a diagnosis of ME

Respondents concluded that they would like services to be consultant-led, with professionals trained on the causes and impact of ME. This approach would help meet respondents' desire to establish a common understanding of ME with their healthcare professionals and would improve the relationships between patients and healthcare staff.

Thematic analysis identified many respondents reporting being left without any ongoing support or follow up, leaving them feeling abandoned and without help.

Evidence on the experience of people who have had interventions for ME

The results indicate that services are unsuitable and often had a negative impact on the health of respondents, with a majority reporting they were unsatisfied and found at least some aspects of the service 'not appropriate'. A total of 82.3% of respondents believed that the clinic they attended needed to adapt to provide different services or to close and start anew. Of the 51.9% respondents who reported that attending the clinic changed their health status, over twice as many reported they were worse having attended the clinic than reported improvement.

CBT was not helpful for 63.3% of those who had received it, adding further evidence that it should not be considered a treatment for ME. The most common advice received on activity, to find a sustainable daily level and then increase week by week, clashed with what respondents report they would have found most helpful: to find a sustainable daily activity level without embarking upon weekly increases.

Whilst there is some variation between clinics, the large proportions reporting negative experiences demonstrates that there is a problem across the board with current ME services.

Specialist paediatric services performed worse than services overall, with respondents reporting higher incidences of negative experiences in key areas analysed, including a majority reporting they were worse when they stopped attending their clinic than when they started. A higher proportion than overall thought the service they attended should close.

43.6% of respondents reported that they had been pressured to undergo treatment, rising to 65.2% amongst users of paediatric services, suggesting that a culture of voluntary consent is not present. This is directly contrary to current NHS guidelines on defining consent that say “[t]he decision to either consent or not to consent to treatment must be made by the person, and must not be influenced by pressure from medical staff.”[1]

Looking to the future, this data demonstrates that there is a need for urgent intervention into the provision of services for people with ME across the UK before more deteriorate as a result of poor quality advice and harmful treatments.

Comments from respondents demonstrate how important it is to utilise the collective knowledge of those with lived experience of this disease. There is a real desire to see clinics developed that have a positive impact on health, with ongoing assistance for those living with this long term illness from staff who understand ME and the most effective ways to support patients.

As #MEAction UK, we therefore agree with the succinct conclusion of one respondent that:

> *“Current services are not fit for purpose.”*

---

[1] NHS - Defining Consent: https://www.nhs.uk/conditions/consent-to-treatment/

Appendices

Appendix 1 - Further charts

Full chart of UK clinics attended by respondents

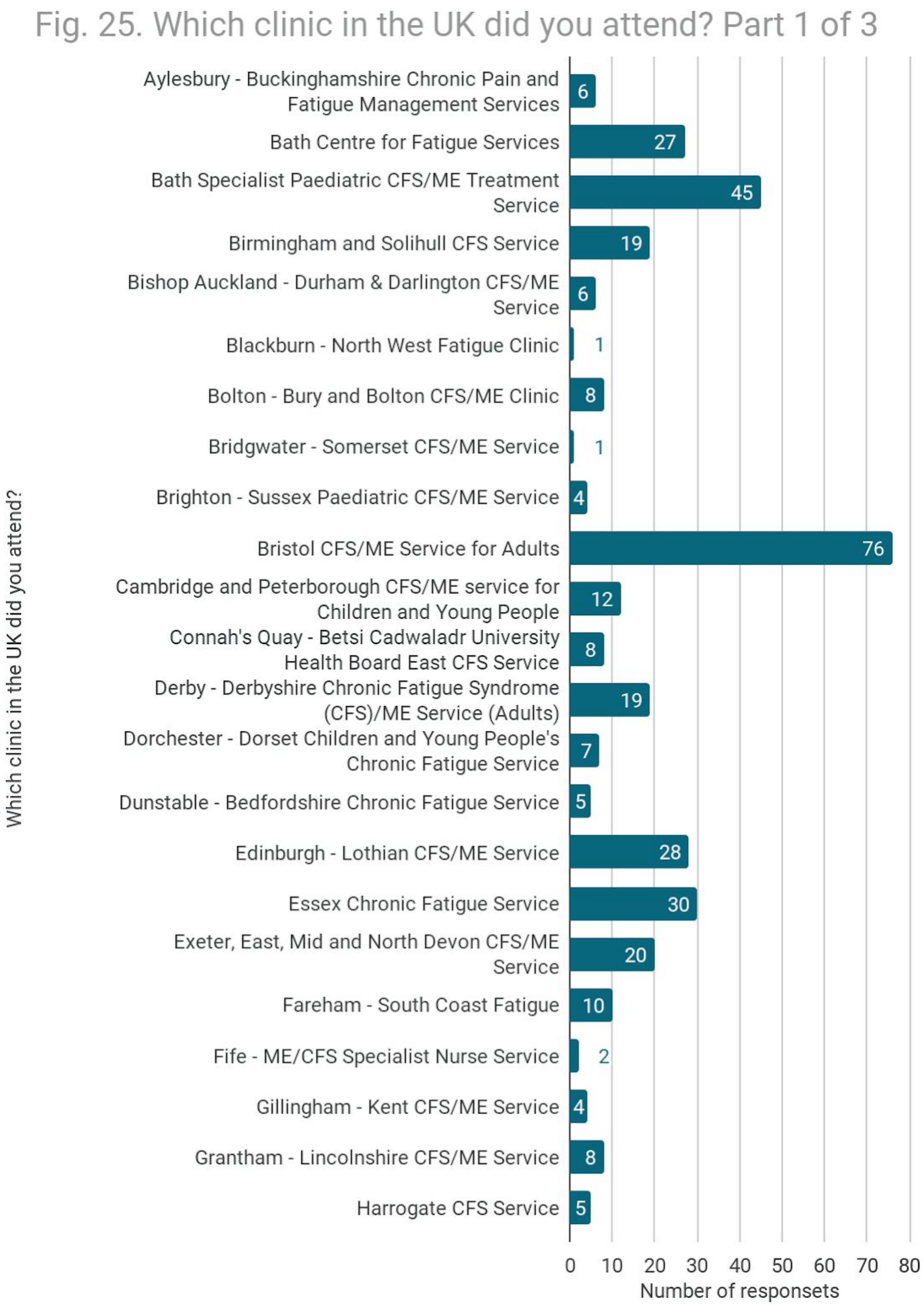


Fig. 26. Which clinic in the UK did you attend? Part 2 of 3

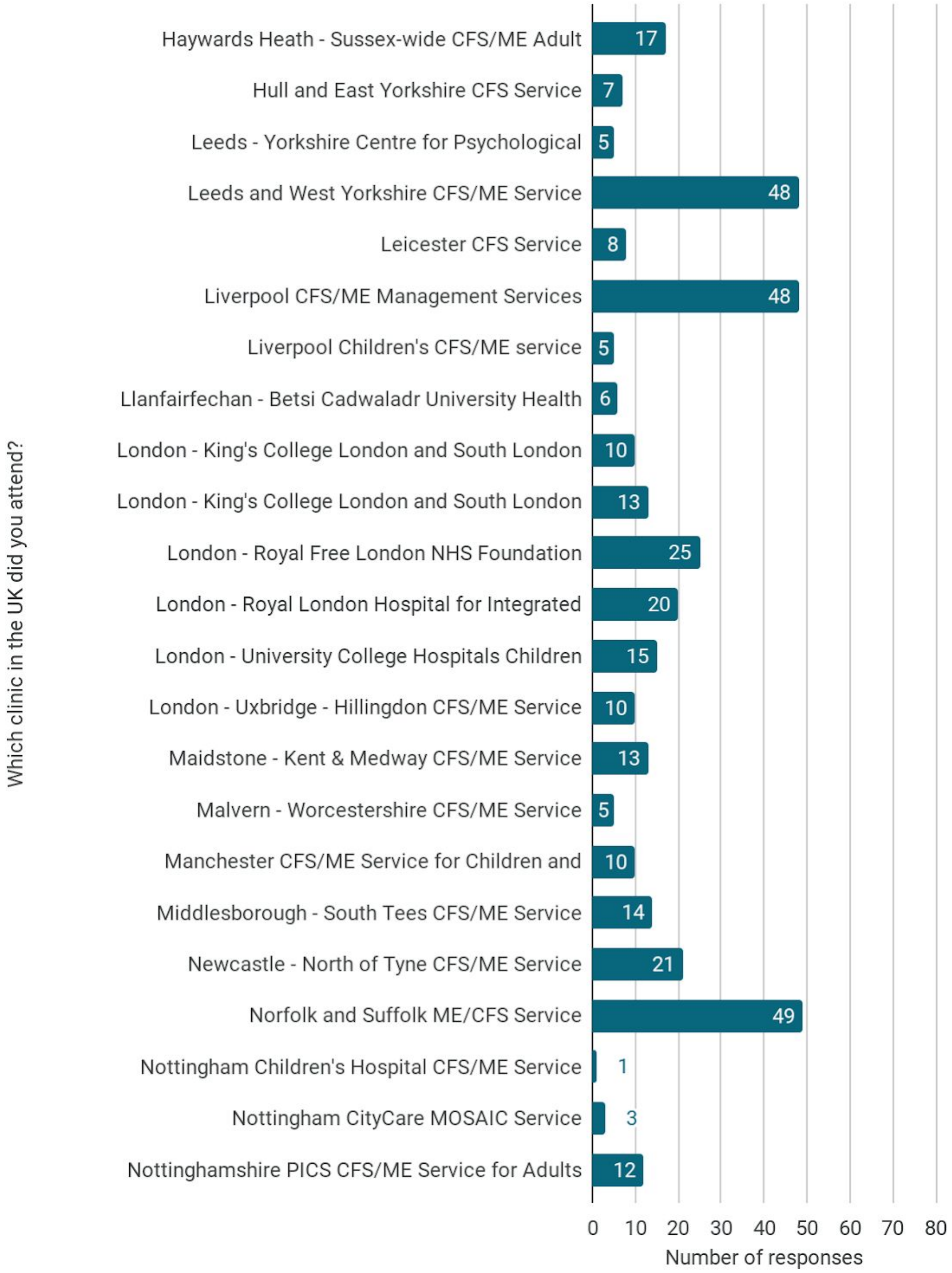
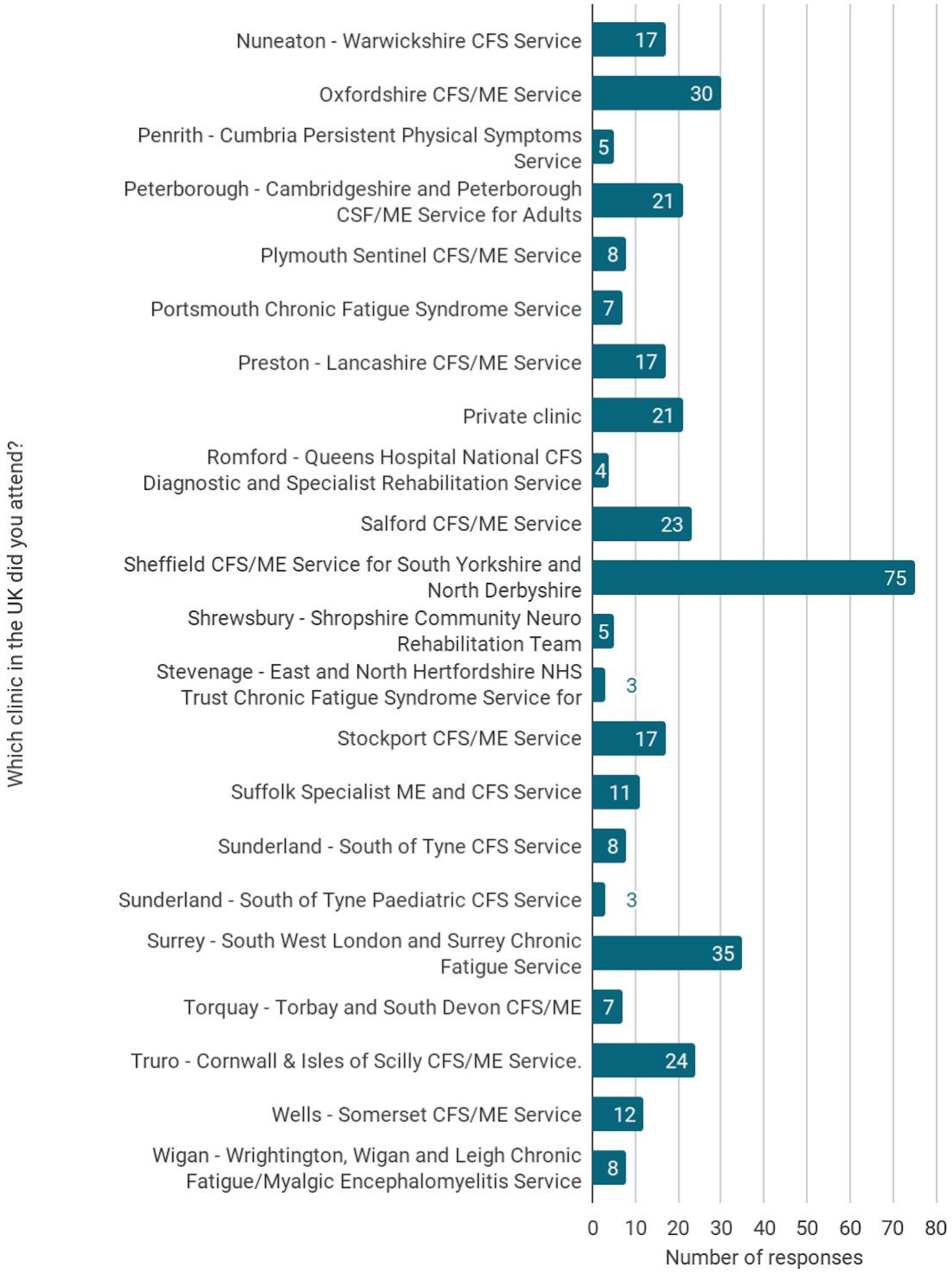
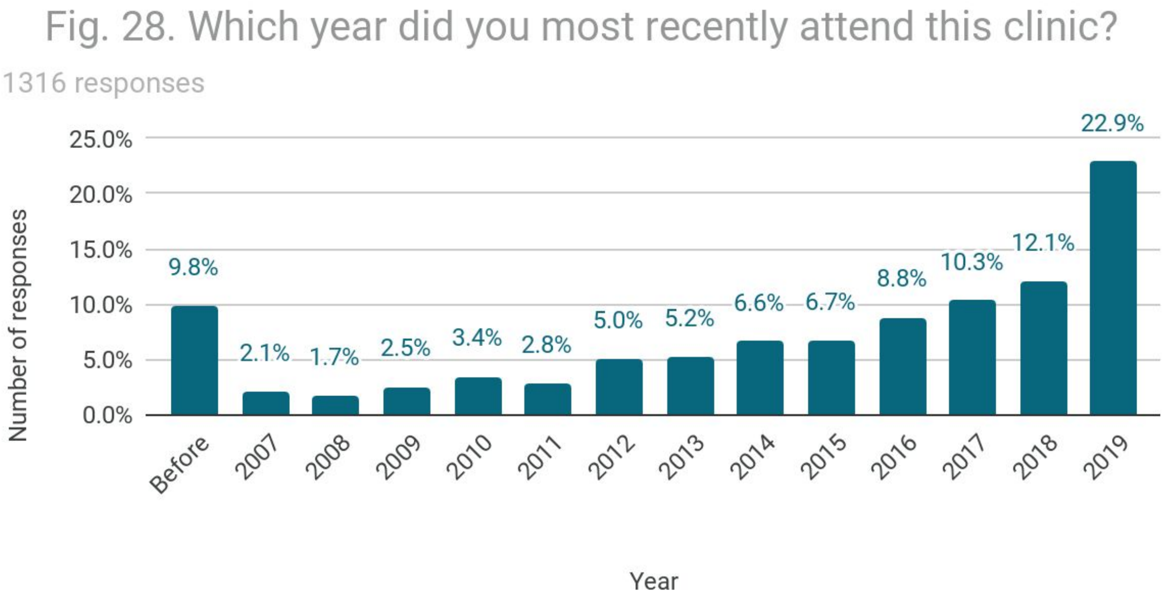


Fig. 27. Which clinic in the UK did you attend? Part 3 of 3



247 respondents reported that the service they attended was not listed.

Year service attended



Impact of attendance at each UK ME clinic

Fig. 29. Impact of attending UK ME/CFS services
Part 1 of 3

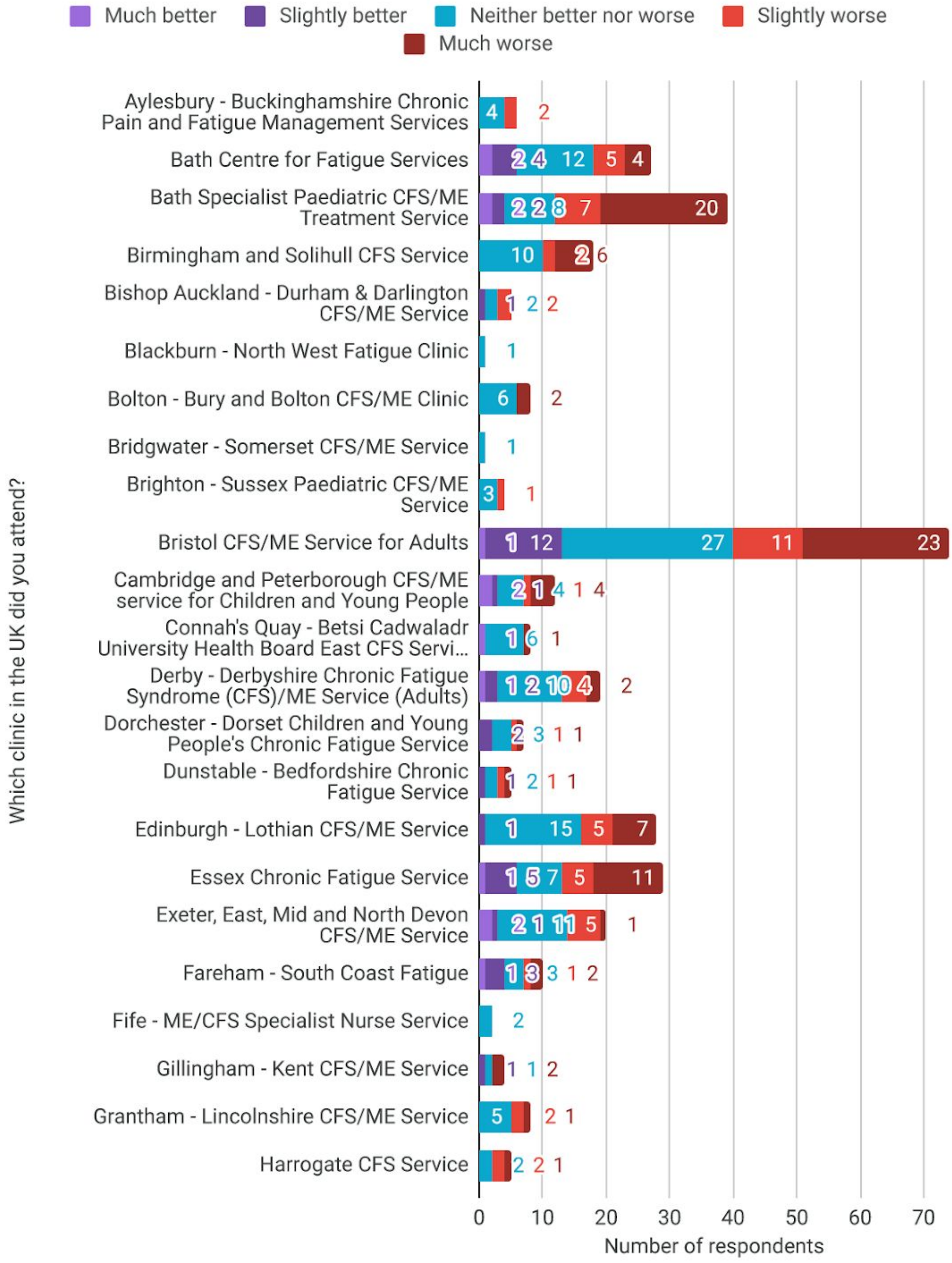


Fig. 30. Impact of attending UK ME/CFS services
Part 2 of 3

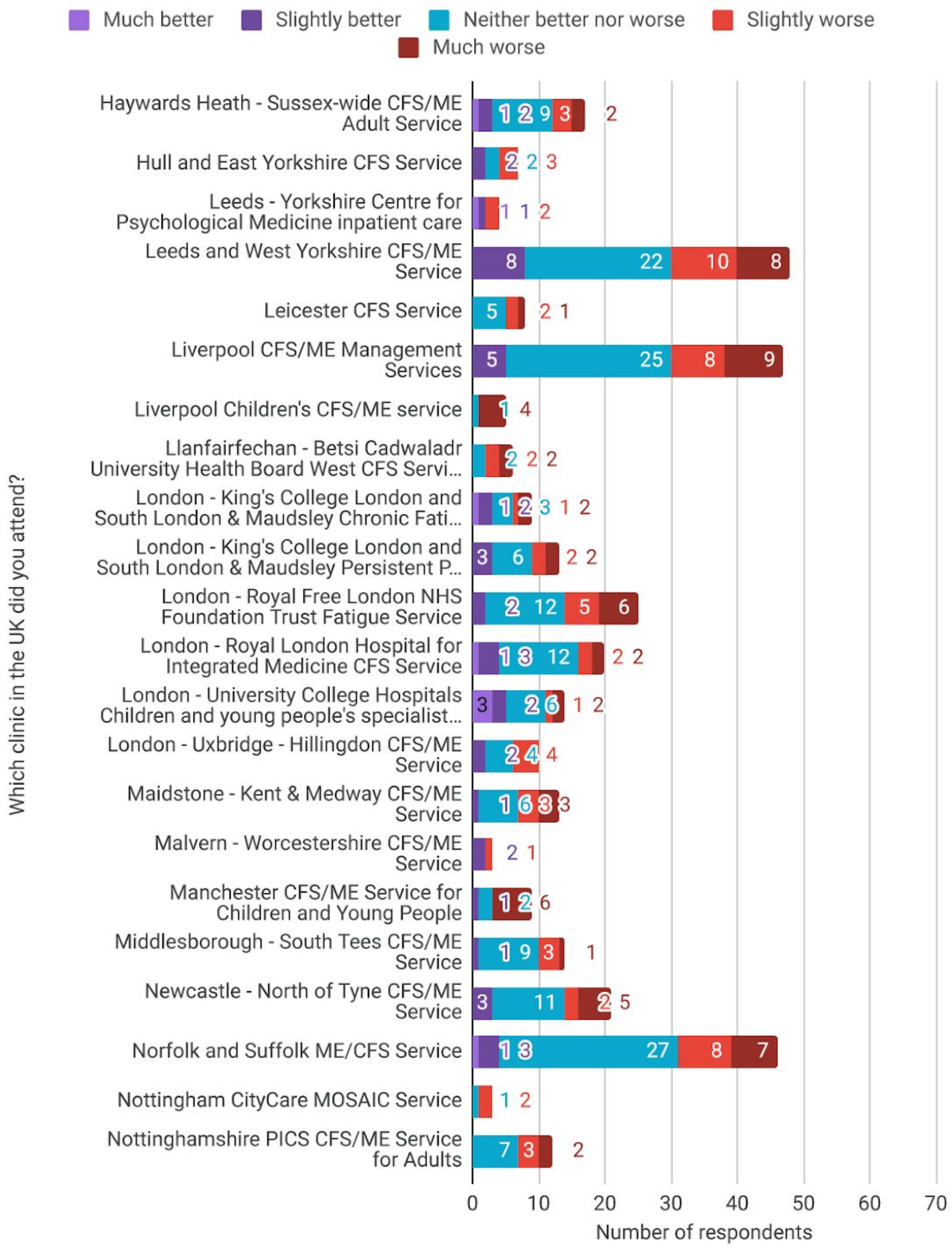
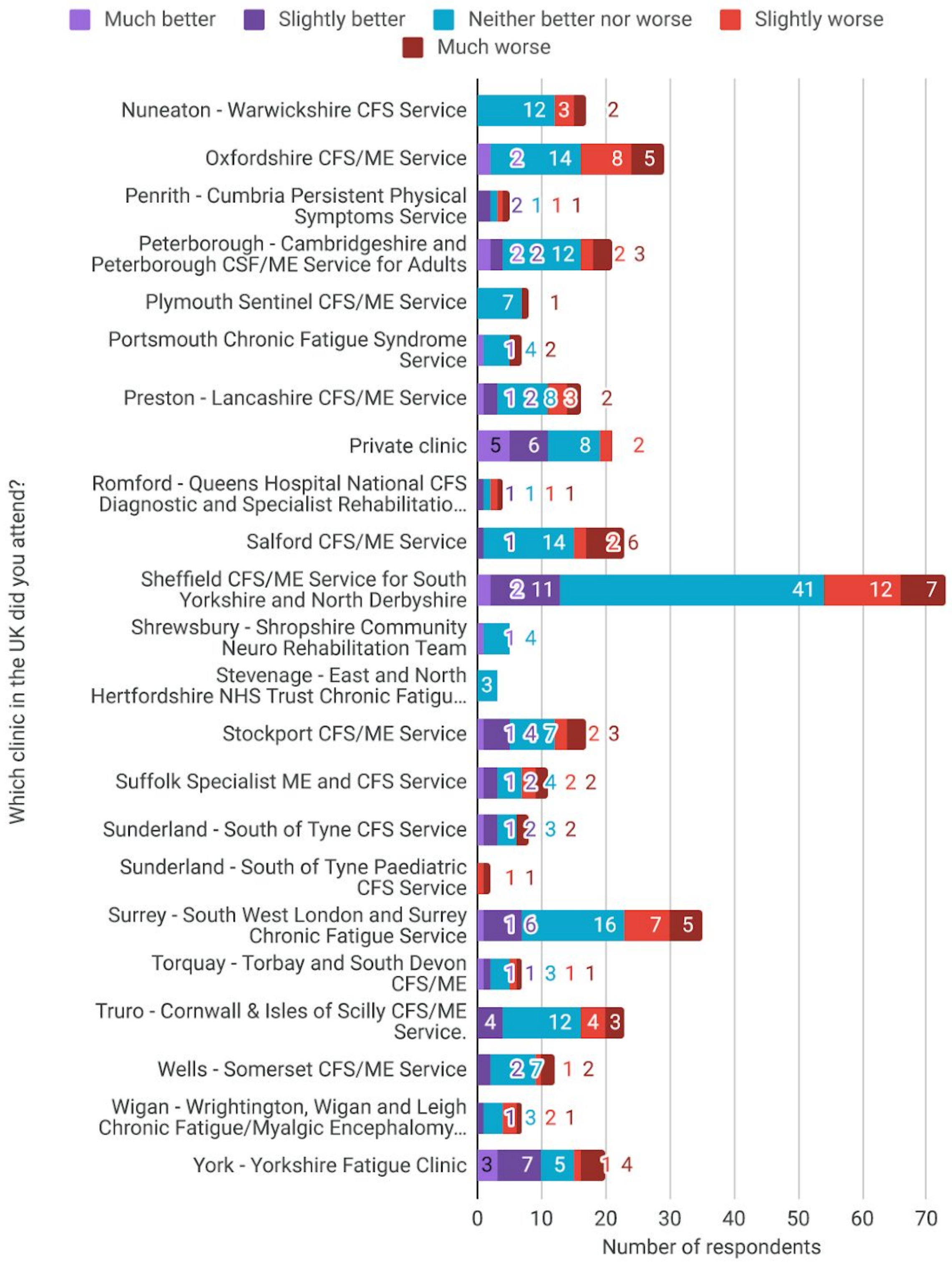


Fig. 31. Impact of attending UK ME/CFS services
Part 3 of 3



Respondents’ views on the future of each UK ME clinic

Fig. 32. Respondents' views on the future of UK ME/CFS clinics
Part 1 of 3

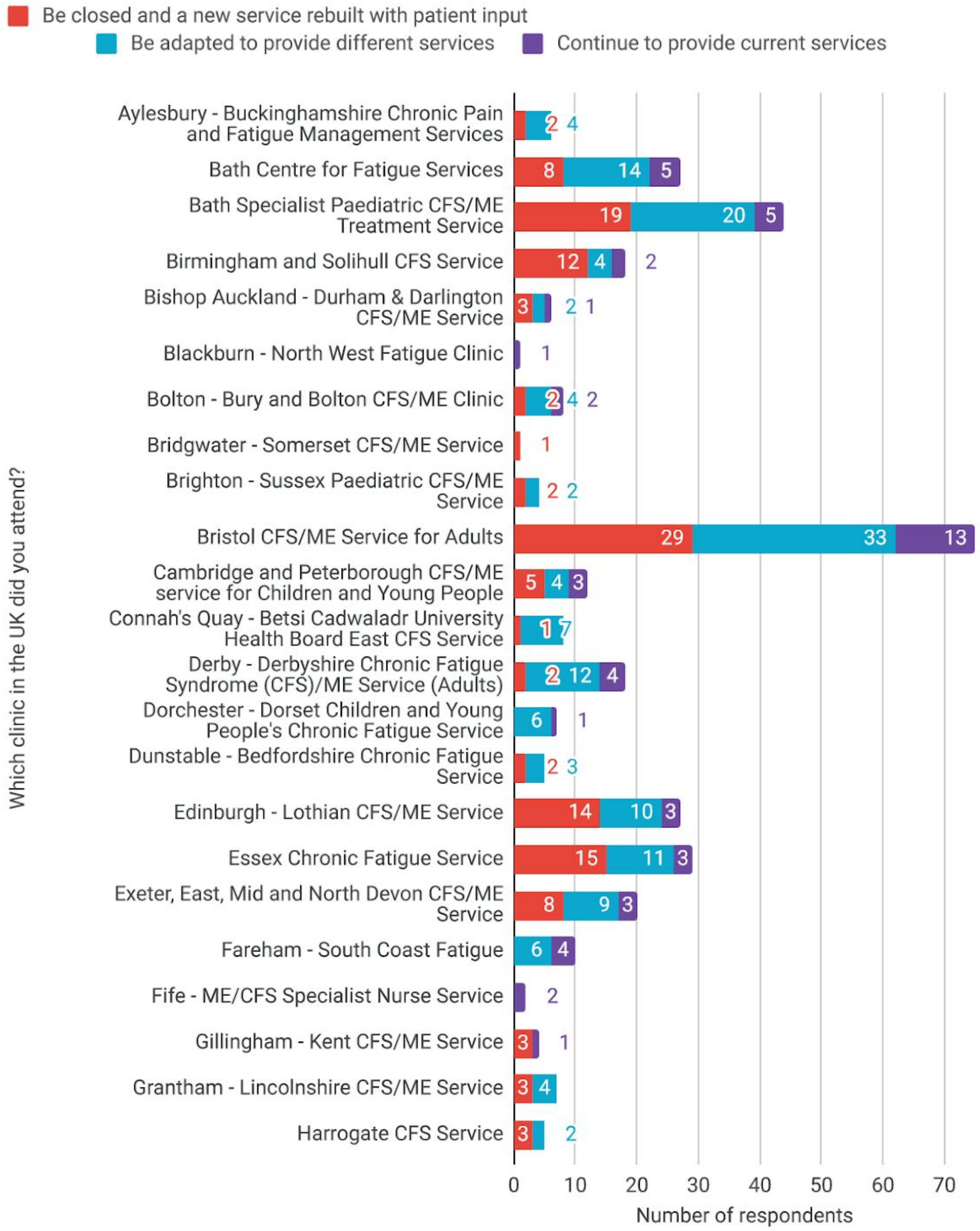


Fig. 33. Respondents' views on the future of UK ME/CFS clinics
Part 2 of 3

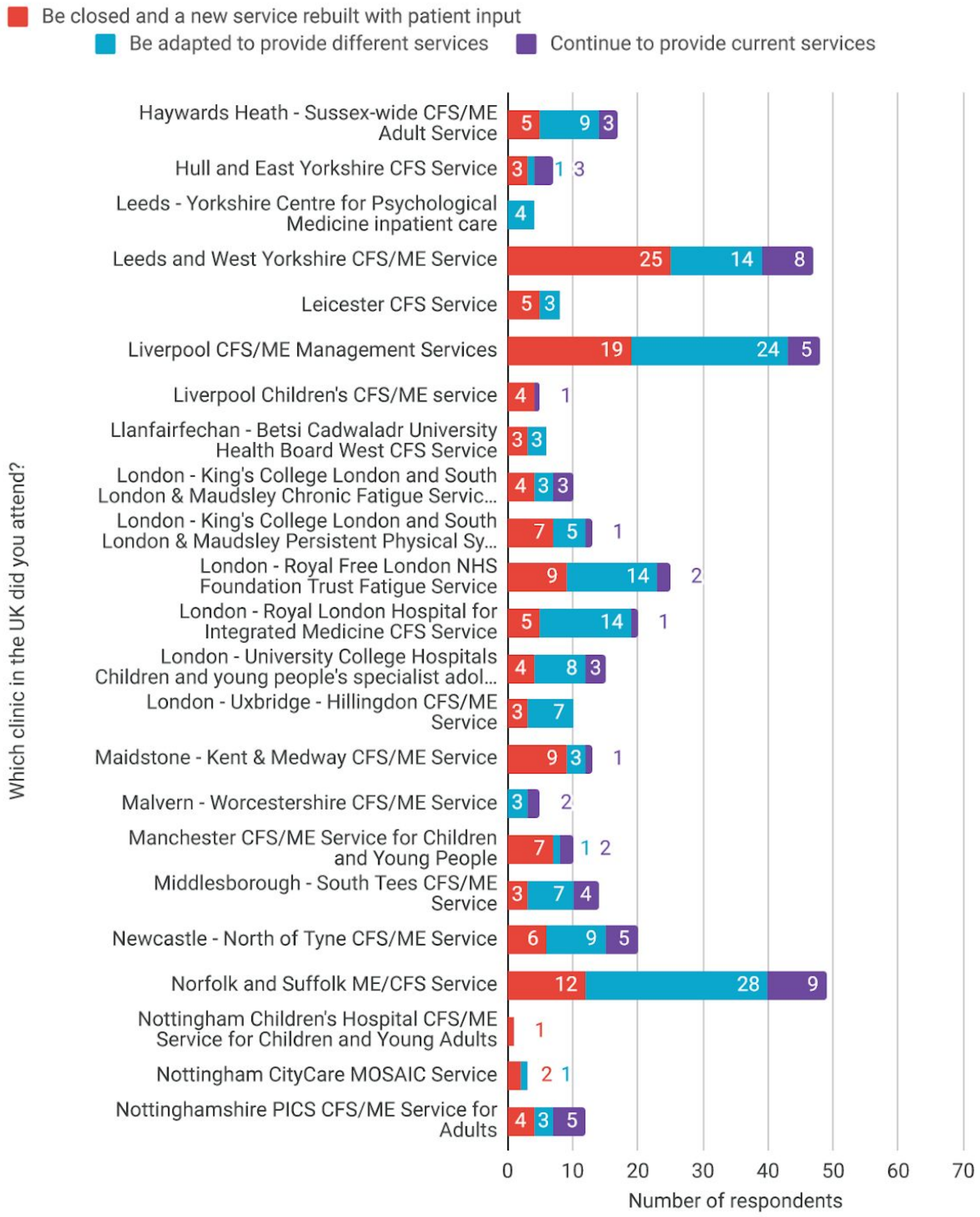
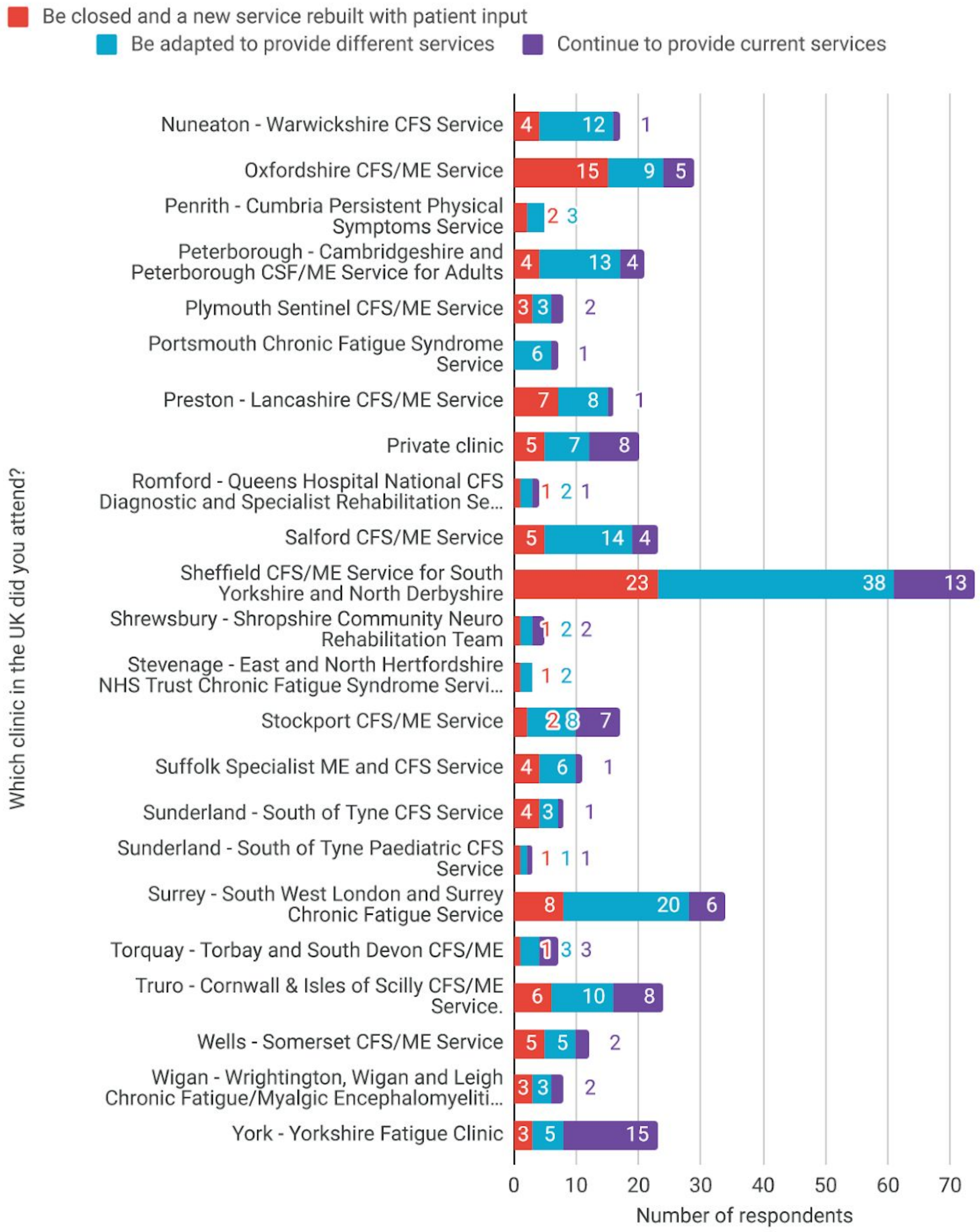


Fig. 34. Respondents' views on the future of UK ME/CFS clinics
Part 3 of 3



Pressure to undergo treatments at UK ME clinics

Fig. 35. Did you ever feel pressured to undergo certain treatment? Breakdown by UK ME Services. Part 1 of 3

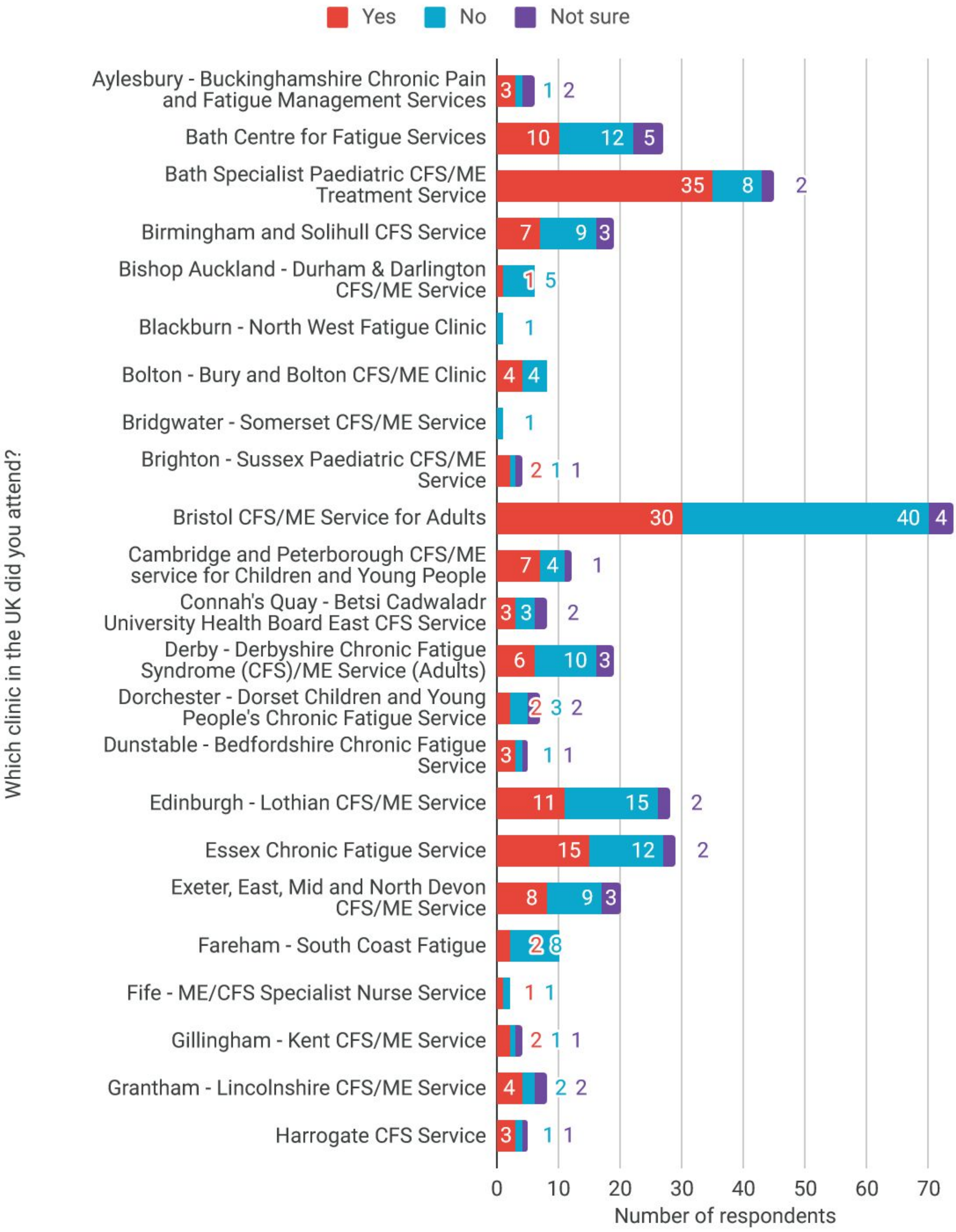


Fig. 36. Did you ever feel pressured to undergo certain treatment? Breakdown by UK ME Services. Part 2 of 3

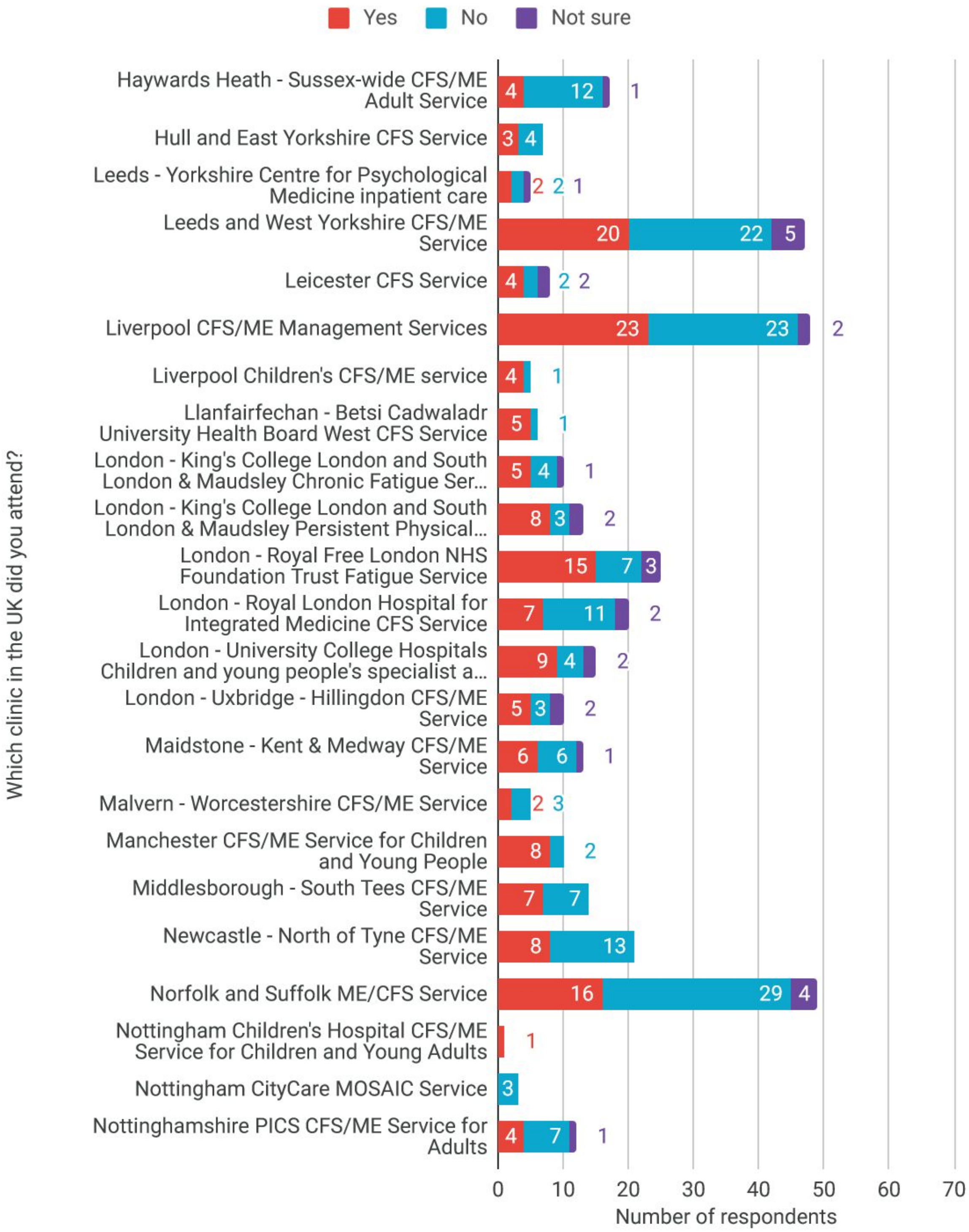
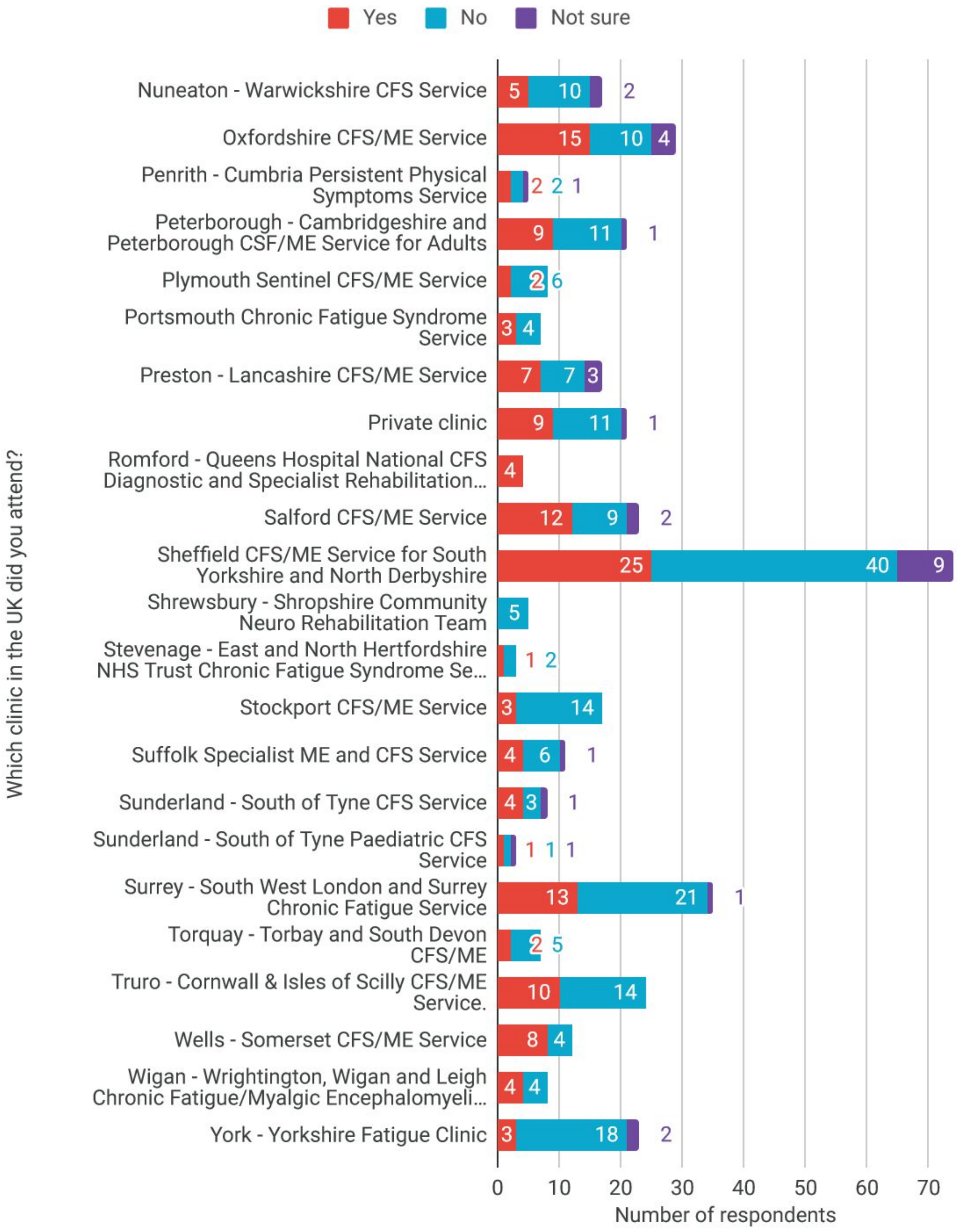


Fig. 37. Did you ever feel pressured to undergo certain treatment? Breakdown by UK ME Services. Part 3 of 3



Cognitive behavioural therapy at UK ME clinics

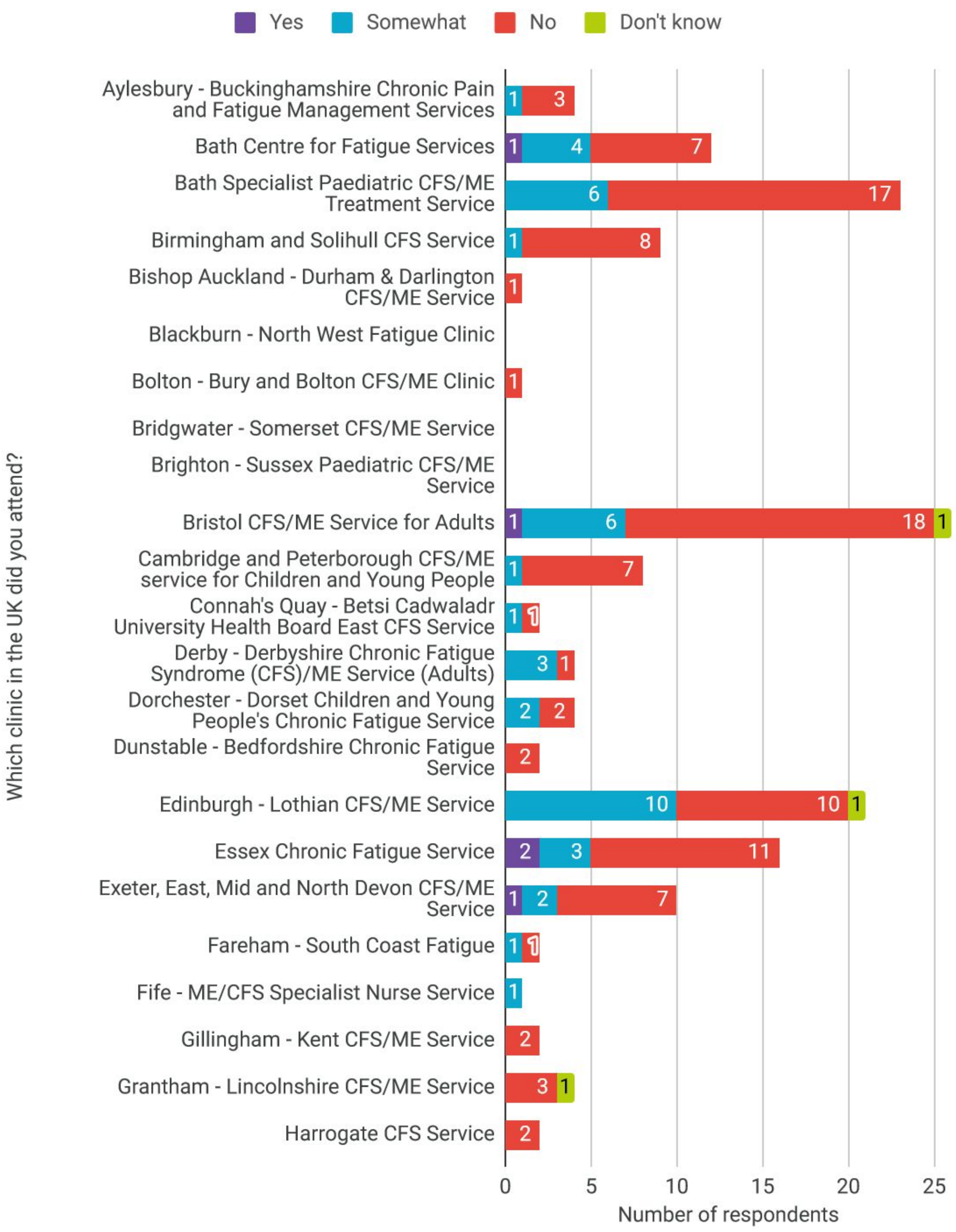


Fig. 38. Was the cognitive behavioural therapy received at UK ME/CFS clinics helpful? Part 1 of 3

Fig. 39. Was the cognitive behavioural therapy received at UK ME/CFS clinics helpful? Part 2 of 3

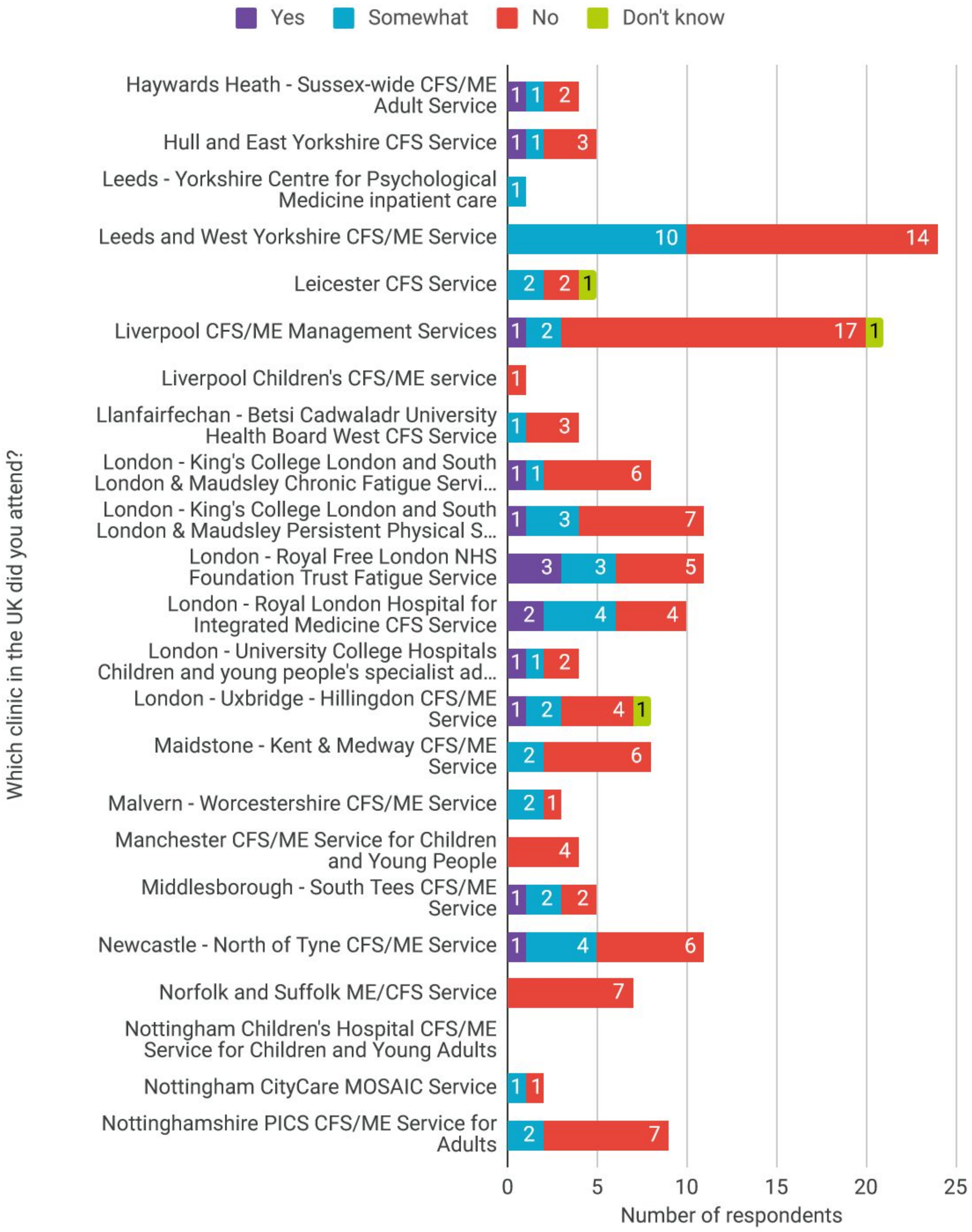
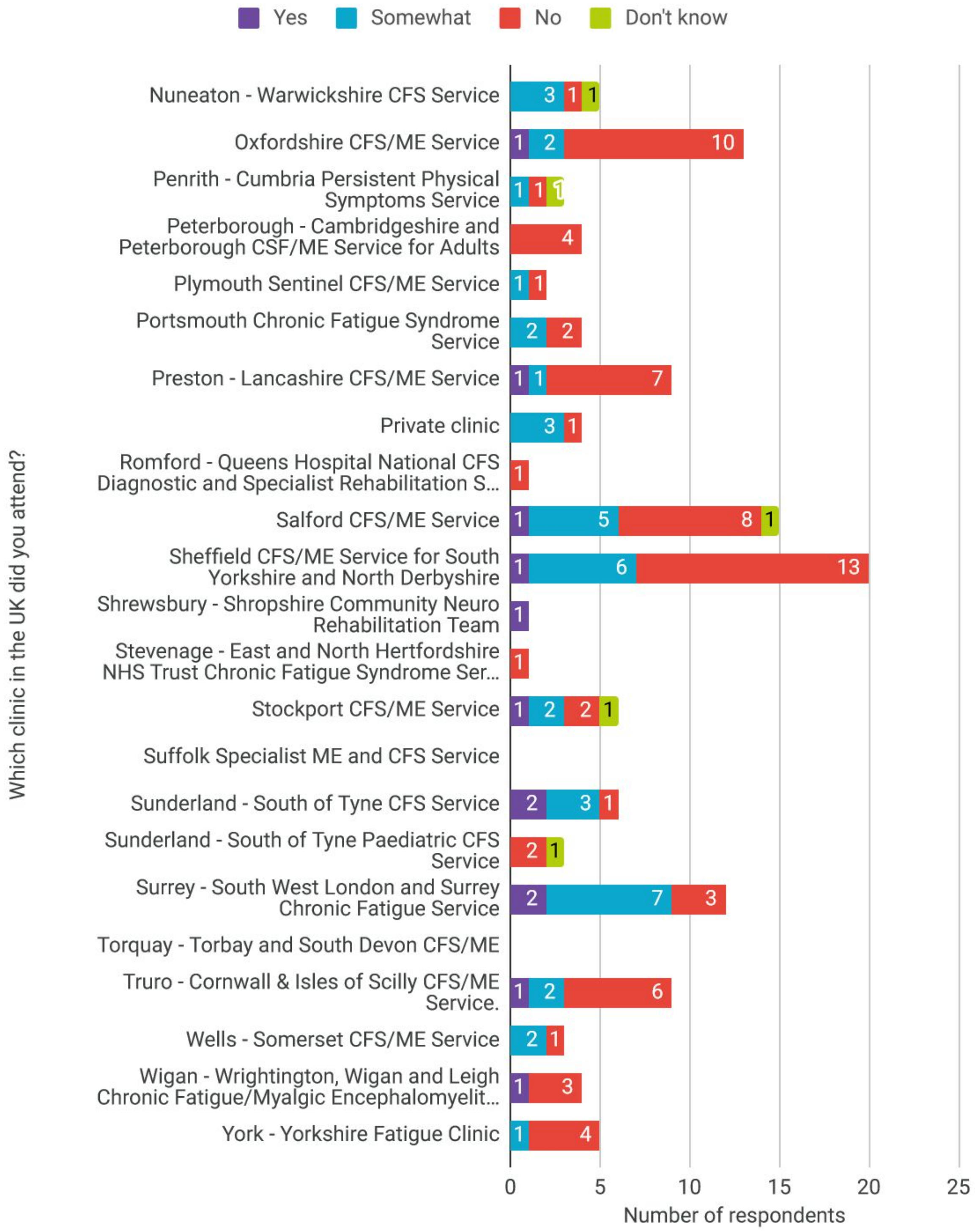


Fig. 40. Was the cognitive behavioural therapy received at UK ME/CFS clinics helpful? Part 3 of 3



Activity management advice received at UK ME clinics

Fig. 41. Activity management advice received at UK ME/CFS service. Part 1 of 3

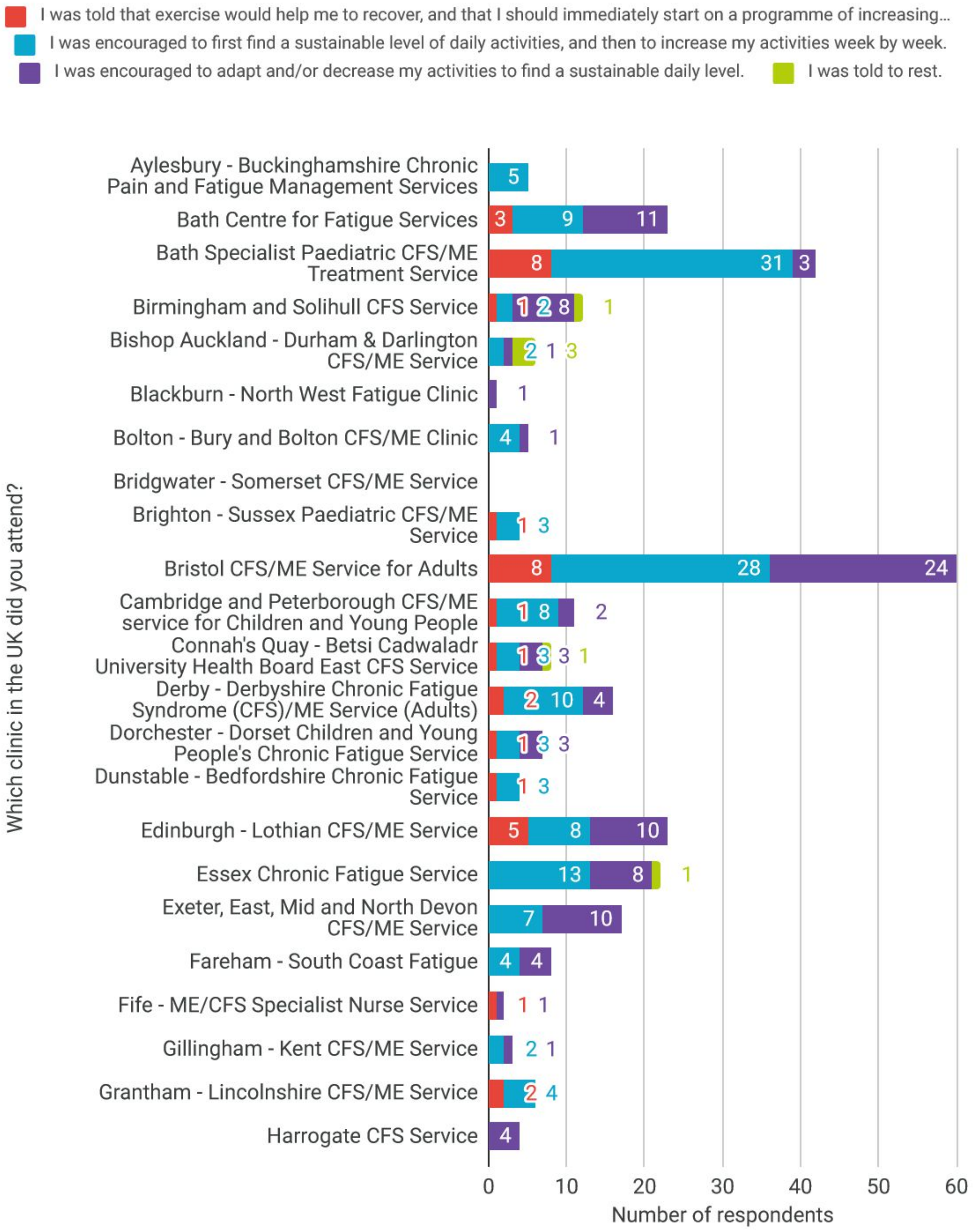


Fig. 42. Activity management advice received at UK ME/CFS service. Part 2 of 3

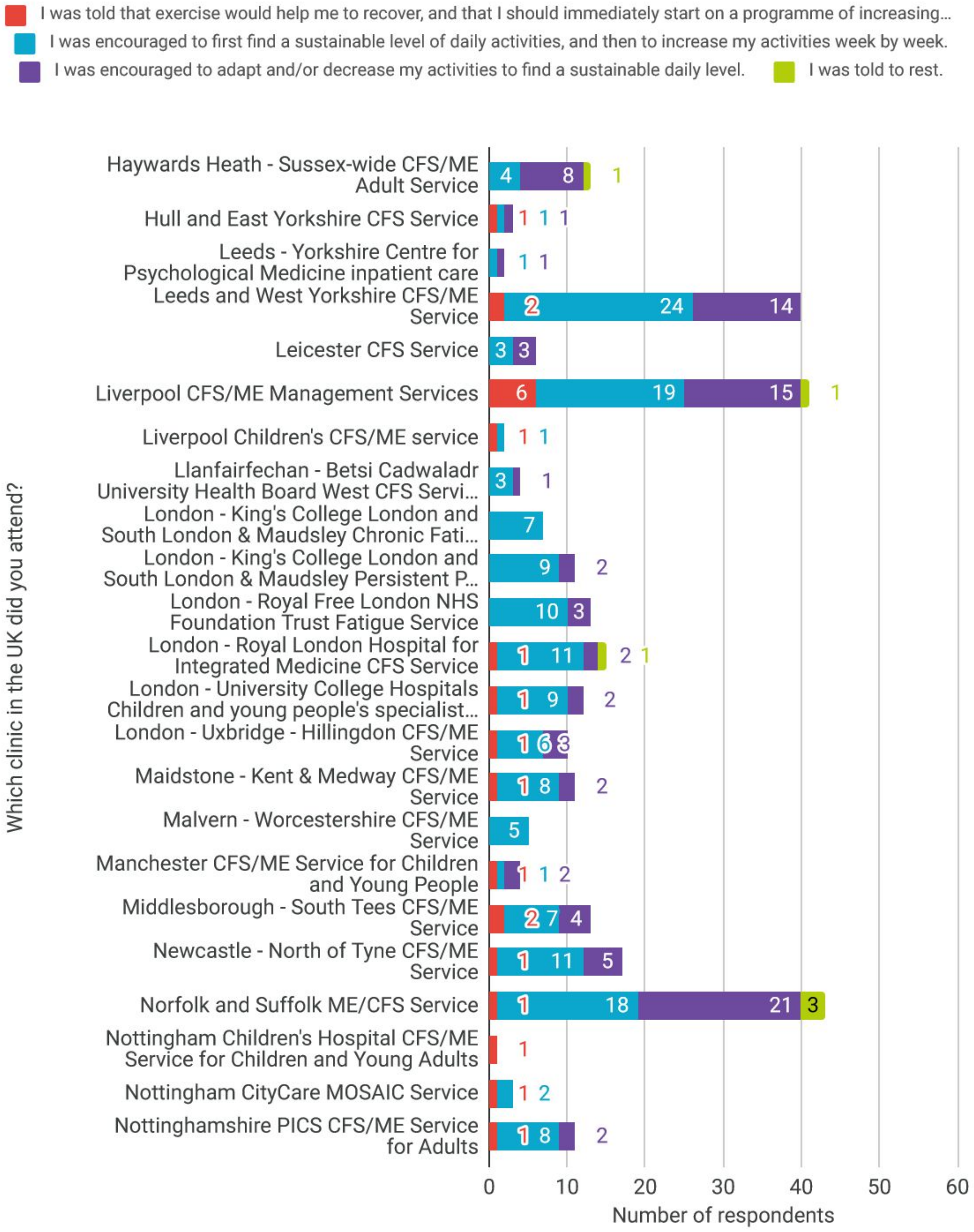
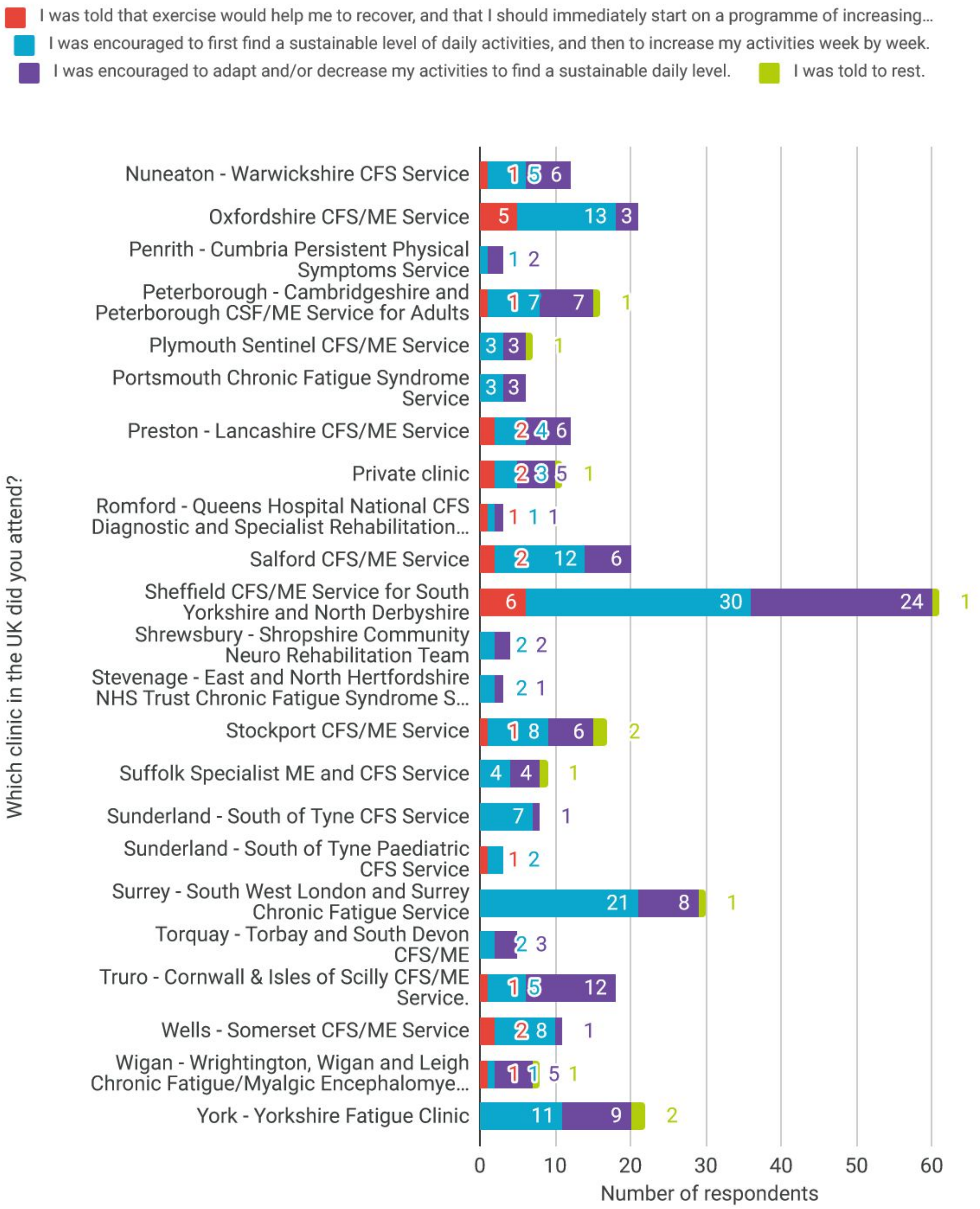


Fig. 43. Activity management advice received at UK ME/CFS service. Part 3 of 3



Appendix 2 - Survey questions

Your experience of ME/CFS services - Survey by #MEAction UK

The National Institute for Health and Care Excellence (NICE) are updating their guidelines on ME/CFS; as part of this they have published a call for evidence. The survey asks about advice given on managing your symptoms when you first spoke to a healthcare professional about your symptoms and your experience at ME/CFS clinics in the UK, including the treatments and advice provided. It also asks what you would have found most helpful in hindsight.
You may take part if you have a diagnosis of ME, CFS or ME/CFS and have attended an ME/CFS clinic in the UK. If you have attended more than one ME/CFS clinic in the UK please fill out this survey once for each clinic you have attended.
We use the combined term ME/CFS as this is what NICE use and people in the UK are often diagnosed with CFS.
The deadline for responses is 7th October 2019. Whilst we realise this is a short window, we hope the data gathered will add some evidence in areas that aren't well researched for the NICE committee to deliberate.

We estimate the survey will take 8-10 minutes to fill in. The majority of questions are optional.

All responses are anonymous - meaning we cannot identify and remove individual responses from the data set after you click submit. The anonymous data from this survey will be shared with NICE. It will also be published on www.meaction.net.
If you have any questions about this survey please contact uk@meaction.net

- * Required

You may answer this survey on behalf of someone you care for if they give consent, or a child in your care.
Please assume all questions relate to the person with ME/CFS.

1. What is your diagnosis? *

Mark only one box.

☐ Myalgic encephalomyelitis (ME)
☐ Chronic fatigue syndrome (CFS)
☐ ME/CFS or CFS/ME
☐ None of the above - *Stop filling out this form.*

2. Do you experience post exertional malaise? *

This is a worsening of symptoms after minimal physical, cognitive or emotional exertion which can be delayed 24-72 hours or more.
Mark only one box.

- ☐ Yes
- ☐ No

Management strategies whilst being assessed for ME/CFS

These questions cover the advice you were given on managing your symptoms before being given your diagnosis of ME/CFS.

3. Which option best describes the advice you were given when you first spoke with a healthcare professional about your symptoms?

Mark only one box.

- ☐ To decrease my activity levels and rest whilst I felt ill
- ☐ To maintain my activity levels whilst feeling ill
- ☐ To increase my activity levels whilst feeling ill
- ☐ I wasn't given any advice on activity levels

4. Do you think following the advice you were given when you first spoke with a healthcare professional about your symptoms impacted your illness?

Mark only one box.

- ☐ Yes, I deteriorated having followed the advice
- ☐ Yes, I improved having followed the advice
- ☐ No, it made no difference

5. In hindsight, which option best describes the advice you would have found most helpful when first speaking with a health care professional about your symptoms?

Mark only one box.

- ☐ To decrease my activity levels and rest whilst I felt ill
- ☐ To maintain my activity levels whilst feeling ill
- ☐ To increase my activity levels whilst feeling ill

6. Have you attended a clinic/service for your ME/CFS symptoms in the UK? *

Mark only one box.

- ☐ Yes Skip to question 8.
- ☐ No Continue to question 7.

All other questions in this survey are only relevant if you have attended an ME/CFS service in the UK. Thank you for taking the time to tell us about your experience of advice when you first spoke to a health professional about your symptoms.

7. Is there anything else you would like to add?

____
____
____
____
____
____
____
____

Stop filling out this form.

ME/CFS Clinics

8. Which clinic in the UK did you attend? *

Clinics are listed by city/town name first. If you have attended more than one clinic in the UK please fill out this survey once for each clinic you have attended.

Mark only one box.

- ☐ Aylesbury - Buckinghamshire Chronic Pain and Fatigue Management Services
- ☐ Bath Specialist Paediatric CFS/ME Treatment Service
- ☐ Bath Centre for Fatigue Services
- ☐ Birmingham and Solihull CFS Service
- ☐ Bishop Auckland - Durham & Darlington CFS/ME Service
- ☐ Blackburn - North West Fatigue Clinic
- ☐ Bolton - Bury and Bolton CFS/ME Clinic
- ☐ Bridgwater - Somerset CFS/ME Service
- ☐ Brighton - Sussex Paediatric CFS/ME Service
- ☐ Bristol CFS/ME Service for Adults
- ☐ Cambridge and Peterborough CFS/ME service for Children and Young People
- ☐ Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service
- ☐ Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)
- ☐ Dorchester - Dorset Children and Young People's Chronic Fatigue Service
- ☐ Dunstable - Bedfordshire Chronic Fatigue Service
- ☐ Edinburgh - Lothian CFS/ME Service Essex Chronic Fatigue Service
- ☐ Exeter, East, Mid and North Devon CFS/ME Service
- ☐ Fareham - South Coast Fatigue
- ☐ Fife - ME/CFS Specialist Nurse Service
- ☐ Gillingham - Kent CFS/ME Service
- ☐ Grantham - Lincolnshire CFS/ME Service Harrogate CFS Service
- ☐ Haywards Heath - Sussex-wide CFS/ME Adult Service
- ☐ Hull and East Yorkshire CFS Service
- ☐ Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service
- ☐ Leeds and West Yorkshire CFS/ME Service
- ☐ Leeds - Yorkshire Centre for Psychological Medicine inpatient care
- ☐ Leicester CFS Service
- ☐ Liverpool CFS/ME Management Services Liverpool Children's CFS/ME service
- ☐ London - King's College London and South London & Maudsley Chonic Fatigue Service for children and adolescents
- ☐ London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit

- ❏ London - Royal Free London NHS Foundation Trust Fatigue Service
- ❏ London - Royal London Hospital for Integrated Medicine CFS Service
- ❏ London - University College Hospitals Children and young people's specialist adolescent services
- ❏ London - Uxbridge - Hillingdon CFS/ME Service
- ❏ Norfolk and Suffolk ME/CFS Service
- ❏ Maidstone - Kent & Medway CFS/ME Service
- ❏ Malvern - Worcestershire CFS/ME Service
- ❏ Manchester CFS/ME Service for Children and Young People
- ❏ Middlesborough - South Tees CFS/ME Service
- ❏ Newcastle - North of Tyne CFS/ME Service
- ❏ Nottingham Children's Hospital CFS/ME Service for Children and Young Adults
- ❏ Nottinghamshire PICS CFS/ME Service for Adults
- ❏ Nottingham CityCare MOSAIC Service
- ❏ Nuneaton - Warwickshire CFS Service
- ❏ Oxfordshire CFS/ME Service
- ❏ Penrith - Cumbria Persistent Physical Symptoms Service
- ❏ Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults
- ❏ Plymouth Sentinel CFS/ME Service
- ❏ Portsmouth Chronic Fatigue Syndrome Service
- ❏ Preston - Lancashire CFS/ME Service
- ❏ Romford - Queens Hospital National CFS Diagnostic and Specialist Rehabilitation Service
- ❏ Salford CFS/ME Service
- ❏ Sheffield CFS/ME Service for South Yorkshire and North Derbyshire
- ❏ Shrewsbury - Shropshire Community Neuro Rehabilitation Team
- ❏ Stevenage - East and North Hertfordshire NHS Trust Chronic Fatigue Syndrome Service for Children and Young People
- ❏ Stevenage - Herts Chronic Fatigue Syndrome & Chronic Pain Self-Management Service for Adults
- ❏ Stockport CFS/ME Service
- ❏ Suffolk Specialist ME and CFS Service Sunderland - South of Tyne CFS Service
- ❏ Sunderland - South of Tyne Pediatric CFS Service
- ❏ Surrey - South West London and Surrey Chronic Fatigue Service Torquay -
- ❏ Torbay and South Devon CFS/ME
- ❏ Truro - Cornwall & Isles of Scilly CFS/ME Service
- ❏ Wells - Somerset CFS/ME Service
- ❏ Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service
- ❏ York - Yorkshire Fatigue Clinic

- ☐ Not listed
- ☐ Private clinic

9. Which year did you most recently attend this clinic?

Mark only one box.

- ☐ 2019
- ☐ 2018
- ☐ 2017
- ☐ 2016
- ☐ 2015
- ☐ 2014
- ☐ 2013
- ☐ 2012
- ☐ 2011
- ☐ 2010
- ☐ 2009
- ☐ 2008
- ☐ 2007
- ☐ Before 2007

10. How satisfied were you with the services, for example any treatments or courses, provided by the clinic?

Mark only one box.

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Neither satisfied or unsatisfied
- ☐ Unsatisfied
- ☐ Very unsatisfied

11. Was the service, for example any treatments or courses, you received appropriate to your needs?

Mark only one box.

- ☐ Yes, everything was appropriate
- ☐ Yes, most of it was appropriate
- ☐ There were some appropriate and some not appropriate aspects
- ☐ No, most of it was not appropriate
- ☐ No, all of it was not appropriate
- ☐ Not sure

12. When you stopped attending the clinic, how were you in comparison to when you started attending the clinic?

Mark only one box.

- ☐ Much better
- ☐ Slightly better
- ☐ Neither better nor worse
- ☐ Slightly worse
- ☐ Much worse

13. Healthcare professional understanding of ME/CFS

Mark only one box per row.

	Yes	Somewhat	No	Not sure
Did your healthcare professional give you an explanation of what ME/CFS is and what causes it?				
Did your healthcare professional's understanding of ME/CFS match your own?				
Is it important for your healthcare professional to have the same understanding of ME/CFS as you do?				

14. Based on your experience at the clinic, should it:

Mark only one oval.

- ☐ Continue to provide current services
- ☐ Be adapted to provide different services
- ☐ Be closed and a new service rebuilt with patient input

15. Please explain why you chose this answer

____

____

____

____

____

____

16. Did you ever feel pressured to undergo a certain treatment?

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Not sure

17. Who would you most want on a multidisciplinary team delivering services for people with ME/CFS? Please tick up to 3 answers

Mark up to 3 boxes.

- ☐ Consultant
- ☐ General Practitioner (GP)
- ☐ Specialist nurse
- ☐ Occupational Therapist
- ☐ Psychologist
- ☐ Physiotherapist
- ☐ Dietician
- ☐ Other (please specify):________________________

Cognitive Behavioural Therapy (CBT)

18. Did you receive cognitive behavioural therapy at the clinic you attended? *

Mark only one oval.

- ☐ Yes Continue to question 19.
- ☐ No Skip to question 23.

Experience of cognitive behavioural therapy (CBT)

19. As part of your CBT, were you told deconditioning was leading to some or all of your symptoms?

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Don't know

20. As part of your CBT, was it suggested that if you were able to change how you thought about your symptoms their severity would decrease?

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Don't know

21. As part of your CBT, were you advised on strategies to better manage you illness?

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Don't know

22. Did you find the CBT you received helpful?

Mark only one oval.

- ☐ Yes
- ☐ Somewhat
- ☐ No
- ☐ Don't know

Continue to next page

Managing your activity levels

23. Were you given advice from a healthcare professional at the clinic on how to manage your activity levels? *

Mark only one oval.

- ☐ Yes Continue to question 24.
- ☐ No Skip to question 26.

Advice on activity management

24. Which option best describes the advice your were given on activity management?

Mark only one oval.

- ☐ I was told to rest. - *Skip to question 26.*
- ☐ I was encouraged to adapt and/or decrease my activities to find a sustainable daily level. - *Skip to question 26.*
- ☐ I was encouraged to first find a sustainable level of daily activities, and then to increase my activities week by week. - *Continue to question 25.*
- ☐ I was told that exercise would help me to recover, and that I should immediately start on a programme of increasing exercise. - *Continue to question 25.*

Advice on increasing activities

25. Which option best describes the advice you were given on increasing activities?

Mark only one oval.

- ☐ I was told to continue this planned increase even if my symptoms worsened.
- ☐ I was told to pause the planned increase if my symptoms worsened, but then to continue the increases as soon I felt I could.
- ☐ I was told that I should halt the planned increase if my symptoms worsened, and that I may not be able to increase beyond a certain point.
- ☐ None of the above

Helpful advice on activity management

This section asks about what advice you would have found most helpful.

26. In hindsight, which option best describes the advice you would have found most helpful on activity management?

Mark only one oval.

☐ To rest.
☐ To adapt and/or decrease my activities to find a sustainable daily level.
☐ To first find a sustainable level of daily activities, and then to increase my activities week by week.
☐ That exercise would help me to recover, and that I should immediately start on a programme of increasing exercise.

27. In hindsight, which option best describes the advice you would have found most helpful on increasing activity?

Mark only one oval.

☐ To continue any planned increase even if my symptoms worsened.
☐ To pause any planned increase if my symptoms worsened, but then to continue the increases as soon I felt I could.
☐ To halt any planned increase if my symptoms worsened, and that I may not be able to increase beyond a certain point.

28. Is there anything else you would like to add?

End of survey

Appendix 3 - Comments from respondents who had not attended a specialist ME service

https://www.meaction.net/wp-content/uploads/2019/10/Appendix-3-Your-experience-of-ME-services-report-by-MEAction-UK.pdf

Appendix 4 - Multidisciplinary team ‘other’ responses

https://www.meaction.net/wp-content/uploads/2019/10/Appendix-4-Your-experience-of-ME-services-report-by-MEAction-UK.pdf

Appendix 5 - Comments on the future of UK clinics

https://www.meaction.net/wp-content/uploads/2019/10/Appendix-5-Your-experience-of-ME-services-report-by-MEAction-UK.pdf

Appendix 6 - Final comments from respondents

https://www.meaction.net/wp-content/uploads/2019/10/Appendix-6-Your-experience-of-ME-services-report-by-MEAction-UK.pdf