



# YOUR EXPERIENCE OF ME SERVICES



Survey report by  
**#MEAction UK**

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**APPENDIX 5**

## Appendix 5 - Comments on the future of UK clinics

All comments have had identifying information redacted.

	<b>Which clinic in the UK did you attend?</b>	<b>Based on your experience at the clinic, should it:</b>	<b>Please explain why you chose this answer</b>
<b>1</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>I found it obstructive for more severely ill patients who were unable to attend the clinic. I did not gain any new information, I had learned more researching myself. I was diagnosed by a psychologist who never examined me. I have been unable to have further testing or treatments. I self-discharged as I was expending precious energy for no gain.</i>
<b>2</b>	Not listed	Be adapted to provide different services	<i>There is scientific knowledge that could be incorporated about trauma and ACES and the poly vagal theory</i>
<b>3</b>	Salford CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The clinic didn't listen to me. When I improved from medication bought privately, they attributed this to their 'evidence-based treatment' which I hadn't even begun yet! Once I began their treatment I got significantly worse.</i>
<b>4</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	Be adapted to provide different services	<i>It should run follow up courses every 12months</i>
<b>5</b>	Wells - Somerset CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Too basic told me what i already knew and still dont think they got it. Better if got a nutritionalist on board to assist in a diet to reduce inflammation.</i>
<b>6</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>They were useless, arrogant and positively harmful</i>
<b>7</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be adapted to provide different services	<i>The practioner was nice caring and competent but misinformed. She believed the PACE trial was solid science and GET and CBT had a solid evidence base.</i>

<b>8</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Continue to provide current services	<i>Practitioners were trained by [a professional], leading ME specialist.</i>
<b>9</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Occupational therapists have no place in ME 'therapy'. It should be consultant physician led by someone who can do specialist level differential diagnosis, and understands PEM, with specialist nurses who can help with practicalities like learning to pace, using step and heart monitors, dealing with families, employers, schools, and benefits agencies.</i>
<b>10</b>	Harrogate CFS Service	Be closed and a new service rebuilt with patient input	<i>Even my GP agreed treatment was contributing to a worsening of symptoms, especially given the travel time on top.</i>
<b>11</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>The clinic (so far after four appointments) has recommended rest, to identify the energy threshold at which I can operate without incurring PEM. Whilst I agree with this, I currently have little confidence that I'll be able to increase my activity in the future without it being detrimental to my health. What I'd really like to see in a ME/CFS clinic is medical tests to rule out all other potential causes, followed by a tailored recovery plan for each individual. Ideally this would be linked to knowing the biomedical cause!</i>
<b>12</b>	Edinburgh - Lothian CFS/ME Service	Be adapted to provide different services	<i>The counselling was helpful but the guidance was difficult to implement in a busy working life. It was also time limited without on-going guidance or support.</i>
<b>13</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>This illness has different stages. Some people can do very mild physical activities, some are housebound and in continual pain. The explanation of the illness is suitable for all, but the prescribed way of life varies based on symptoms &amp; history of the illness.</i>
<b>14</b>	London - University College Hospitals Children and young people's specialist adolescent services	Be adapted to provide different services	<i>Even though my daughter was diagnosed with ME/CFS this was never properly explained, sadly we had to do our own homework from other parents and charities to get proper answers. It was and is still viewed as 'deconditioning' as in you are not fit and need to get fitter - well I'm sorry but the terrible symptoms my daughter was experiencing were and are still definitely not 'caused' by needing to do more and be fitter. It's all wrong. Symptoms were never properly addressed and when we did our own investigations we were told that 'could have been done there' - but it wasn't.</i>

<b>15</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>My clinic (Southampton) was closed 10 years ago and the nearest one now advocates GET and CBT, both pointless.</i>
<b>16</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Graded exercise therapy is damaging in the long term</i>
<b>17</b>	Nottinghamshire PICS CFS/ME Service for Adults	Continue to provide current services	<i>We were given a lot of factual information and ways of dealing with flare ups. The explanations of different symptoms were very good.</i>
<b>18</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>It is basically a psychology and physio service. These are not suitable. I needed help with physical medical stuff.</i>
<b>19</b>	Not listed	Continue to provide current services	<i>Physio helping me monitor symptoms and pace. CBT did not work for me but perhaps would help others. Physio very understanding and I am continuing to see her. My own GP has never gave me any advice/info re: my diagnosis other than tell me I have CFS.</i>
<b>20</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>I had to cancel 2 appts as I was unable to get out of bed. I was then told I couldn't come to any further sessions. When you're dealing with patients with complex, chronic illness I think you need to show some flexibility. Before this I had an appt with the Dr there who told me she couldn't do anything to help, what did I expect her to do and things were "only going to get worse anyway".</i>
<b>21</b>	Nuneaton - Warwickshire CFS Service	Be closed and a new service rebuilt with patient input	<i>It was a mess, massively under-staffed. never saw same person twice, noisy bright location made me feel iller every time. Lead consultant v aggressive. Always saw different people, who seemed not to communicate with one another at all. Did get referred to helpful OT and physio, but the clinic itself was no help.</i>

22	Fareham - South Coast Fatigue	Be adapted to provide different services	<p><i>Some of the advice was very helpful (sleep hygiene, resting, pacing and getting aids for the house) but the graded activity (based on activity like washing etc. as I am severely ill) did not help me as I wasn't able to comply, the advice wasn't appropriate. There was too much focus on setting goals and targets, regardless of my ability, and they were unrealistic and pushed me to do more than I could. This also made it harder to cope with the illness emotionally as it made me feel as if it was my fault when I wasn't improving, as if I could control this illness and 'cure' myself, which I now know is not true, I can only manage my symptoms. I also felt that the reports written about me, presumably to secure future funding, were misleading. It was often recorded that I could do things that I couldn't. While they had some correct information about ME, I felt that they didn't know enough. I was also led to believe I would get better, which I haven't, and this is probably due to their lack of understanding of the disease and its prognosis.</i></p>
23	Bristol CFS/ME Service for Adults	Continue to provide current services	<p><i>I attended the CFS services in 2006 and they have developed and expanded to include mindfulness course, relaxation courses, art therapy and more. No one is forced to do anything. These services were based originally on a model created by the Bristol charity Westcare and have since been greatly increased. It would be a great shame if they were to be stopped,</i></p>
24	Edinburgh - Lothian CFS/ME Service	Be closed and a new service rebuilt with patient input	<p><i>Was based on CBT and GET</i></p>
25	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Continue to provide current services	<p><i>New department equipped for my condition</i></p>

26	Nottinghamshire PICS CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<p><i>It is not accessible by people severely affected at all. Not even by phone. It is based on the unsubstantiated notion that CFS is due to deconditioning and that increasing energy levels helps reduce symptoms. It does not recommend the use of mobility aids such as scooters because staff believe people will 'become dependent on them', when in fact they can be highly useful and return people's independence. It does not explain or recommend pacing with a heart rate monitor, even though this is contained hidden within the current NICE guidelines and is widely accepted amongst the patient community as a highly useful pacing tool. It is held in venues which are hard to get to, and uses rooms that are a long walk from the entrance and that smell of chemicals and fragrance. It does not consider concomitant diagnoses that should be investigated, such as POTS and hypothyroidism. The practitioners are unable or unwilling to listen to the substantial amount of legitimate criticism of either the deconditioning theory or the PACE trial. They recommend graded activity, which is widely accepted to be ineffective as a treatment management plan in the CFS community. If it worked we'd all be doing it and getting better - we're not. The Ed's stick rigidly to the guidelines and are unwilling to explore other management approaches. The service is currently based within the pain service, which is misleading because many people with CFS do not have pain. It is short term, and does not record or evaluate the longer term impacts of following their advice - for example, many people undertake their gentle strengthening exercise programme but the length of involvement fails to note that people reduce activity in other areas to accommodate the exercises or that plateaus of activity are often reached.</i></p>
27	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<p><i>I was blamed for not improving because of GET, I said it was an improper treatment for me and they said "we get good results at this clinic"</i></p>
28	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be adapted to provide different services	<p><i>Teaching activity management and pacing is important but not to increase activity and not them not having no understanding of the peaks and troughs of the condition.</i></p>
29	Romford - Queens Hospital National CFS Diagnostic and Specialist Rehabilitation Service	Be adapted to provide different services	<p><i>The service needs to be able to provide treatments and support but without research that will never happen.</i></p>

<b>30</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>I'm waiting for my treatment to restart and have relapsed since</i>
<b>31</b>	Edinburgh - Lothian CFS/ME Service	Be adapted to provide different services	<i>The service wasn't all bad, it helped me at the start to speak to a kind and supportive medical professional who appeared to understand what a huge adjustment I was going through. I learned some useful techniques about pacing my activity, but there was a constant undertone of GET which was inappropriate. I also never felt comfortable that the service I was attending for my neurological disease was in a psychiatry department. Thankfully I had done my research, I knew how flawed the research behind GET/CBT was, so I was very vocal about what I would and would not do and there was no pressure to undertake GET. What I got from the service was basically in-depth one-on-one therapy to help me cope with my diagnosis of ME. I looked at it as being tutored on how to manage my ME as best I could, but I never expected it would help me to recover, that's just not possible, talking therapy cannot cure a neurological disease. By the end of my ten appointments, roughly one per month, my ME had deteriorated, I expect from the over-exertion of attending these appointments. I think the service could have a place, but not as it currently is. Perhaps this particular service could be adapted to simply provide emotional support to people who have been diagnosed with a life-altering illness (any illness, not just ME) to help them get through it.</i>
<b>32</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>Need to be able to have one to one consultation with a fully trained Doctor. An appointment was offered for CBT or Physio but I declined as I was too poorly. There are treatments available that will ease symptoms. I need validation and a full clinical assessment.</i>
<b>33</b>	Not listed	Be adapted to provide different services	<i>Needs to be more robust in advising good rest.</i>

34	Private clinic	Be closed and a new service rebuilt with patient input	<p><i>Private consultant believed that I was sufficiently educated and reasonable to share with me how awkward, uncooperative and wrong many of his patients were (in response to questions regarding controversies that I was under-informed of at the time, despite my research background in computational behavioural statistics).</i></p> <p><i>After following his advice as to how to gradually increase exercise, I collapsed totally, going from a diagnosis of mild/moderate to moderate/severe. I then stopped outsourcing my comprehension and read the literature myself. It was then obvious that he had been basing his assumptions and advice on "mistaken illness belief" paradigms attributed to sufferers, an idea without scientific basis or merit.</i></p> <p><i>Originally starting in the law, I would go so far as saying that litigation could even be raised in such situations where professional norms match neither the science nor the evidence, in particular where they persist in what can only be described as making it up.</i></p>
35	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<p><i>Patients have the best understanding of their illness/condition and should be able to offer their advice on best treatments/options.</i></p>
36	Maidstone - Kent & Medway CFS/ME Service	Be closed and a new service rebuilt with patient input	<p><i>The service is currently built around psychological supports and methods that are inappropriate for ME.</i></p>
37	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<p><i>Their focus was on graded exercise therapy and CBT</i></p>
38	Surrey - South West London and Surrey Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<p><i>At the clinic, over the phone, I was advised to use their "factsheets and resources". It said that I should not be resting in bed for too long (more than a few days) and should be up and about more and encouraged finding a baseline and increasing activity. At the time I was bedbound due to having done too much activity/exercise, and yet again I was still encouraged to increase my activity! I was also told that if I felt "in control" of my illness I would get better. I was also encouraged to go through physio again even though that made me very ill before. I was told that it was my anxiety that was causing and contributing to symptoms.</i></p>

<b>39</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>Overall their understanding and little treatment options available are detrimental to the wellbeing of patients long term health</i>
<b>40</b>	Edinburgh - Lothian CFS/ME Service	Be adapted to provide different services	<i>The treatments I received didn't work</i>
<b>41</b>	Manchester CFS/ME Service for Children and Young People	Be closed and a new service rebuilt with patient input	<i>Accused me of FII and I was really ill. Wanted to incarcerate in psych unit for GET and CBT. Evil bunch of people should not be anywhere near children esp those with ME. Said too young to have ME, should have got better after 2 years and worsening blamed on lack of patient engagement. told me you could not have more than one family member affected and atypical i that I had fluctuations. Did not understand why I was so ill.</i>
<b>42</b>	Not listed	Be adapted to provide different services	<i>The clinic was closed down which was terrible. The new clinic that replaced it is utterly useless. The old clinic would have benefitted from continuing to be funded and implementing some of the newer treatments that are now being used in other countries.</i>
<b>43</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>Because of the different levels of the illness and different symptoms</i>
<b>44</b>	Bath Centre for Fatigue Services	Be adapted to provide different services	<i>There's improvements to be made, like appointment times. I was required to be there early even though it was a huge struggle.  I was put thorough CBT which i did not want to do as it didn't work for me. I would go to appointments and be told if I didn't do the homework or didn't put in effort they would stop helping me and discharge me. I was often too tired to do the homework and also it didn't help me but I still had to do it.</i>
<b>45</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	Be closed and a new service rebuilt with patient input	<i>It is important to patients to have support from the medical professionals. However the form that support takes at the moment is poor and damaging to patients' health. As so little is known in the UK medical profession about ME, there is far greater knowledge about appropriate treatments and what works and what doesn't among the patient community.</i>
<b>46</b>	Edinburgh - Lothian CFS/ME Service	Continue to provide current services	<i>Current service is mostly fine, but I found their language of goals v unhelpful</i>

<b>47</b>	Stevenage - East and North Hertfordshire NHS Trust Chronic Fatigue Syndrome Service for Children and Young People	Be adapted to provide different services	<i>I don't know how their approach is currently, but at the time it was not actively damaging, but neither was it helpful.</i>
<b>48</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>They need to better understand the needs of ME/CFS patients on an individual basis and admit that it they have no idea what causes it and that every case is different. Services offered should involve acceptance and mental health support as well as practical support for living with the condition.</i>

**49** Norfolk and Suffolk  
ME/CFS Service

*We desperately need support, so closing clinics will just leave us even more neglected than we already are. However, in their current form the clinics really aren't very useful (in my experience). I have had ME/CFS for 10 years and been under the care of NHS ME/CFS clinics for the last 7 years. I found some of the advice on pacing strategies helpful, but the clinics take a purely psychological and behavioural approach to treatment which has been completely ineffectual for me, and has caused more frustration and distress than anything else because I don't have a psychological or behavioural problem. My experience has been that the clinics trivialise the condition, and really don't understand the pathophysiology or biomedical research. Not having anybody in the clinic who is medically trained is really frustrating, because I cannot get help with things that require someone with medical training, such as medications, neurological symptoms, bowel problems, etc. They can't even measure our blood pressure. It is well understood now that ME/CFS is a real, biological disease that affects the central and peripheral nervous systems but we have no access to anybody with any training in neurology. It affects the immune system but we don't have access to anyone with training in immunology. And it affects the cardiovascular system, especially with autonomic problems such as orthostatic intolerance, but the staff in the ME clinics don't know about orthostatic intolerance even though it has been part of the diagnostic criteria in the USA since 2015. Instead, the clinics give me simplistic, inaccurate and outdated models of the disease, which say that my 'thoughts and feelings' affect my 'behaviours' to perpetuate my illness. This is completely out of date when the biomedical research of the last few years is taken into account, so it really frustrates me. Because of this I have made no progress with my health through the clinics. I only go because there isn't an alternative specialist service to go to. The only progress I have made has been through reading the biomedical research myself and taking it to my GP so he can do appropriate tests and prescribe appropriate medications, and this has only happened in the last few months, largely*

			<p>neurologists (who still see ME/CFS as a 'functional disorder' which it isn't) and cardiologists to assess and treat our autonomic and cardiovascular issues, and exercise physiologists and physiotherapists who understand the specific metabolic impairment in ME/CFS (such as the heart preload failure and impaired systemic oxygen extraction found by Dr David Systrom and his team at Harvard), and significantly decreased anaerobic threshold (as found by the team at the Workwell Foundation). The current biopsychosocial approach is completely out of date compared to this latest biomedical research, and is a completely inappropriate approach to managing the disease. We need to have access to a multidisciplinary BIOMEDICAL team, and a biomedical approach to disease management that is primarily about assessing and treating those aspects which are treatable such as orthostatic intolerance, digestive problems, neurological hyper-sensitivity, dysautonomia, etc. Occupational therapy and psychological therapies should be and adjunct to this, based on pacing (not forcing increases in activity if this causes PEM), counselling to help with the emotional impact of the disease which is highly disabling, and specialist physiotherapy which is based on the biomedical understanding of exercise intolerance in ME/CFS, not the biopsychosocial model (GET is contra-indicated by the most recent biomedical research).</p>
<b>50</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	Continue to provide current services	<p><i>the services provided were appropriate and helped</i></p>
<b>51</b>	Torquay - Torbay and South Devon CFS/ME	Be closed and a new service rebuilt with patient input	<p><i>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!</i></p>
<b>52</b>	Not listed	Be adapted to provide different services	<p><i>I was referred for CBT treatment elsewhere. (Which I wasn't thrilled about as my symptoms are physical not mental, but do what the specialist tells you right!) The place I was referred to couldn't meet my needs as I wasn't allowed to have phone consultations, I wouldn't have been able to get to the appointment every week as I'm physically disabled and the process would have not just been physically demanding but mentally too. Nothing else was offered, nothing else was done. I was not referred back to the specialist and that was that. I never heard from the specialist again despite phoning and leaving messages.</i></p>

53	Dunstable - Bedfordshire Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<p><i>At the assessment the clinic seemed promising - they had a physio check my heart-rate before, during, and after light exercise (repeated sitting &amp; standing for 30 secs, pacing for 60 secs, etc). There was a psych there who made a comment about how I view my "self worth" after warning the physio that one of my hips was very tight before she attempted to manipulate it which I thought could be a warning sign. But the courses they had on offer were appealing - group sessions with other patients to meet &amp; socialise with others who have understanding of the condition - physiotherapy - an occupational therapist, etc etc. However upon arriving at the first session, it was just CBT/GET run by a different psych (who was not even fully qualified). She had no understanding of CFS/ME and was very dismissive and readily blamed my condition on me. When reporting back to my GP, she said that she had heard similar from other patients and that in general she had not come across anyone who thought very highly of the clinic. On going through the information provided during the first session, I realised it was GET and decided not to return to the clinic. I recieved a letter from the psych who had conducted our session informing me that I couldn't expect to recover if I kept enabling myself to be sick by not attending the clinic. I never saw or heard from the physio or the psych who did my initial assessment again.</i></p>
54	Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service	Be adapted to provide different services	<p><i>They could do with a doctor with experience CFS and Fybromyalgia</i></p>
55	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<p><i>The clinic focused almost exclusively on graded exercise as a therapy. This has been established, in my view, to be positively harmful. The people offering this therapy in the UK seem to belong to a cult that believes that ME/CFS consists of patient who have become deconditioned and fearful of exercise. They need to be swept away and replaced by better educated clinicians who are capable of critically appraising clinical trial evidence - including the glaring errors in PACE - and who have not fallen subject to this insulting and ridiculous groupthink.</i></p>
56	Salford CFS/ME Service	Be adapted to provide different services	<p><i>It doesn't provide follow up services</i></p>

<b>57</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I don't think it is fit for purpose. I was told that my negative thoughts about my illness were making more ill and that I needed more exercise and that anti. depressants would help. I was then seen by a psychiatrist at the ME clinic whose input was very unhelpful. The different therapists expressed frustration when I did not get better from the CBT/GET treatment.</i>
<b>58</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>It has already been closed. A new service should be provided based on the patient needs and with patient input.</i>
<b>59</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>The culture surrounding ME/CFS within the NHS seems so shaped by prejudice and quackery that I believe a fresh start is needed, with a commitment to being honest with patients about how little we know rather than creating systems that encourage clinicians to pretend that they know more than they do.</i>
<b>60</b>	Private clinic	Be adapted to provide different services	<i>Sent to consultant with no knowledge as they didn't know where to refer me!</i>
<b>61</b>	Nottingham CityCare MOSAIC Service	Be adapted to provide different services	<i>The people seemed to have a decent understanding of CFS/ME, but they primarily focus on GET which actually made my symptoms worse.  The CBT therapist was excellent. He understood that CBT won't cure CFS/ME, but it's very useful for developing coping strategies.</i>
<b>62</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be adapted to provide different services	<i>More emphasis on Pacing</i>
<b>63</b>	Bristol CFS/ME Service for Adults	Continue to provide current services	<i>The Bristol clinic are amazing and compassionate at a difficult time in diagnosis it made me feel like I wasn't alone and my symptoms were normal</i>
<b>64</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because the head of the clinic who I saw was an immunologist with excellent understanding of CFS as a biological disease has been replaced by a doctor who believes in the invalid psychological approach.</i>
<b>65</b>	Bristol CFS/ME Service for Adults	Be closed and a new service	<i>It is too bad and too harmful to be allowed to continue in any form.</i>

		rebuilt with patient input	
<b>66</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>I was offered CBT, which I didn't find helpful!</i>
<b>67</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>The member of staff who I saw at the Gloucester satellite clinic provided the standard information but was kind, considerate &amp; I never felt pressured to continue increasing activity levels when I had felt so poorly after trying. I think the staff may be open to changes in services. (They are aware of our local support group &amp;, informally, they pass our contact details onto new patients.</i>
<b>68</b>	Fife - ME/CFS Specialist Nurse Service	Continue to provide current services	<i>Advised to pace its the only thing that helps</i>
<b>69</b>	Not listed	Be adapted to provide different services	<i>Because there is no medical monitoring or investigation. Just pacing.</i>
<b>70</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>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!</i>
<b>71</b>	Edinburgh - Lothian CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I was offered CBT and GET based on pacing but increasing. When I couldn't make it work the psychiatrist there wrote a letter to my GP criticising me for 'giving up easily', even though I had already been trying to adapt to my symptoms for a decade before getting a diagnosis. She met me for half an hour on a tough day and decided she knew all about me. I remain angry. She clearly thought that ME/CFS was phsycosomatic and that I just needed to try harder.</i>
<b>72</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>There needs to be a service for people who are ill with ME. However, that service needs to provide treatment based on solid scientific research which needs funding to happen. The people working at the service were nice people but ultimately there is no cure for ME so all that was offered was someone to encourage me &amp; ways of trying to live with ME when what is needed is a cure for ME.</i>

<b>73</b>	Dorchester - Dorset Children and Young People's Chronic Fatigue Service	Be adapted to provide different services	<i>The advice is limited and has had little positive effect</i>
<b>74</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>No help to anyone</i>
<b>75</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Follow up with I formation giving and with details of groups...seem v disorganised in giving out information</i>
<b>76</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>I have seen a consultant who diagnosed me but gave no advice. I see a physio who works with how active I am. 11 months after being diagnosed I got too see the occupational therapist. It was then that I finally heard that I should scale back activities and incorporate rest until my activities don't make me feel ill. Then hopefully I'll be able to build up slowly. My symptoms got significantly worse before seeing the occupational therapist. The team are great but with diagnosis, advice on managing the condition *must* be given and an outline of occupational therapy advice should be provided because the waiting list is so long. Despite repeatedly asking about various drugs to help keep me awake, nobody mentioned that resting more might be what would help.</i>
<b>77</b>	Newcastle - North of Tyne CFS/ME Service	Continue to provide current services	<i>The clinic is geared mostly towards diagnosis. There is no medical/physical treatment offered. There is a local service that I think offers CBT/GET &amp; referral to physio but they don't really address physical issues eg when I was referred with back pain/weakness.</i>
<b>78</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>Pacing info was useful, group sessions were useful, but most other treatments were based on building up activity.</i>
<b>79</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>There are different levels of ME/CFS and each level needs a different approach. Some subsets of patients need antibiotic therapy and antiviral drugs which were not available to me when I went, but are offered abroad. Pacing and CBT alone are too broad and do not hone in on individual requirements and do not come close to treating this complex condition.</i>

<b>80</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>Trust is broken. Newly trained staff are required.</i>
<b>81</b>	Private clinic	Be closed and a new service rebuilt with patient input	<i>Most consultants have no realistic understanding of the condition or the impact on daily life</i>
<b>82</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be closed and a new service rebuilt with patient input	<i>Continuing to provide GET has undermined my trust in this service and I want a new service that actually listens to me</i>
<b>83</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be closed and a new service rebuilt with patient input	<i>It is or was an abusive place and unsafe place for ME patients to attend.</i>
<b>84</b>	Malvern - Worcestershire CFS/ME Service	Be adapted to provide different services	<i>Kind staff but really no clue about treatment</i>
<b>85</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be adapted to provide different services	<i>After &amp; continuing care</i>

86	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<p><i>I was diagnosed before the clinic existed. I got better medical care beforehand because I saw an immunologist who addressed different symptoms, prescribing appropriately. The staff at the Clinic were nice, they didn't pressure me to do GET and even dissuaded me from CBT (as not right for me personally). But I lacked appropriate medical care during those years, it was all focused on activity management and I felt borderline whether it cost more energy than it helped conserve.</i></p> <p><i>After a dramatic, bed/housebound relapse I asked to see a doctor because I felt there was something else going on but this wasn't available. I could only be randomly allocated to one of the staff team (physiotherapist, occupational therapist etc, not people trained to do differential diagnosis). My GP suggested herself that the clinic wasn't much use beyond initial activity management training and we agreed to give up on them. I did my own research and worked out I had POTS and now see a cardiologist for that and get prescriptions which made a big quality of life improvement (fludrocortisone, bisoprolol, ivabradine). My GP didn't know POTS existed so this diagnostic process was reliant on my own ability to research and initially after my relapse I was struggling to read a paragraph.</i></p>
87	Not listed	Be closed and a new service rebuilt with patient input	<p><i>I was actually told I was a lazy teenager, that i needed to try harder, and that there wasn't anything really wrong with me, i just needed to exercise. Thankfully my parents had seen me go from a happy, active, involved teenager to someone who was unable to get out of bed and when i did i was beyond exhausted and got the worst headaches etc... So they supported me and loved me well. But I feel the doctors were rude, you shouldn't assume someone is lazy and try and persuade their parents of that. But also, i was a teen at the time, and you believe doctors know what they are talking about and so they must be right and so it really messed with my mental health and with my understanding of what was true and what wasn't if that makes sense. I started to think that if there was nothing wrong with me, how on earth did other people cope with life because this was really hard. I just couldn't understand how everyone else was functioning, if this was "normal". I got really depressed as i lost sight of my truth and what was really happening. Then they started to say it was all down to depression, but i swear that came after. I was happy when i got sick, and it took a few years of what i would call abuse, from doctors messing with my head before the depression set in.</i></p>
88	Norfolk and Suffolk ME/CFS Service	Be closed and a new service	<p><i>I feel its governed by Nice guidelines rather than listening to real people suffering from this illness</i></p>

		rebuilt with patient input	
<b>89</b>	Bath Centre for Fatigue Services	Be closed and a new service rebuilt with patient input	<i>There is no medical specialism offering treatment so they only offer management. They seem totally uninformed, not with up to date thinking. When I asked about blood pressure monitoring for pacing the OT helper said we think people might get obsessed with it. I never attended the clinic itself as I am bedbound. They don't offer a home service and I struggle with the phone. All together totally unsuitable for my needs. Was never offered CBT or graded exercise</i>
<b>90</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>The clinic appears to work on the basis that ME is a psychsomatic rather than biomedical condition, focusing I "confidence" to do activities rather than "physical ability" to do them. They have showed no interest in exploring new experimental biomedical treatments.</i>
<b>91</b>	Bath Centre for Fatigue Services	Be adapted to provide different services	<i>The advice they give, to slowly increase activity levels, is harmful for people with ME.</i>
<b>92</b>	Salford CFS/ME Service	Continue to provide current services	<i>If u have any disease it stands to reason that u need continuously treatment</i>
<b>93</b>	Suffolk Specialist ME and CFS Service	Be adapted to provide different services	<i>I had a great specialist who helped me alot by changing and adapting to what I needed</i>
<b>94</b>	Not listed	Be adapted to provide different services	<i>They still focused on GET, this needs to change!</i>
<b>95</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>There was only counselling on offer - giving helpful medical advice for conditions such as POTS would be an improvement.</i>
<b>96</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>They are providing the best treatment they can with the current knowledge and understanding of ME/CFS.</i>

97	London - University College Hospitals Children and young people's specialist adolescent services	Be closed and a new service rebuilt with patient input	<i>The experience at UCLH was disastrous as they regard ME as MUS and ignore worse of physical symptoms. They believe sleep hygiene is curative and push reintegration at school while children are very unwell. They threaten social service involvement is you query their advice. They gave false information to our local authority which resulted in an offer of home tuition being withdrawn.</i>
98	Surrey - South West London and Surrey Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>There are protocols set out by the NHS that are extremely unhelpful to ME/CFS patients</i>
99	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<p><i>I think the dr i saw is now retired so his clinic is now closed. It was [a professional] who had a clinic at his home, but i think was out of the Essex cfs service? He gave me a definitive diagnosis which helped me, after 8 years of being told there was nothing wrong and i was just lazy, finally have a peace about what was going on in my body. He treated me with respect which until then had not been my experience of medical "professionals" (e.g. my assigned gp when i moved to Essex told me ME/CFS didn't exist so if i was making an appointment about anything to do with that then i shouldn't bother as he would not see me for that, he would just leave me in the waiting room. Terrifying...)</i></p> <p><i>So being given a diagnoses and understanding of what was going on in my body helped a lot, the depression that had developed out of confusion at what was happening completely lifted.</i></p> <p><i>However, with hindsight, [the professional] was pushing a CBT and GET agenda, which saw me go from mild ME (able to work, have a tiny social life, care for myself etc...) to severe ME (lost my job, in bed for a year and still in a wheelchair 8 years later, lost my home, friends, had to move back in with my mum etc...) And his explanations of cfs, it turns out were based on really bad science and ideas and ideologies, and i feel as an intelligent man and as a dr, he should have known better. He was involved with the ME Association for a while, and so actually, i don't see how he can't have known better as they are constantly pointing out the flaws in this particular area of "science". I wish he had listened, and read, and been critical of the junk science, because then maybe i'd still be only mild, still have a job and a life. I'm cross about that. He told me to avoid patient support groups, apart from his own one, as it wouldn't help my recovery, so i had no idea about all the politics and nonsense going on behind the scenes in terms of treatment for ME, and i trusted him. I hate that i trusted him, i wish i had just googled it and checked out that what he was saying was ok. It's left me unable to trust medical professionals, even when the issue is completely unrelated to my ME.</i></p>

<b>100</b>	Essex Chronic Fatigue Service	Continue to provide current services	<i>It had a good understanding of what ME is and what makes it worse.</i>
<b>101</b>	Manchester CFS/ME Service for Children and Young People	Be closed and a new service rebuilt with patient input	<i>It is based on false beliefs that increasing activity will improve your health</i>
<b>102</b>	Shrewsbury - Shropshire Community Neuro Rehabilitation Team	Be closed and a new service rebuilt with patient input	<i>Personal experience far outweighs what professionals think ME is like</i>
<b>103</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>We need new staff with biomedical training whose mindset is not coloured by a psychosomatic view of M.e and who use strict M.e diagnostic criteria so as not to conflate M.e with depression-related 'tiredness'. We will then have a service that has a proper understanding of our illness and therefore not use the harmful 'treatments' of G.e.T and the potentially harmful form of coercive CBT.</i>
<b>104</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be adapted to provide different services	<i>They need to actually treat the patients.</i>
<b>105</b>	Not listed	Be adapted to provide different services	<i>ME specialists required</i>

<p>106</p>	<p>Edinburgh - Lothian CFS/ME Service</p>	<p>Be closed and a new service rebuilt with patient input</p>	<p><i>I had already been to an ME service elsewhere, and due to going from mild to severe, i had started to research it myself more, to try and understand why i had gotten so much worse when i did all that the previous clinic said in terms of GET and CBT. So, in the previous clinic i was unaware of all the controversy and of how bad the "science" what had been done to me was based on, but now i knew a lot more. My background is in Psychology and i was utterly appalled at what colleagues in the profession were doing and writing and saying. I would read the papers they had published and realise that if i had submitted any of these at Uni i would have been failed immediately, and probably called to see the Dean and asked why my work was so bad and why i was taking my education for granted...</i></p> <p><i>So, i knew that what this dr at the Edinburgh clinic was telling me wasn't right and had already done me significant harm. I only kept going as i was in a catch 22 and needed him to write to DWP to confirm my diagnosis and that i was cooperating with treatment.</i></p> <p><i>This dr was rude and unkind on a regular basis. I was not depressed, but he kept going on about it just being depression. At one point even uttering this farcical statement, "Well then, you must have depression without the depression." That's not a thing!</i></p> <p><i>And yet i was persuaded to go on an antidepressant, Duloxetine, which he said would help in other ways, not just the depression (which i didn't have). This began an horrific year of side effects from the drug and then side effects from withdrawal of this drug. It was horrific, to say the least. And totally unnecessary.</i></p> <p><i>Another time i saw him, it had taken every last bit of energy to get into the clinic, which was an hour and a half, two bus journeys away. Because of previous encounters with doctors, this one included, i get incredibly anxious when i'm near them, and my ME was so severely bad that my symptoms were becoming overwhelming. I remember sitting in the waiting room knowing i was surrounded by medical people who could at least try and help me if they wanted to, but none of them were. I needed help with pain management, i needed help with exhaustion, i needed hope that this wasn't going to be forever. I was called in to see the dr, he was dismissive and unhelpful, and with all that was going on in my head and body, i burst into tears. This was further confirmation i was just depressed, not a completely understandable reaction to bad treatment, bordering on abuse.</i></p> <p><i>Eventually i was discharged, seen as uncooperative and not wanting to get better. I doubt any of the harms done to me were recorded, that doesn't seem important to anyone. This dr retired shortly after i was discharged, thankfully, so i don't have to worry that he is still damaging people.</i></p> <p><i>Now, even 4 or 5 years later, if you were to take me back to that ward i would have a panic attack.</i></p>
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<b>107</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>I feel if a new service began, with input from sufferers it would be better adapted to give the correct treatment .</i>
<b>108</b>	Torquay - Torbay and South Devon CFS/ME	Be adapted to provide different services	<i>Need services but helpful services based on scientific evidence and knowledge</i>
<b>109</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>The treatment is harmful and the patient knows more about their illness than health care professionals.</i>
<b>110</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>I liked having one consultant who understood me and had an integrated approach, but the services they offered (CBT or occupational therapy) were not helpful. I would have liked more alternative services all linked together eg dietician, mental health support (but not CBT), physiotherapy (to help with muscle aches and fatigue, not GET). It needs to be more regular, for example I'm lucky if I have an appointment more than once a year as each time they cancel and rearrange to a time that I can't do (often last minute and I don't have the capacity to change everything).</i>
<b>111</b>	Newcastle - North of Tyne CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The clinic recommends inappropriate treatments based on PACE - a bogus trial The doctor got the basics of my recorded answers wrong The doctor got the basics of bacterial infection laughably wrong While harping on about "diagnosis of exclusion" the doctor failed to exclude or even understand existing diagnoses or exclude any others As you have taken on a DWP funded scam study as the basis for treatment it is understandable that your staff can do little more than scam treatment</i>

<b>112</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I was referred to the infectious diseases team who put my symptoms down to burnout rather than CFS/ME (despite already having been diagnosed by another clinic in London over a year ago). I was then told to see a physio who was lovely but prescribed me to do GET. This made my symptoms significantly worse, yet each time I went back it came down to issues that I wasn't motivated or wasn't being consistent enough with my activity levels (but I tried my absolute hardest and suffered significantly mentally from the pressure I was putting on myself to push through to meet unachievable targets). I asked for some mental health support and was told I had to wait a year, which would have been unacceptable given the state I was in so I looked for a private therapist (who used to work in the NHS clinic). They did CBT with me, again forcing me to increase activity levels and saying that the lack of motivation was holding me back and I should just push through. The whole system needs changing and there aren't the staff to do it at the moment.</i>
<b>113</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>It seems to offer a good all round service. I've only had consultation so far but have been offered a variety of options</i>
<b>114</b>	Aylesbury - Buckinghamshire Chronic Pain and Fatigue Management Services	Be adapted to provide different services	<i>Because while I think the clinic has potential, the treatments need tweaking</i>
<b>115</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>The therapists have no understanding of M.E. I was told I knew more about the illness than they did! I took a book on M.E to give to the clinic, the therapist had never read any information on M.E. I visited a week before Missing Millions in Sheffield, there were no posters or information. It is not patient led.</i>
<b>116</b>	Nottingham Childrens Hospital CFS/ME Service for Children and Young Adults	Be closed and a new service rebuilt with patient input	<i>There is no paediatrician dedicated to ME, they have no understanding or knowledge</i>
<b>117</b>	Not listed	Be adapted to provide different services	<i>no clinic care was given to me in norfolk as all done online of which is not helping patients. No treatment or therapy was ever advised apart from that of GET of which made my condition a million times worse and stopped my care.</i>
<b>118</b>	Maidstone - Kent & Medway CFS/ME Service	Be adapted to provide different services	<i>Stop pushing get</i>

<b>119</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>The clinic I attended had no understanding of PEM or the potential harm that can be caused through overexertion.</i>
<b>120</b>	Bath Centre for Fatigue Services	Be adapted to provide different services	<i>Current services are focused around GET and CBT. As a therapist I was well placed to talk about my lack of psychological illness, but was offered nothing to address my physical illness, ME. The occupational healthcare was useful for adaptations around my home and she was very supportive of resting until well, making very useful physical suggestions like keeping a box of meds, drinks a easy access foods by my bed.</i>
<b>121</b>	Hull and East Yorkshire CFS Service	Be closed and a new service rebuilt with patient input	<i>Hull is run by the Psychological Department they think it has a psychological base and therefore are not interested in bio medical research or approach and offer no medication including medical cannabis or Mestinon which have been proven to help with symptoms in other countries. They offer no home visits, no help with financial support or occupational health services, disability help or indeed any practical help at all. They discharged me for missing one appointment which I cancelled over the phone due to being too unwell to attend and then did not tell me, neither did the GP. The service was under threat at the time and I presumed it had closed down. It was years later I found out I had been discharged. They offered physiotherapy which was useless and then cancelled due to lack of funding. 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. 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.</i>
<b>122</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>Gloucester is not on your list above for some reason!?</i>
<b>123</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>I would need to be bullied into a strict regime to receive a confirmation of my diagnosis of ME - the doctors words not mine. No sleeping during the day and set bed times despite however I was feeling</i>

<b>124</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Continue to provide current services	<i>Though not the experience of all patients, I felt heard and understood. The clinicians were able to explain my illness to me in a way that fitted with my experience, made sense, and gave me hope and a path towards recovery.</i>
<b>125</b>	Not listed	Be adapted to provide different services	<i>Psychological treatments are not the only treatment</i>
<b>126</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>There were no investigations into other causes of symptoms. Failing to improve was blamed on the anxiety of the young person who has CFS/ME and their mother. A different NHS hospital identified 3 other medical conditions which required treatment</i>
<b>127</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>Needs a more open approach and to work jointly with fibromyalgia.</i>
<b>128</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be closed and a new service rebuilt with patient input	<i>We need biomedical clinics offering biomedical Investigations and bio Medicare care. No exercise and no psychology or cbt.</i>
<b>129</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Totally unhelpful. We did gentle exercise and relaxation techniques which made no difference. And diet advice which was unnecessary.</i>
<b>130</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Some people like hand holding. I just want to get better. Using my limited energy Getting there to be given no new information by people who appeared to have read less up to date data than I had was frustrating. The fact that they spend so much time telling us they believed us was annoying. It never occurred to me that I wouldn't be believed. I wanted to discuss what we could do to help ourself and given the lack of trial data if they had any real life info to pass on but I didn't learn anything I couldn't read online. I realise the nice guidelines and pace trial have complicated matters but I was very deflated when I left not motivated.</i>
<b>131</b>	Grantham - Lincolnshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Need new biomedical service, not psychological service</i>

<b>132</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Pacing was the only advice I was given and no treatment was offered. No provisions for severely affected patients or long term patients</i>
<b>133</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>Makes everything worse going. Telephone support would be ideal</i>
<b>134</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be closed and a new service rebuilt with patient input	<i>I saw [a professional at the Royal Free London Hospital]. She is a huge proponent of the idea that we *were* ill but now we just have problematic illness beliefs. Memorably she informed me that I should take an antidepressant, but refused to explain why because it was all "higher brain science that you won't understand". I am a postgraduate level psychologist, as she was well aware. She criticised everything, explained nothing, and then tried to force me into PACE without explaining that was what she was assessing me for. When I realised what was happening I refused consent.  <i>My partner ran into someone at an event shortly thereafter who casually chatted with him about a doctor friend who was completely burned out and hated her job and her patients. You'll never guess who it turned out to be!</i></i>
<b>135</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>The entire approach of this service harms people with chronic fatigue conditions</i>
<b>136</b>	Leicester CFS Service	Be adapted to provide different services	<i>The service was very good for helping me pace and understand a bit of what was happening to me, but the GET treatment offered when tried made me feel worse, has been disproven multiple times, and I don't think it would be wise to continue this treatment for other patients. I also felt like I could be made better just by me trying hard enough, which I've since learned the hard way isn't the case.</i>
<b>137</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be closed and a new service rebuilt with patient input	<i>Not fit for purpose</i>
<b>138</b>	Maidstone - Kent & Medway CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>They are using an inappropriate psychiatric model of care.</i>

<b>139</b>	Norfolk and Suffolk ME/CFS Service	Continue to provide current services	<i>The OT was amazing. Consultations by phone to avoid travelling. Sound advice.</i>
<b>140</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	Be adapted to provide different services	<i>The OT offers no practical advice on symptom management or support with applying for benefits etc.</i>
<b>141</b>	London - University College Hospitals Children and young people's specialist adolescent services	Be closed and a new service rebuilt with patient input	<i>The specialist WAS Lead at GOSH she calls herself Dr yet her title is consultant nurse ! Who advocates the Lightning Process now</i>
<b>142</b>	Oxfordshire CFS/ME Service	Be adapted to provide different services	<i>Offer more investigative options to rule out comorbidities e.g POTS, autonomic dysfunction</i>
<b>143</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be adapted to provide different services	<i>More treatments such as physio and psychological services provided.</i>
<b>144</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I tried both a couple of group sessions and a couple of one to one sessions. The group sessions were patronising, nonsensical, and irrelevant it was like going back to infant school with their talk of "the jug of life" and other metaphors. In the 1-2-1 sessions my questions about cause, mechanism, symptoms and treatment were evaded. A graded exercise approach was promoted, but by then i had enough experience to realise that was dangerous for me. It was clear they were not going to provide anything useful to me. The effort and travel to attend by a 2- bus journey each way was making me worse, leaving me in bed with PEM so I stopped attending.</i>
<b>145</b>	Grantham - Lincolnshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I was told that I was hanging on to illness behaviours and beliefs, and I was ill because of this. I believe this to be wrong and feel that many people with ME who had not previously been in the care of an excellent ME clinic in another area, as I had, would be damaged by this advice and attitude.</i>
<b>146</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Continue to provide current services	<i>I don't know enough about their services to comment.</i>

<b>147</b>	Not listed	Be adapted to provide different services	<i>Some of the information was good I.e. pacing, but there was a slant towards GET. Also no medical advice. Run by Ots, no medical input.</i>
<b>148</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>This illness is a physical illness not a mental one. Bath treat it like a mental illness</i>
<b>149</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Continue to provide current services	<i>I saw a Consultant, GP with special interest, specialist nurse and oT at various times. The combination of treatment approaches were very helpful to me in both the short and long term. They were very understanding, supportive and gave valuable practical assistance too.</i>
<b>150</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>The service did nothing to help my condition, and I have had different advice from different people on how to manage the condition. The only helpful part was providing documents for my job to show cfs/me for reasonable adjustments (no support was given for how to work with a employer who didn't put into place reasonable adjustments)</i>
<b>151</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be adapted to provide different services	<i>Difficult to say really, I also have Fibromyalgia and didn't feel they had a very good insight as to how to deal with having both CFS/ME and Fibro.</i>
<b>152</b>	Norfolk and Suffolk ME/CFS Service	Continue to provide current services	<i>As I can go there in person (not bedbound) it is a very useful service with good explanations and follow ups</i>
<b>153</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>The advised to keep increasing our exercise over time periods and you were made to feel ashamed or that you were doing something wrong if you said you felt worse not better. The small amount of pain management treatments they suggested that might have been useful such as accupuncture they said they could only give us two tries and nothing more even if we found it helped. There was no follow up just a short course and left to fend for ourselves. AGAIN.</i>

154	Not listed	Be adapted to provide different services	<p>Advice given at clinic was great (explaining ME, pacing, activity management, diet, dealing with stress of a chronic illness, impact on relationships, managing setbacks etc.). However ongoing support after the service is not currently routinely offered and I know it would be extremely valuable to reinforce what was learnt, and to provide ongoing support &amp; management in relapses (my original GP was pressurising me to go back to work quickly &amp; I knew from having monitored my health &amp; activity levels for the last couple of months it would have caused me to relapse, but would not have been confident enough to insist this myself if I hadn't had the OT at the ME programme saying that she also thought I was not ready to return to work yet &amp; to do so would cause relapse). The changes that would be helpful throughout the programme were accessibility related. Sessions were weekly and required a 1-2 hour journey each way for most patients. Most of those attending had mild ME, but juggling 4-6 hours of an outing every week for 10 weeks was too much for most of us (some of us with it being the only thing on in the week, and others juggling part-time work). It also meant the service is inaccessible to those with severe ME. Things that could help: spacing out sessions e.g. one a month, allowing longer recovery time between sessions. Choosing locations to reduce travel time &amp; if possible helping with transport or choosing a location easily accessible by public transport (e.g. I couldn't have driven myself, had no family or friends to give me a lift, couldn't have managed public transport with a change, &amp; was only able to attend as another group member lived nearby &amp; offered to give me a lift). Using videoconferencing software to stream the sessions online would be really helpful. If there was still a way to facilitate group/partner discussion (even if typed) this would be beneficial (there was a lot of therapeutic value in shared experiences &amp; developing friendships with others who understand what you are going through). Venue having lift access, high back comfortable chairs &amp; keeping information sessions short &amp; split up with group/partner discussions &amp; tea break in the middle really helped. e.g. 10-15mins chat time, 30 minutes presentation/ group discussion, then tea &amp; comfort break, then another 30 mins presentation/ discussion.</p>
155	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<p>Any changes to service provision should have input from patients. As the service covers a vast geographical area it needs to consider how works with areas other than Sheffield; telephone consultation is not an adequate response to this issue. An introduction to ME session and the offer of attending one short group is the only thing on offer currently despite this condition changing every aspect of your life and preventing you from working; you are left in a void trying to work out pacing practices from books, self-help media and private clinics.</p>

<b>156</b>	Norfolk and Suffolk ME/CFS Service	Be closed and a new service rebuilt with patient input	<i>Professionals don't believe symptoms, no support and have to research your own information when yr condition is deteriorating</i>
<b>157</b>	Maidstone - Kent & Medway CFS/ME Service	Be adapted to provide different services	<i>I received a diagnosis after 23 years of suffering with ME. I enjoyed meeting other sufferers because we all had so much in common. I enjoyed getting the coping mechanisms but the pushing the physical exercise was no help as things either got worse or didn't make me feel any better. One of the CBT ladies actually believed that they were going to cure me! She stated that I was well on my way to recovery in a in their final letter to my GP. I had to go back for further treatment as I was no better but all they could offer was a Psychologist. I think if they could offer support and tell people to listen to their body's it may help more. Presently I am still ill and have had to stop work.</i>
<b>158</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Everything I was asked I tried , anything I suggested I was shot down . They were not interested in what I had to say . I found the neurologist were the worst for this . Nobody wanted to take my opinion onto account. This was very disheartening. I should have had more input.</i>
<b>159</b>	Private clinic	Continue to provide current services	<i>The service is very knowledgeable about CFS/ME and pacing</i>
<b>160</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>The clinics knowledge far exceeded any of the previous 3 paediatricians my son had been under. It was so welcoming you have questions answered thoroughly, the illness explained and support given.</i>
<b>161</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>The service did not cater for severe patients and when we were unable to travel we were discharged</i>
<b>162</b>	Maidstone - Kent & Medway CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>When I attended it was part of the psychiatric/ mental health clinic which determines its advise &amp; is not appropriate</i>
<b>163</b>	Not listed	Be adapted to provide different services	<i>Some subjects the clinic covered where 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.</i>

<b>164</b>	Aylesbury - Buckinghamshire Chronic Pain and Fatigue Management Services	Be adapted to provide different services	<i>Graded Exercise Therapy with the physio exacerbated my symptoms.</i>
<b>165</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Continue to provide current services	<i>Provided there are currently no treatments offered they do the best they can.</i>
<b>166</b>	Not listed	Be adapted to provide different services	<i>Comorbid conditions like POTS not understood.</i>
<b>167</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>People with ME/CFS require ongoing support both socially with other sufferers and physically / mentally. I feel the service we have is one of advisory rather than tangible ongoing support.</i>
<b>168</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Long wait to be seen by which time I had received all of the advice given to manage my CFS/ME (CBT, Pacing, rheumatology appointment) all self referred. No advice on pain management, very unhelpful rude staff. Requested my mum went out of the room because I was 19, even though my brain fog an anxiety means I want someone with me. Complete waste of time, I had a diagnosis confirmed (year after my GP diagnosed) apart from that no help at all</i>
<b>169</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>It is essential that pwme are treated for their physical condition without harm.</i>
<b>170</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be adapted to provide different services	<i>I don't feel as though the help I was offered was of any use to me in helping with managing my ME/CFS. The psychologist I was referred to, who works for the ME/CFS service, seemed more interested in my history of depression and trying to figure out the root cause of that than talking about the ME. I don't understand the point of the session and it left me feeling psychologically worse than I have felt in a long time and at a complete loss as to what I was doing there. I'm VERY reluctant about attending the next session with her but was told if I don't attend I'd be discharged from the service.</i>
<b>171</b>	Suffolk Specialist ME and CFS Service	Be adapted to provide different services	<i>It was very useful but after my sessions were over, I have to be re-referred to the get more support.</i>

<b>172</b>	Suffolk Specialist ME and CFS Service	Be closed and a new service rebuilt with patient input	<i>We need a biomedical marker and treatments, not psychological fobbing off. We are seriously ill with a life destroying illness and pacing as a suggested treatment strategy is an insult.</i>
<b>173</b>	Dunstable - Bedfordshire Chronic Fatigue Service	Be adapted to provide different services	<i>New treatments needed, the current ones ineffective &amp; can be damaging.</i>
<b>174</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Continue to provide current services	<i>I've recently moved from an area which had nothing so it's great to have access to professionals!</i>
<b>175</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Because I have been left with nothing. They ran out of funding for me.</i>
<b>176</b>	Manchester CFS/ME Service for Children and Young People	Be closed and a new service rebuilt with patient input	<i>The advice we were given was prescribed and standard one size fits all advice. It wasn't individualised and I feel that every one is different and should be given individualised advice.</i>
<b>177</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>When I said that CBT and GET were ineffective they just discharged me offering no further support. I had to go back to my GP who prescribed me medication and referred me to a pain clinic.</i>
<b>178</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>They need to focus on physical needs not mental health</i>

<b>179</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>Intent is good but it needs to be a consultant led service with prescribing and onward referral powers like Suffolk. I have never seen a clinical person since diagnosis. I deteriorated massively due to insufficient monitoring (too few appointments far too far spaced out) and insufficient inappropriate staff clinical skill (now have pots and vestibular diagnoses that were overlooked) and frequent staff changes causing inconsistent care and long delays accessing and reaccessing help. It is 1 hours drive each way to a city for clinic attending is unfeasible or self harming and they do not come to housebound cases. this is a rural county but there's a small hospital 15 minutes away in a town with a ME support group .A mobile staff member who visits worst affected is needed. Though I do NOT have depression I could have benefitted from health bereavement grief counselling as an onward referral on receiving my diagnosis.</i>
<b>180</b>	Edinburgh - Lothian CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>They had no understanding of the illness</i>
<b>181</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Continue to provide current services	<i>I just think there needs to be more staff as appointments are sparse</i>
<b>182</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>Because I felt they weren't interested in helping my daughter as she was quite severe. They just seemed interested in you being part of the trials and making their figures look good. We were fobbed off to two different departments who could t helped and then discharged!</i>
<b>183</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Would be better if it was closer and not under the psychiatric department</i>
<b>184</b>	Not listed		<i>Clinic closed shortly after my referral</i>
<b>185</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>The Clinic was mostly focused on giving advise about pacing and not much else</i>
<b>186</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>I was treated very poorly, I was encouraged to take part in clinical trial and I was discharged as soon as I had completed the trial even though I had not received any sort of treatment from the clinic and I was still ill</i>

<b>187</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>They only provide advice on managing condition through group support. There is a lot more they could do but it's minimal due to funding.</i>
<b>188</b>	Preston - Lancashire CFS/ME Service	Continue to provide current services	<i>The clinic was shut down some years ago but has reopened last year and they are a new team, still forming their treatment, and want to do it differently from other clinics and really make a difference. The new clinic should be given a chance but their hands are tied on many issues due to the current not fit for purpose NICE guidelines, e.g. they would like to do nutrition, test for MTHFR gene mutations and provide treatments that they currently can't be funded for.</i>
<b>189</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>The way services improve is to use research and feedback to change and adapt.</i>
<b>190</b>	Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service	Be adapted to provide different services	<i>The Group environment with other sufferers was helpful but some of the content was in need of update e.g being told to ignore the bidy as it was lying!</i>
<b>191</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because their perspective on how to tackle ME is outdated and they don't actually ask any patients what would help them. They stipulate to patients what they need to do and how the patients thought process works rather than asking patients how their thought process has an affect on them or how the illness has an affect on their thought process. Maybe listen to the patients more rather than talking at the patients. Listen to the capabilities level of the patient and the consequences to the patient as well rather than suggesting unrealistic goals for the patient. Discuss the patients needs individually rather than in a group as each patient's symptoms and levels are different and so will need different treatment. Involve the GPs more so that they are more aware of the patients needs. Include other consultants to do thorough health checks to rule out any other causes of CFS/ME which could be treatable. Include a holistic approach with diet and supplements, maybe accupuncture that could help. Send information packs of symptoms of ME and what treatments can help to GPs plus what can make it worse.</i>
<b>192</b>	Birmingham and Solihull CFS Service	Be adapted to provide different services	<i>there was little in the way of biomedical research or support. Most of it was about psychological attitude, which did not alter my symptoms, but helped me cope with the emotional toll of being ill.</i>

<b>193</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because they were not listening to my level of capability</i>
<b>194</b>	Liverpool Children's CFS/ME service	Be closed and a new service rebuilt with patient input	<i>They wanted to incarcerate severe patient in remote psychiatric unit , the Dewi Jones( for accommodation purposes only!!) limited parental access, expose to light and noise to normalise, GET and CBT , strict routine waking up and education. Transported to Alderhey everday for physio and hydrotherapy with no contra indication as [the professional at Liverpool Children's Clinic] said do not get worse, that whatever caused the ME no longer exists. Told professionals that Without the treatment said would get worse, led to care proceedings at court to enforce this, accused of harm for not agreeing to [the professional's] ' treatment' . Which he claims had 98% success and that this is what NICE had deemed was best for children. the clinic was in for loads of funding from the referring CCG. NICE guidelines 4.1 GET and CBT management not recommended for severe or children. Why is [this professional] on NICE guidelines panel?</i>
<b>195</b>	Liverpool Children's CFS/ME service	Be closed and a new service rebuilt with patient input	<i>[The professional at Liverpool Children's Clinic] wanted to forcibly incarcerate in the remote tier 4 psych unit for physion and hydrotherapy whilst I was severe, said I would get worse if didn't have his treatment. Taken to court for not agreeing. Do not treat ME but say it is deconditioning and MUPS.</i>
<b>196</b>	Manchester CFS/ME Service for Children and Young People	Be closed and a new service rebuilt with patient input	<i>Accused of FII by [the professional at Manchester CFS/ME Service for Children and Young People], as more than one family member affected, told I was too young, should not have fluctuations. wanted to incarcerate in Galaxy House psychiatric unit with limited parental access. Commenced court proceedings when we refused.</i>
<b>197</b>	Liverpool Children's CFS/ME service	Be closed and a new service rebuilt with patient input	<i>Told to increase school attendance all the time but was getting much worse. clinic said 'you can't not go to school just because you feel tired' refused to assist with school support. threatened to hospitalise if I got worse and didnt increase school attendance.</i>
<b>198</b>	Manchester CFS/ME Service for Children and Young People	Be closed and a new service rebuilt with patient input	<i>accused of FII as my brothers have ME, wanted to incarcerate in tier 4 galaxy house psych unit which specialises in pervasive refusal syndrome. limited parental access. told I was too young to have ME aged 6, told me to go to school and told school not to send me home even if I felt really ill, just sit on a chair outside the class for 10 minutes unattended.</i>

<b>199</b>	Bolton - Bury and Bolton CFS/ME Clinic	Be closed and a new service rebuilt with patient input	<i>'take these antidepressants you will feel like a new woman'....hmmm... no and I wasn't depressed I was in pain and felt really really ill.</i>
<b>200</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Workwell Foundation studies show how to manage the disease it is not rocket science but help to rest enough and heart rate pace is essential</i>
<b>201</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	Be adapted to provide different services	<i>The clinic and the treatments I received were life saving as the psychologist recognised immediately that I had chronic PTSD. My psychologist spent about 4 years helping me to cope. I have absolutely no criticism of the psychological services on offer. The Neurologist who diagnosed me however, based on an informal 5 minute chat, did not follow the NICE guidelines in any way. If he had done, he might have ruled out the 2 sleep disorders I had underlying my condition and exasperating it. Also he might have asked for the blood tests recommended and discovered several serious underlying problems. Unfortunately as I was mentally unwell at the time, this completely biased the way I was treated and has done for the last 8 years. The service in Connahs Quay needs a Neurologist, a GP and access to physical tests and scans. If the NICE guidelines were followed at any point in the last 8 years I might have had earlier interventions and not been left to rot at home. Separating mental health issues from physical issues does not happen, you are told outside of the clinic that the clinic will help you, you are fobbed off. The clinic can only help with your mental health, nothing else, what about your physical health? The clinic cannot carry out blood tests or scans or any biomedical research, so it isn't really a holistic clinic, it is set up with the bias that CFS/ME is a purely psychological condition - it is not. I had viral meningitis which triggered my symptoms and my PTSD only started 4 years later, which logically makes sense. This is a chicken and egg situation and patients are telling you their problems are physical and the medical community is saying they are psychological, how about giving equal treatment to both aspects? This is the only true way of ever finding the truth, although as I sit here with a problem with the nerves to my bladder, for which 2 Neurologists have attributed to my childhood trauma, and a Urology specialist and a test has shown this to be impossible and that I need invasive treatments to keep my bladder functioning - I wonder when this psychiatric bias will stop?</i>
<b>202</b>	Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service	Be closed and a new service rebuilt with patient input	<i>This clinic causes harm</i>

<b>203</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be adapted to provide different services	<i>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.</i>
<b>204</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>Only really used them to get letters for education. We see an OT. She doesn't push GET but in the first appointment talked about increasing activity levels. We ignored this advice and rested.</i>
<b>205</b>	Leeds - Yorkshire Centre for Psychological Medicine inpatient care	Be adapted to provide different services	<i>They denied any biomedical cause / effect. The consultant said 'there is no disease state behind your illness'. They disbelieved published biomedical research and were exasperated and condescending when I explained to them what published research had shown. They made me feel guilty for looking into the published research because what I was looking for wasn't psychological, and so didn't fit *their* narrative or *their* illness beliefs. They pretended to listen to me, but ultimately told me I was wrong and didn't accept that there could be a physiological cause for symptoms.</i>
<b>206</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>No symptoms are completely the same.</i>
<b>207</b>	Bath Centre for Fatigue Services	Be adapted to provide different services	<i>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. Thankfully my GP is lovely</i>
<b>208</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>The services fit with the antiquated GET and CBT model which has been proven to harm some people. Whilst it didn't harm me because I refused to push myself which caused great unease with the service I used, I know people who have been made irreversibly more unwell. We have science now, we should use it. HR monitoring and pacing. Dr Myhills approach and the kind of therapies found in MS centre to help not cure until such times as we find treatments that work. PWME have nothing right now unless they are very slightly affected. There's a melting pot of depression and fatigue people get thrown into proven by Julia Newtons work that 40% of people in her clinics have something else causing their issues. We need proper screening, proper support instead of this awful attitude towards us most Drs and consultants have, and better support. Shrink theses clinics and spend money better educating all clinicians and just have specialist nurses until such times as we have treatments.</i>

<b>209</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I feel that even though some health care professionals have an understanding of CFS/ME they don't fully understand the full impact this devastating illness has on each and every one of us. What works for one person doesn't always work for everyone, due to the different levels of symptoms and severity you can't give a one answer or advice that helps all. There is still so many people who don't understand this illness and still think it's psychological and that needs to change.</i>
<b>210</b>	Essex Chronic Fatigue Service	Continue to provide current services	<i>It was cbt which helped me understand CFS a little more when first diagnosed</i>
<b>211</b>	London - University College Hospitals Children and young people's specialist adolescent services	Be adapted to provide different services	<i>Once a month traveling to London was exhausting, I have recently been under Dunstable, once a fortnight and found that far better for management my fatigue levels.</i>
<b>212</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>No follow up contact or treatment was offered after attending an initial course on pacing. No liaison with gp who refuses to acknowledge ME</i>
<b>213</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Some things helped but other things are outdated and not good for people and information not correct for the illness.</i>
<b>214</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>The "clinic" I went to was the rheumatology departments in Milton Keynes hospital. The rheumatologist explained to me that they are not equipped to deal with people with myalgic encephalomyelitis and that I should take care of myself.</i>
<b>215</b>	Not listed	Be adapted to provide different services	<i>Longer term treatment and support needs to be offered</i>
<b>216</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>Because I lived an hour away they could only offer phone catch ups 4 monthly after my initial appointment in the clinic</i>
<b>217</b>	London - Uxbridge - Hillingdon CFS/ME Service	Be adapted to provide different services	<i>Although I opted for personalised 1-1 sessions it was very "sausage factory" and not actually very tailored to me</i>

<b>218</b>	Aylesbury - Buckinghamshire Chronic Pain and Fatigue Management Services	Be adapted to provide different services	<i>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'.</i>
<b>219</b>	Hull and East Yorkshire CFS Service	Continue to provide current services	<i>I went years ago</i>
<b>220</b>	Preston - Lancashire CFS/ME Service	Be adapted to provide different services	<i>There was a psychiatrist and a physiotherapist in attendance no medical professional.</i>
<b>221</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>They were more about trying to tell people they didn't have M.E and had other things such as anxiety rather than trying to help as well as pushing people to do things they couldn't do.</i>
<b>222</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be adapted to provide different services	<i>It would be useful to have help for much longer.</i>
<b>223</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Continue to provide current services	<i>I feel that it was doing everything possible. However when I attended I was only allowed to choose one treatment. For example, pacing. After I had finished I believed the CBT would have helped.</i>
<b>224</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Service stopped when specialist retired as no further funding</i>
<b>225</b>	Nuneaton - Warwickshire CFS Service	Be adapted to provide different services	<i>Needs to remain an active patient and regular updating to the sufferer not left/dismissed</i>
<b>226</b>	Wells - Somerset CFS/ME Service	Be adapted to provide different services	<i>Focus on pacing and graded excercise, not really much to help deal wirh symptoms.</i>
<b>227</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be adapted to provide different services	<i>There was an emphasis on pacing (which I found helpful) and GET which is really detrimental. CBT (or a very loose interpretation of it was also pushed.)</i>

<b>228</b>	Nottinghamshire PICS CFS/ME Service for Adults	Continue to provide current services	<i>Practitioner [at Nottinghamshire PICS CFS/ME Service for Adults] is great. Helpful, knowledgeable, doing her best to help while working within/around the unhelpful NICE guidelines. However, (inevitably) she can only help me learn how to manage symptoms, not cure me, so until medical research makes some progress, this kind of service is only a sticking plaster. I'm grateful to have someone who is not actively making things worse (after 2 years of GP telling me to "just push through it"). Practitioners like [this professional] need to be backed up by a) correct NICE guidelines, not the current mess, and b) medical research, properly funded and with no political agenda, to help with definitive diagnosis and hopefully a cure.</i>
<b>229</b>	Private clinic	Continue to provide current services	<i>I like the Optimum Health Clinic's approach to treatment and feel that they are continually trying to improve and provide new solutions.</i>
<b>230</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>Still recommend GET despite evidence based research that this is detrimental to ME sufferers</i>
<b>231</b>	Not listed	Continue to provide current services	<i>Clinic is not there anymore unfortunately</i>
<b>232</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Continue to provide current services	<i>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>

<b>233</b>	Bath Centre for Fatigue Services	Be adapted to provide different services	<p><i>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.</i></p> <p><i>The course leaders were all psychology based people which meant the focus was not physical and made me doubt how much they knew and understood about the physical manifestation of the illness</i></p> <p><i>The clinic is part funded at least by Maximilian Cancer and they also run very similar courses for people recovering from chemotherapy. I think this is totally inappropriate as these patients will have a very good chance if full recovery through pacing whereas with ME/CFS there are no guarantees</i></p> <p><i>The course was very much aimed at mild/moderate cfs and wasn't appropriate for anyone with more severe symptoms</i></p> <p><i>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.</i></p>
<b>234</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<p><i>Needs to be much better treatments for ME. The ones offered felt very much like learning to accept it rather than getting better from it.</i></p>
<b>235</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be closed and a new service rebuilt with patient input	<p><i>I was promised to see different professionals at clinic in future but almost a year later they have booked me in with an Occupational therapist, with no mention of anything else. Consultant seemed to think it was ok to carry on exercising at Tate I was doing at gym and running when I know it gave me PEM and said drinking alcohol was fine. When I know I over do it, it has severe repercussions.</i></p>
<b>236</b>	Not listed	Be closed and a new service rebuilt with patient input	<p><i>The team had a complete lack of modern understanding for CFS/ME, they insisted it was psychosomatic and due to deterioration and the way to treat it was by forgetting everything you know, increasing exercise daily, not taking breaks &amp; trying to ignore your symptoms &amp; push forward which was extremely dangerous, i went in able to walk small distances and each appointment/week came out being able to walk even less to the point i was no longer able to walk or even move before 4pm. they also sent me to an eating disorder clinic for a non-eating disorder which almost ended me in a psychological ward despite having no issues with it.</i></p>
<b>237</b>	Wells - Somerset CFS/ME Service	Be adapted to provide different services	<p><i>At the time I attended the clinic I was advised to stop all activities and stay at home. I was a teenager and I wanted to attend college with my peers. There was only one programme</i></p>

			<i>and their programme would not allow me to go to college at all.</i>
<b>238</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>given myalgic encephalomyelitis is not a fatigue condition but a testable and measurable progressive degenerative life shortening and fatal multi-systemic disease that's caused by the enterovirus, no fatigue clinic would help and would indeed be dangerous and even fatal for anyone who has myalgic encephalomyelitis. there is no such disease entity as me/cfs.</i>
<b>239</b>	Nottingham CityCare MOSAIC Service	Be closed and a new service rebuilt with patient input	<i>It has since been closed and moved to community based, however same issues still stand with some staff members. I was told the reason GET did not work for me previously was down to me not doing it right, not because it is known to be detrimental for most and no acknowledgement of the harm it can cause was discussed. I was treated as if I had no understanding of CFS despite having been diagnosed 3-4yrs prior and severe for the most part with extensive research to keep abreast of what was happening as part of my self Help and to maintain some hope of a cure. There was no leeway in their understanding or desire to come up to speed with current research, I found the person very rude &amp; dismissive of both my previous experience and concerns. I would like for the service to remain Community based so more people can attend (previous clinic was not suitable for most due to location) but with well trained staff who are up to date with current research, do not promote GET or misuse CBT regarding false illness beliefs that have been debunked, have the ability to listen to and work with patients to educate on coping techniques/symptom management and any testing to help rule out misdiagnosis, underlying conditions that could be contributing for example my thyroid was only ever tested for TSH, it was slightly elevated around 2012 for me but within range it wasn't until 2018 when TSH when our of range thyroid issues were discovered and treated, had FT3 &amp; FT4 been tested sooner they may have been out of range or borderline and treatment trialed 6yrs sooner to help some symptoms. Specialist in CFS would know to look for these sort of things and where CFS patients need optimal levels rather than NHS normal ranges.</i>
<b>240</b>	Plymouth Sentinel CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>This clinic is not fit for purpose, the GP attached to it is excellent but the service actively works to prevent patients being able to access help from the GP</i>

<b>241</b>	Leeds and West Yorkshire CFS/ME Service	Continue to provide current services	<i>It's very important for my service in Leeds to continue to operate in order to assist ME patients but it could do with some current training and current research, eg Dr Sarah Myhill, Dr Ray Perrin, more knowledge about Epstein Barr and glandular fever, POTS, EDS, Hashimotos, Thyroid, CCI and cross over with other neurological chronic illness, eg MS. Neurology referral should be normal to check for other diseases or to rule out.</i>
<b>242</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Totally inappropriate for patient needs. My severely ill son was told to attend a course 2 hours away for 8 weeks, he can barely walk and is bed bound 80% of the time. It was impossible for him to attend, the person who diagnosed him seemed to have no understanding of severe M.E. He has not been well enough to leave the house since, this was after attending the assessment which he was forced to do by GP to provide benefit evidence despite being diagnosed 2 years earlier by another clinic. My son was actively harmed by the process. The clinic has never followed up with him.</i>
<b>243</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Continue to provide current services	<i>It was the better of the 2 clinics I have been to- compared to the Bristol clinic, the Truro one was so much better.</i>
<b>244</b>	Sunderland - South of Tyne CFS Service	Be adapted to provide different services	<i>It's predominantly CBT focused using the biopsychsocial model maybe more beneficial</i>
<b>245</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because CBT and GET are gaslighting patients and making the majority worse. We need professionals who understand our condition not those pushing the biopsychosocial model, which is fundamentally flawed.</i>
<b>246</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>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</i>
<b>247</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>The infrastructure is there, but it needs to be used to deliver evidence-based services, not CBT/GET nonsense (with no warning of harm risk).</i>
<b>248</b>	Newcastle - North of Tyne CFS/ME Service	Be adapted to provide different services	<i>I think the services are stretched, making appointments and support very limited. I would like more tests and answers to help me to improve my condition.</i>

<b>249</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>Waiting for GET/physio-led treatment is far longer, so they need to boost physical therapy support</i>
<b>250</b>	Not listed	Be adapted to provide different services	<i>they still teach Graded Exercise Therapy, which I think is dangerous</i>
<b>251</b>	Bath Centre for Fatigue Services	Be closed and a new service rebuilt with patient input	<i>How can any so called medical professional 'treat' an illness it does not understand!!</i>
<b>252</b>	London - University College Hospitals Children and young people's specialist adolescent services	Be closed and a new service rebuilt with patient input	<i>Advice such as GET was detrimental to my health, we need more research to provide adequate care.</i>
<b>253</b>	Not listed	Continue to provide current services	<i>It does help with pacing, but not to cure me</i>
<b>254</b>	Bishop Auckland - Durham & Darlington CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Because there is not a one fits all answer in managing the illness. So the health professional needs to work with the individual to a tailored plan.</i>
<b>255</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>You are left in limbo with no support once finished course</i>
<b>256</b>	Middlesborough - South Tees CFS/ME Service	Be adapted to provide different services	<i>They still promote GET which made me worse</i>
<b>257</b>	Not listed	Continue to provide current services	<i>The course was to help deal with the illness so individuals could use what worked for them.</i>
<b>258</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	Be adapted to provide different services	<i>Help with care.</i>

<b>259</b>	Leeds and West Yorkshire CFS/ME Service	Continue to provide current services	<i>Additional services should be provided. More help with pacing.</i>
<b>260</b>	Not listed	Be adapted to provide different services	<i>Because it was apparent that the people running the clinic knew a lot but were forbidden to use treatments they knew to be effective</i>
<b>261</b>	Not listed	Be adapted to provide different services	<i>Graded Exercise Therapy was recommended - I did this and it made my symptoms worse.</i>
<b>262</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because the service only addressed psychological aspects and nothing else</i>
<b>263</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>The consultant was clearly not interested in M.E. - he gave the impression that he didn't want to be there.</i>
<b>264</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Continue to provide current services	<i>Treatment programme contained lots of useful information and helped me to adapt my lifestyle</i>
<b>265</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>Needs to offer lifelong support for chronic illness</i>
<b>266</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>It's not fit for purpose. They do not have a clue about ME/ CFC</i>
<b>267</b>	Bath Centre for Fatigue Services	Be closed and a new service rebuilt with patient input	<i>No evidence to suggest what they do works/ refusal to try different treatment options</i>

<b>268</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>They gave dangerous advice putting everything down to deconditioning when new symptoms like increased spasming when it was due to change medication. Physio seemed to have no recognition of what activity could do do very severe sufferer some OT's treated me like an idiot asking me to do some cognitive work beyond my capability. She was fascinated to be in community hearing about symptoms she not come across before the initial assessment by had OT and consultant was good I felt they listened well . And understood where I was at but on delivery they didn't meet my needs consistently</i>
<b>269</b>		Be closed and a new service rebuilt with patient input	<i>Very rigid in the advice and service given. Still advising about GET but refer to it by another name 'activity management'. It's as though once they have given advice about Pacing, you're on your own as though you have been cured. I'm not cured but feel I'm on my own now.</i>
<b>270</b>	Birmingham and Solihull CFS Service	Continue to provide current services	<i>It could do follow up appointments instead of discharging once diagnosed and also listen to your symptoms more</i>
<b>271</b>	Bolton - Bury and Bolton CFS/ME Clinic	Be adapted to provide different services	<i>Clinic offered one consultation and then a lifestyle management course and follow up. Course Included pacing, graded exercise, sleep and pain management. Have not been seen by a specialist since then - 12 years ago - so I am left to manage my own illness with no advise apart from private services which I have had to pay for. Clinic should offer check ups, reviews, physio, counselling and OT services in my opinion.</i>
<b>272</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Continue to provide current services	<i>I was really impressed with the treatment I got from the clinic in comparison to the support I've had from GPs</i>
<b>273</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>It's not fit for purpose. It encouraged me to pace, but told me I should try to avoid too much resting. It gave me no other support, such as for the pain and depression. It was only after I stopped going and massively reduced my activities and rested more, that my symptoms improved a bit.</i>
<b>274</b>	Newcastle - North of Tyne CFS/ME Service		<i>The clinic doesn't exist anymore</i>
<b>275</b>	Not listed	Be adapted to provide different services	<i>The service I attended, in Beckenham, offered GET, which has been shown to make pwME worse, so should be stopped.</i>

<b>276</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>get has been proven harmful at that is my experience. CBT itself is harmless but not a treatment, the premise that I need my attitude to my illness corrected from my wrong beliefs about my illness is harmful. I have 20 years experience of me an knowledge of all those years research into the illness.</i>
<b>277</b>	Not listed	Be adapted to provide different services	<i>St Leonard's Hospital London</i>
<b>278</b>	Oxfordshire CFS/ME Service	Continue to provide current services	<i>Outstanding care to severely I'll homebound patients, providing techniques, home visits, hope. I have nothing but praise for this excellent, supportive service which has made an immense difference to the past 3 years, in contrast to original advice given when I first got I'll 30 years ago.</i>
<b>279</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be adapted to provide different services	<i>Adding something like Hyperbaric oxygen sessions.</i>
<b>280</b>	Not listed		<i>I have been to more than one clinic. I would not expect a so called expert at a me/cfs clinic to say they couldnt do anything to help yet they did</i>
<b>281</b>	Not listed	Be adapted to provide different services	<i>Only given basic advice to manage condition but they couldn't provide any practical help for instance couldn't organise physio, pain relief or equipment, only talking was provided, a lot of sympathy but no actual help and once the set course of talking completed then your on your own with no back up or understanding from the health service in general</i>
<b>282</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>its no longer available</i>
<b>283</b>	Private clinic	Be adapted to provide different services	<i>There is new advice all the time.</i>
<b>284</b>	Fife - ME/CFS Specialist Nurse Service	Continue to provide current services	<i>I've lived with this condition for more than 20 years and had input from pain management which ultimately made things worse. Meeting with [professional at Fife] ME Nurse affirmed my experience trying to manage the condition for myself. I feel more confident in my own judgement.</i>

<b>285</b>	Not listed	Continue to provide current services	<i>I am treated for my ME by the Primary Care Wellbeing Service. They offer physio, cbt and advice on pacing</i>
<b>286</b>	Shrewsbury - Shropshire Community Neuro Rehabilitation Team	Continue to provide current services	<i>It is understanding and supportive without pushing inappropriate treatments</i>
<b>287</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>It's a mental health facility with mental health trained staff who don't have a clue about the condition, the research or all the co-morbidities. A very patronising, ignorant service</i>
<b>288</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Continue to provide current services	<i>It was a bit helpful to have a diagnosis rather than being a hypochondriac since 1978. I only had a few telephone calls about pacing. I'm sure they have moved on.</i>
<b>289</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Long time ago - no longer exists</i>
<b>290</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	Be closed and a new service rebuilt with patient input	<i>Service didn't change my illness experience at all. Needs re designing in line with new research. Very obvious was designed with an 'its all in there head' approach and has not adapted in line with research development.</i>
<b>291</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>I think there are old systemic beliefs , which are vastly outdated and hard to change from an old culture of seeing M.E. as having a large psychological element.</i>
<b>292</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be closed and a new service rebuilt with patient input	<i>CBT and GET are not effective treatments for ME/CFS and we NEED BIOMEDICAL CARE!</i>
<b>293</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Continue to provide current services	<i>Physiotherapy is important as well as OT and seeing consultant, but have to wait too long between appointments</i>

<b>294</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>Need to be patient respectful and work with us to support our needs</i>
<b>295</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>Not enough focus on biomedical view of illness, some pressure put on patients to conquer disease psychologically</i>
<b>296</b>	Nuneaton - Warwickshire CFS Service	Be adapted to provide different services	<i>The clinic provided a good service for those with moderate to mild ME/CFS. I benefitted from a thorough diagnosis and from the wonderful physiotherapy service. However when I became severely affected following a minor surgery, I was deemed too unwell to attend the pain clinic offered. As a result I was left extremely unwell, isolated without any treatment. The GP would sign me off for 6 months at a time, wishing me good luck with great compassion in her eyes. My friends feared I was dying because I was no longer functioning, bedbound with max 1 hour 'very low key activity' (hydrating, eating) spread through the day. In the end my friends supported me to move to a different area with provision for the severely affected.</i>
<b>297</b>	Wells - Somerset CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Horrendous illness that has robbed me of my life! Treatment offered me nothing that I wasn't already doing.</i>
<b>298</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>No one really knows what causes ME. Maybe by polling patients you could provide a variety of support rather than the rigid guidelines you follow now</i>
<b>299</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>It's based on psychosomatic treatment and the "specialist" told me he had no idea how his patients were affected by the treatment offered and didn't care as he was only interested in his "model"...</i>
<b>300</b>	Leeds - Yorkshire Centre for Psychological Medicine inpatient care	Be adapted to provide different services	<i>Unfortunately Leeds is a two and a half hour drive away from where I live, so it was deemed impractical for me to attend any treatments or courses. I managed to attend once and received advice on how to manage my activity levels, plus I was referred on to social services. It was suggested that I receive telephone support, however that only happened once. I think that some sort of outreach service would have been invaluable.</i>

<b>301</b>	Not listed	Be adapted to provide different services	<i>I attended a long time ago when I was a teenager - it was teenage specific and involved in the pacing and get trials - I was mostly just given cbt which (partly) helped me feel more positive about managing my condition but in the long run hasn't really helped - there was no follow up support once I had the initial course of treatment</i>
<b>302</b>	Maidstone - Kent & Medway CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I was bed ridden for most of the day . Some days I could do stuff for an hour or so . I lived alone and so pushed just to eat and wash . I would have benefited from total bed rest . As I felt I'll all the time. Some sort of convalescence would maybe have given me a chance</i>
<b>303</b>	Norfolk and Suffolk ME/CFS Service	Be closed and a new service rebuilt with patient input	<i>Because the current model at the service doesn't require it to be physician led. This has huge consequences for severe patients because it means there's no expert for the GP to consult. In fact my massive deterioration to becoming tube-fed was in part due to the fact that when there WAS a consultant in my area he was so over worked my GP was told initially he couldn't access for me any expert support or advice for a year AFTER he put in an urgent request. When I drastically worsened the consultant did visit my home and transformed to a degree my care but it was too late. This is unacceptable. ME/CFS like all serious disabling physical illness should have expert drs in place caring for patients and facilitating the nations biomedical research effort.</i>
<b>304</b>	Not listed	Be adapted to provide different services	<i>It should also include pain management</i>
<b>305</b>	Leicester CFS Service	Be closed and a new service rebuilt with patient input	<i>It is a psychological-based service based at a mental health unit. The main therapy is a cookiecutter CBT. It is demeaning, and wholly inappropriate.</i>

<b>306</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>The people are nice but don't fully understand or have the tools to provide the correct care, my care was mainly focused on physical therapy to rebuild my strength and to be able to walk again, it had the opposite effect and i am now severe with 24 hour pastoral care, I have used the ME service in Sheffield and Lancashire and both were giving totally the wrong advice. Ive recently used again the Sheffield service, visiting me at home but its now too little, too late and I'm in hospital regular for infections etc. The best doctor I have had is [a professional] from Kings-mill, Mansfield, he is not a ME expert but he listened and did not give up on me and fought to get my pain under control, most Doctors and nurses don't know how to listen and when they do, don't have anyone to talk to so they make take the appropriate action. My suggestion is to have specialist multi discipline teams to manage the condition with the patient immediately the condition is not just diagnosed but suspected.</i>
<b>307</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>Most of what I was told did not tally with the lived experience of the condition. None of the staff listened to me when I explained this. Instead I was told WE are the experts and we will tell you what your condition &amp; is how to treat it</i>
<b>308</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>I needed to pick something &amp; that was the closest. There's no specialist ME/CFS clinic in my area (Newcastle-Under-Lyme/Stoke-On-Trent) &amp; so my referrals have been to 1. a pain management group (mindfulness based), 2. neuropsychology, &amp; 3. rheumatology, &amp; I don't think any, especially neuropsychology or rheumatology, have been helpful at all &amp; think there should be a specialist service for ME/CFS</i>
<b>309</b>	Preston - Lancashire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Because focus is too much on pushing to get better when we need help to find our baselines. The current approach causes over exertion and leads to deterioration.</i>
<b>310</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>I felt like they were doing their best but in hindsight I now know and understand a lot more about this illness than they ever did. The advice they gave me made me worse and the majority of the things I learnt along the way that have helped were not taught at this service.</i>
<b>311</b>	Essex Chronic Fatigue Service	Be adapted to provide different services	<i>OT, CBT and GET were offered, and very few patients seem to benefit from these</i>
<b>312</b>	Sheffield CFS/ME Service for South	Be adapted to provide	<i>They need to listen to patients and amend treatments offered.</i>

	Yorkshire and North Derbyshire	different services	
<b>313</b>	London - University College Hospitals Children and young people's specialist adolescent services	Be adapted to provide different services	<i>Appointments need to be based at patients home or via internet. Getting to the appointments resulted in huge crash which left my son bedbound, now homebound</i>
<b>314</b>	Private clinic		<i>The clinic closed years ago.</i>
<b>315</b>	Not listed	Continue to provide current services	<i>It was a gentle and open approach</i>
<b>316</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>'Treatment' consisted of servers weeks of 2 hour long PowerPoint sessions and lengthy handouts. I cannot focus for 2 hours, I cannot read lengthy handouts. very impersonal. Like doing a BTec in ME, delivered by people who had read about ME but had very little understanding/empathy/ compassion about actually living with it. Didn't learn anything new. Didn't feel supported.</i>
<b>317</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>It has been closed after so many complaints</i>
<b>318</b>	Stockport CFS/ME Service	Continue to provide current services	<i>It taught pacing and when I can't rest, to alternate parts of body and mind to cope until I can.</i>
<b>319</b>	Suffolk Specialist ME and CFS Service	Be adapted to provide different services	<i>I was told no one recovered and I knew as much if not more about pacing as they did? So compared to what happened with my GP this was preferable but hardly useful, hardly insightful, hardly functional help, is it?</i>
<b>320</b>	Maidstone - Kent & Medway CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The consultant believed it is a psychiatrist condition and used psychiatric treatments</i>
<b>321</b>	London - Uxbridge - Hillingdon CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Because the thoughts of the people who actually have CFS are not taken into consideration</i>

<b>322</b>	Leeds and West Yorkshire CFS/ME Service	Continue to provide current services	<i>They helped immensely with advice &amp; information, together with support. Sadly I became worse but I don't believe that was due to them or their treatment, it was just the course of my ME. They are v compassionate &amp; kind there.</i>
<b>323</b>	Nuneaton - Warwickshire CFS Service	Be adapted to provide different services	<i>[The professional at Nuneaton-Warwickshire CFS Service] is awesome but everyone else there is clueless. [The professional] is an endocrinologist but they need more like him who actually understand ME from different departments. Priority for Neurology.</i>
<b>324</b>	Stockport CFS/ME Service	Be adapted to provide different services	<i>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 ebs and flows. I received treatment privately and I was not notified the nhs service even existed until 2019 (I actually stumbled upon it myself) when I was diagnosed in 2013. They know they are severely limited. 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.</i>
<b>325</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be closed and a new service rebuilt with patient input	<i>The neurologist asked if I had anything to look forward to, implying I was depressed. I was the worst case they had ever seen, yet all he could do was imply I was depressed. He told my parents that it definitely wasn't mitochondrial dysfunction...how could he know either way without proper testing? Only good thing was I wasn't told to increase activity, I couldn't even keep my head upright at the time. Nurse made a comment about being able to tell 'the fakers'. Again without any proof. These are nothing more than gaslighting clinics giving useless or often dangerous advice with little empathy.</i>

326	Not listed	Be adapted to provide different services	<p><i>There are no ME Clinics or Specialists that I can access where I live in Glasgow. People with ME here are referred to the Centre for Integrative Care (CIC) which offers alternative medicine and treatments. I was offered Homeopathy and Acupuncture, but these have no science to back them up, in the case of Homeopathy there is literally no way it could help with anything as it is water or sugar pills with no active ingredient. I was also offered mindfulness, and nutrition advice. I declined all of these treatments as I did not feel they would have any benefit. I was offered some help with pacing, but not a lot, this help was given by a physiotherapist. I was offered a programme of exercises which would increase. This is Graded Exercise, although it was never mentioned by that name, which can be very damaging for those with ME. I declined this as I felt it would be very damaging for me.</i></p> <p><i>I have now being referred for counselling, which I hope may help me with my pacing, but I will have to wait and see. If there is any mention of ME being Psychological, or false illness beliefs I will stop this counselling immediately.</i></p> <p><i>The staff at the CIC had knowledge of ME, but there doesn't seem to be much they could do that would actually help. There needs to be more biomedical research to find out what causes ME and how to treat it. And there needs to be much more access to specialised ME clinics in Scotland, one clinic in Edinburgh (which I didn't know about until I took this survey), and one ME Nurse in Fife, is nowhere near enough for the 50,000 ME sufferers in Scotland, as only a small number of people can access these services.</i></p>
327	Penrith - Cumbria Persistent Physical Symptoms Service	Be closed and a new service rebuilt with patient input	<p><i>The service had changed from the previous ME/CFS clinic to a non- specialist one and professional I dealt with was not up to date with latest evidence and clearly didn't understand the physical nature of the condition</i></p>
328	Newcastle - North of Tyne CFS/ME Service	Be adapted to provide different services	<p><i>It helped me to accept the condition, but did not improve the condition.</i></p>
329	Not listed	Continue to provide current services	<p><i>St Albans Adult CFS Team closed. It was an excellent service. The replacement service doesn't appear to be as comprehensive and is difficult to navigate and locations are more difficult to access. I valued my consultant's, [redacted], expertise, explanation and guidance. The new service doesn't appear to be up to date especially in regard to GET and CBT being appropriate treatments. Moreover, the report sent to my GP, in contrast to [the professional], was very vague.</i></p>

<b>330</b>	Not listed	Be adapted to provide different services	4 <i>I attended the CFS clinic in Belfast, but no service has been provided since 2013 when the medical consultant doctor retired. Prior to this only pacing advice was given, no medical treatment was given to me other than blood tests.</i>
<b>331</b>	Not listed	Continue to provide current services	<i>It has closed and been taken over by Connect Health Hemel Hempstead which seems fine as well.</i>
<b>332</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>Most of the treatment was based on pacing which assumes a stable energy baseline with isn;t the case with CFS/ME</i>
<b>333</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>We could not reduce the naps or do the get walks. Reducing naps led to more fatigue. It was only when my daughter tested and reduced activity that she started to feel better and be able to do more.</i>
<b>334</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Unhelpful and uncaring doctor. No idea how it is to live with me and careless comments on exercise and weight. No offer of anything to help pain or fatigue except booklet on pain management and take less medication. Patronising and waste my energy attending. My body is shutting down and no help offered.</i>
<b>335</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>Needs to focus on clinical care and less on OT. Must return to providing support letters for benefit claims</i>
<b>336</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be closed and a new service rebuilt with patient input	<i>Because their approach made me worse</i>
<b>337</b>	Stevenage - East and North Hertfordshire NHS Trust Chronic Fatigue Syndrome Service for Children and Young People	Be adapted to provide different services	<i>It is very limited. It offers guided self-help which isn't sufficient. There is no psycho-education, no psychology or physiotherapy input. There is no pain management available.</i>
<b>338</b>	Bath Centre for Fatigue Services	Be adapted to provide different services	<i>Once my daughter turned 18 and had to start the adult outpatient they just wasn't bothered she went twice then dropped her she is a lot worse now when she was being seen in Dursley's clinic they were brilliant</i>

<b>339</b>	Salford CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Treatments that dont work.</i>
<b>340</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	Be closed and a new service rebuilt with patient input	<i>I found the occupational therapist I saw had views about ME/CFS that didn't seem to be based on any evidence. I was told in the first session that we were going to work together, I would have to accept that there was an emotional element to the cause of my illness. I tried to explain my stance on this, having lived with quite severe levels of illness for many years, and she was very defensive and resistant to hearing my perspective. My perspective is not extreme - I basically acknowledge that the mind-body connection is very complex and that we just don't know what causes ME CFS. I'm open to the ways in which stress might impact my symptoms day to day. I practise mindfulness. Since I've been ill I've had quite a lot of counselling. I feel I have a good understanding of my own mental and emotional health. Given all of this and other things, over the many years since diagnosis I've come to the conclusion that it is not psychological factors that are keeping me ill. I felt that in trying to explain this (politely) I was judged as being resistant to getting better and anxious or depressed (I am neither). The therapist had no psychology background and no medical training. I am old enough to know how to look after myself but I worry this approach could have been really dangerous for someone newly diagnosed. I was told that at the Cam/Peterborough CFS service they've found that GET doesn't work and so they don't use it which I was glad about. I received quite good advice about pacing which I followed, although it wasn't much that I didn't already know. The service could be changed to just offer pacing advice but I felt the mindset of the OT I saw was very made up, based on a lot of misconceptions and resistant to change. Therefore I'd prefer to see a completely new service.</i>
<b>341</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be adapted to provide different services	<i>The whole course needs to be updated contain more info on nutrition and alternative medicines not include GET.</i>
<b>342</b>	Fareham - South Coast Fatigue	Be adapted to provide different services	<i>Needs to be based on physical illness support and advise for a start</i>

<b>343</b>	Bolton - Bury and Bolton CFS/ME Clinic	Be closed and a new service rebuilt with patient input	<i>The ME Consultant offered very little support. His hands seemed tied up with regard to cost. It was just oh you get migraines I will prescribe you X which I've taken in the past. No help with care, or isolation from the outside world. No help with complimentary therapies or swimming etc Just oh if you need help come back but there's nothing I can help you with. I've been ill for 25 years and my only appointment with the clinic was last year. It's a joke, feel like it's just a tick box to say they have seen you.</i>
<b>344</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>Some services are not appropriate, such as Graded Exercise Therapy</i>
<b>345</b>	Not listed	Continue to provide current services	<i>I am now left with no help</i>
<b>346</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>The services were helpful and staff understanding</i>
<b>347</b>	Sunderland - South of Tyne CFS Service	Be closed and a new service rebuilt with patient input	<i>I felt clinic would have made me worse if i had carried on with graded exercise. Also i felt that professionals felt my illness was in my head</i>
<b>348</b>	Not listed	Be adapted to provide different services	<i>The clinic was the furthest away from main entrance of the hospital it possibly could have been!</i>
<b>349</b>	Preston - Lancashire CFS/ME Service	Be adapted to provide different services	<i>I would like the opportunity to discuss alternative treatments such as diet, supplements, acupuncture, mind body programs such as Lightning process etc, all the various options that may help some people</i>
<b>350</b>	Not listed	Be adapted to provide different services	<i>I have no local specialist ME/CFS clinic that my gp will refer me to. The pain clinic at Winchester hospital (which is all I have attended for about three separate courses since diagnosis in 2004) only seems to offer graded exercise; pain meds. and psychology sessions; all of which i have tried and none of which has made any difference to my pain or levels of mobility. Only pacing has helped me.</i>
<b>351</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>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 &amp; consultants</i>

<b>352</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>I believe it has already closed. The two staff who ran it, one a physiotherapist and the other a psychologist, had no understanding of what ME is and were therefore basing their approach on prejudice and ignorance.</i>
<b>353</b>	Edinburgh - Lothian CFS/ME Service	Be adapted to provide different services	<i>There is zero funding to rebuild clinics for ME or CFS patients.</i>
<b>354</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>It was a huge waste of money, I was already managing my illness, what I want is an effective treatment, until that time comes money should not be wasted on such an ineffective service.</i>
<b>355</b>	Norfolk and Suffolk ME/CFS Service	Be closed and a new service rebuilt with patient input	<i>My health spiralled after the advice I was given and I still haven't recovered many years later. My diagnosis has made it hard to receive any adequate treatment on the NHS for other health problems I encounter. ALL medical staff need training in ME/CFS. We need a whole new understanding of treating ME/CFS tailored to individual needs of patients. We need healthcare professionals to admit they don't understand the disease and let the patient lead their healthcare. It all needs to be done at the pace of the patient. I'm not even well enough to access ME/CFS services anymore. The last treatments I was offered were all a long way from my home in a group setting where I had to stay for 2 hours at a time and was told I wouldn't be able to lie down there. This is absurd given the symptoms that ME/CFS patients have. More questions and compassion needed from healthcare professionals, rather than ineffective treatments that shame patients for their symptoms.</i>
<b>356</b>	Birmingham and Solihull CFS Service	Be closed and a new service rebuilt with patient input	<i>The specialist at time told me a story about a man with a broken leg being positive and life being better. My response was does he have m.e? Was downhill from there..the specialist deals with insurance claims via his bio..what has he got to qualify him dealing with m.e?</i>
<b>357</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because the only real positive I got from the group was meeting people in the same situation as myself. Otherwise I was left feeling quite frustrated at the end of most sessions with the advice given.</i>
<b>358</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be closed and a new service rebuilt with patient input	<i>This was a six week course about ME. There is no ongoing support.</i>

<b>359</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>It is not the clinician's fault, they are restricted by NICE guidelines</i>
<b>360</b>	Penrith - Cumbria Persistent Physical Symptoms Service	Be adapted to provide different services	<i>I was too ill to leave my house and they eventually discharged me without care because I was unable to go to them and cancelled every appointment due to being too ill to leave the house. Patients are too ill to go out, going out would cause severe deterioration, defeating the whole purpose of any treatments offered. So the sickest patients get no care. Treatments are not fit for purpose. They need to be adapted to each patient's needs, we are not all suffering the same way, so we cannot all be treated in the same way. This has to change.</i>
<b>361</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>I have not attended this clinic since 1996 so my current experience is negligible.</i>
<b>362</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>You need to listen to the people who suffer with this god awful condition day in and day out, find out what helps them instead of forcing them to make themselves worse with GET or even fob them off with CBT. It's terrible that we do not get the recognition nor respect we deserve for fighting such a debilitating condition on a daily basis. We accept there is no magic pill we accept there is no cure but our quality of life shouldn't be impeded on because of lack of understanding or medical knowledge.</i>
<b>363</b>	Not listed	Be adapted to provide different services	<i>No help if you have ME. Left to suffer</i>

<b>364</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<p><i>At present we have no demonstrably effective treatments, so certainly specialist services should not be offering GET and CBT aimed at increasing activity levels. For most people the crucial issues are dealing with the practicalities of daily life including support adapting their work environment and or benefits.</i></p> <p><i>Supporting in helping patients pace their activity levels should be offered, but not as covert rehabilitation aimed at arbitrarily increasing activity levels.</i></p> <p><i>But also specialist services should always provide specialist medical input enabling medical symptom management too.</i></p> <p><i>Also medical and practical support for commonly co occurring conditions, including POTS, orthostatic intolerance, IBS, food intolerances, migraines, etc</i></p>
<b>365</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<p><i>GET and CBT must be removed to fit current research guidelines</i></p>
<b>366</b>	Middlesborough - South Tees CFS/ME Service	Be adapted to provide different services	<p><i>I feel how it impacts on your mental health as well. There should be more support.</i></p>
<b>367</b>	Not listed	Be adapted to provide different services	<p><i>There are no hands on treatment. It's all goal based or talk therapy. When your body is in constant pain hands on treatment helps. I've had more success in pain management and flexibility in my body from private osteo than any NHS CFS/me service</i></p>
<b>368</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be adapted to provide different services	<p><i>It needs to change, whether this means starting from scratch or adapting. I was giving 3 appointments with an OT who was sympathetic but didn't really offer any advice. And no treatment options at all. Since then, for years now, I've been on my own. The literature I was given said to increase activity despite how I felt but I was (thankfully) advised against following this. They more or less said to listen to my body, which was against official advice. I imagine I'd be worse off if they hadn't said this and I'd followed the literature.</i></p>
<b>369</b>	Oxfordshire CFS/ME Service	Be adapted to provide different services	<p><i>It needs to keep up with current research on ME and change services to reflect this</i></p>
<b>370</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<p><i>Because I was expected to be better at the end of the course.</i></p>

<b>371</b>	Birmingham and Solihull CFS Service	Be closed and a new service rebuilt with patient input	<i>Have to treat ME as bioorganic not psychosocial as the clinic did.</i>
<b>372</b>	Plymouth Sentinel CFS/ME Service	Be adapted to provide different services	<i>I was advised that I would be better within 5 years and that I should try and increase my exercise. Because of that so am now mostly bedbound &amp; use electric wheelchair. They only offer GET &amp; CBT</i>
<b>373</b>	Not listed	Be adapted to provide different services	<i>It is probably ok for people with other illnesses and conditions. But not suitable for people with ME. The ward doctor I was allocated to did a huge amount of harm. As apparently she had strong feelings that folk should NOT be diagnosed with ME or CFS. I was too ill to realise it at the time. And couldn't understand this at the time. Or why I wasn't getting any actual help there. And that all the symptoms I was trying to describe (and get help with) were being ignored. It was a terrible, even gaslighting, experience. I deteriorated drastically afterwards as a result</i>
<b>374</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>Services I have paid for privately should be provided and an holistic approach should be adopted. The physical aspects of the illness should be acknowledged and treated rather than just a psychological basis.</i>
<b>375</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	Be closed and a new service rebuilt with patient input	<i>The current treatment does not improve symptoms.</i>
<b>376</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>It needs to be able to provide long term support</i>
<b>377</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>They did not believe ME is physical. They did not always listen to me. I had several disturbing conversations with fellow patients who said they were prescribed antidepressants ( I had already made it clear I was well informed, so they did not try that on with me).</i>
<b>378</b>	Norfolk and Suffolk ME/CFS Service	Be closed and a new service rebuilt with patient input	<i>When asked what treatments they can offer I was told that it's more of a talking service. They just record what you say and write a letter to your GP. This provided no support whatsoever.</i>
<b>379</b>	Fareham - South Coast Fatigue	Continue to provide current services	<i>It wasn't perfect, but it was far far better than nothing. I felt the health professionals really tried to understand and appreciate the difficulties of living with this disease.</i>

<b>380</b>	York - Yorkshire Fatigue Clinic	Be adapted to provide different services	<i>Need medical input</i>
<b>381</b>	Preston - Lancashire CFS/ME Service	Be adapted to provide different services	<i>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.</i>
<b>382</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>no one that ever treated me for my m.e. on the nhs knew anything about it, they would make me travel hours to get there which was exhausting in itself, only to talk to me for a bit about nothing relevant and then send me home. the travel in itself caused more damage than the clinic could help with. all it did was offer a place to talk about it, but the only therapy that ever helped me was private. every therapist the nhs or m.e. clinics offered me would give me little to no advice that i haven't heard before and one even told me "i'm not qualified to treat you."</i>
<b>383</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>The foundational model of CBT requires reappraisal in the light of changing understanding of the physical characteristics of ME. The service needs also to provide different focus for different patient groups, namely newly diagnosed, long term patients, and elderly patients, the latter being very poorly served</i>
<b>384</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>I knew more than they did. Even after attending a cfs conference my therapist knew less about the conference this I did from simple internet research. They were unable or unwilling to answer simple questions. When I asked about trials and research I may be able to participate in, I was told 'there is no magic pill'. This was not what I asked.</i>
<b>385</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>I feel that although the health professionals wanted to improve my health I was not given the correct treatment plan . It is a tragic situation when after 10 years of being in and out of the service I finally was helped by Guys Hospital Rheumatology Dept</i>
<b>386</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	Be closed and a new service rebuilt with patient input	<i>service not good enough</i>
<b>387</b>	Norfolk and Suffolk ME/CFS Service	Be closed and a new service	<i>Doctors dont understand M.E and just how much we go thru..Some Doctors have looked at me bewildered and changed the subject, others have said "I dont know anything</i>

		rebuilt with patient input	<i>about M.E"...How can we be understood when they are not taught about our condition.</i>
<b>388</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>I think that a service for patients with ME/CFS is vitally important; however, until doctors share the same opinions and general understanding of the illness that their patients do, these services will never fully be able to treat patients with ME/CFS. 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.</i>
<b>389</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>The most help we received and understanding in two years of seeing health professionals</i>
<b>390</b>	Maidstone - Kent & Medway CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Think it has already closed. They told my husband they couldn't help him. Seemed to have no understanding</i>
<b>391</b>	Suffolk Specialist ME and CFS Service	Be adapted to provide different services	<i>I am mainly housebound. I have had to find my attached an mobility aids / stool for kitchen. Knowing my condition has deteriorated since DX, I hoped for a home visit / ot to provide the aids I need.</i>
<b>392</b>	Birmingham and Solihull CFS Service	Be adapted to provide different services	<i>The only offer of treatment has been CBT which is not helping. It feels a waste of time and my energy going.</i>
<b>393</b>	Not listed	Continue to provide current services	<i>Learning how to pace was important to me and using mindfulness</i>
<b>394</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	Be closed and a new service rebuilt with patient input	<i>Because the treatments are based on psychological assumptions not on biological pathology</i>

395	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<p>The only "treatment" I was offered was GET which the staff member I saw and I both agreed was inappropriate in my circumstances. They agreed I was managing my illness appropriately and discharged me. Since then my health has deteriorated considerably but I know there is no point asking for another referral to see them as there is nothing else they can offer me, and I would not be fit to easily attend in any case. Ongoing monitoring and support, possibly by phone or Skype, is definitely needed when living with ME/CFS but this was not offered. Without ongoing monitoring and support benefit claims are very difficult as no evidence can be produced to support claims of disability. As ongoing support is needed I would not want to see clinics close. They do need to change though. Medical support and pharmacological treatment for symptoms would be welcome rather than only seeing physios or psychologists. I have been referred separately by my GP for specialist assessment and treatment for PoTS. Given how many ME/CFS patients have orthostatic issues this specialist medical intervention should be a standard part of the CFS/ME service. Whilst psychology, physio and OT have their roles to play in managing any chronic illness specialist medical (doctor and nurse) care should be the main focus of clinics.</p>
396	Middlesbrough - South Tees CFS/ME Service	Be adapted to provide different services	<p>My initial appointment at the ME/CFS Clinic was with a Doctor who confirmed my diagnosis. Following this I was able to book a maximum of 6 appointments with a nurse to discuss treatment, this focused on pain relief and pacing. These appointments were 2 weekly so my whole experience of specialist care was limited to around 14 weeks. I was then referred back to my GP for on-going care. I would have appreciated longer involvement with a specialist service and support to manage flares, set backs. Much of the information I received is available on line and did not feel personalised.</p>
397	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<p>It was based on GET and CBT one of which made me much sicker and the other I didn't get access too because the waiting list was too long. Also 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. At the cfs specialist!</p>
398	Maidstone - Kent & Medway CFS/ME Service	Be closed and a new service rebuilt with patient input	<p>It was psychologically based.</p>
399	Not listed	Be closed and a new service	<p>Believed ME was psychology and would regularly section teenagers purely on the fact they believed no one was physically ill</p>

		rebuilt with patient input	
<b>400</b>	Private clinic	Continue to provide current services	<i>It is the only place I found that understood how I was feeling, nothing on the NHS in my area</i>
<b>401</b>	Stockport CFS/ME Service	Continue to provide current services	<i>All offered good, would allow more ongoing support as usually illness doesn't end.</i>
<b>402</b>	Not listed	Be adapted to provide different services	<i>My diet was never questioned, 'Leaky Gut' was never discussed.</i>
<b>403</b>	Middlesborough - South Tees CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>the clinic is part of a much bigger unit which does not specialise in ME/CFS. A separate clinic for ME/CFS is needed</i>
<b>404</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be closed and a new service rebuilt with patient input	<i>It did close years ago, i was given no advise on treatment</i>
<b>405</b>	Stockport CFS/ME Service	Continue to provide current services	<i>My clinic was wonderful. I was assigned one nurse and saw her for over two years and she helped me immensely to come to terms with my condition. I went from being practically housebound to now being able to leave the house 3 times a week. She gave me invaluable advice. Sadly, in order to give me such good advice she had to go against NHS guidelines which suggest only 6-8 sessions per patient, which is definitely not enough for a lifelong illness like CFS/ME. I have also seen a physiotherapist at the same clinic and also found her to be incredibly helpful and understanding. Overall, I could not recommend the clinic enough. It took me several years after first being diagnosed to see them (I was not referred to a clinic until I moved cities) and I only wish I had seen them sooner, as my life could've taken a very different turn had I got the help I needed in the first few years of my diagnosis.</i>
<b>406</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Current services are of little or no help and are sometimes counter-productive, especially CBT and GET.</i>

<b>407</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The current care is based on two theories, neither of which apply to me, both wrongly given to me as an explanation for the pathology. One is the patient health beliefs and behaviour "during illness recovery we tend to avoid physical activity and rest more than usual" (this does not describe me) and the other is that the theory behind the treatment is "deconditioning".</i>
<b>408</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>I was treated with CBT for years, which did not help my symptoms. I have been diagnosed with PTSD because of this treatment and because they constantly insinuated that the pain I had was psychological. They advised us not to research any other conditions or join any support groups and that we should "accept the diagnosis." Parents found out about POTS because I fit every symptom of it. ME service said they would not refer, that treatment doesn't work for this condition and that they would not help me to get a diagnosis. We went privately to see [a professional] who diagnosed me with POTS with a stand test and put me on Midodrine. Years later, aged 16, I was referred to the Sheffield POTS/Syncopy service. They did a tilt table test (which only lasted 5 minutes due to me fainting, confirming how severe mine was) and they also found out that I have severe low blood pressure. I am now on Midodrine, Fludrocortisone and Ivabradine and able to go out of the house. I have improved drastically since treatment was put in place.</i>
<b>409</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>Should prescribe medications, and should focus on pacing not GET</i>
<b>410</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>It was the only place that I felt that my condition was both understood and practically addressed</i>

411	Liverpool CFS/ME Management Services	Be adapted to provide different services	<p><i>To be fair the practitioners there did their utmost and were very open minded. However there are a lot of private clinics providing services, who understand me/CFS much more completely and have more targeted suggestions, largely devised by those from the CFS community, in particular those who do recover. This information should be mined and intertwined with nhs services. In addition such surveys should be massively expanded to explore the nature of symptoms, and what patients have found helpful. Instead of biological research we need to study the population.</i></p> <p><i>Escalate this to whatever level is influential... ME/CFS is real. But it's not what many think. It is in many cases (not all there are a number of routes to the condition; all of which involve system stress... virus/infection/physical&amp;emotional stress) an evolution of PTSD, which in itself is a neurological maladaptation. And effectively a brain injury.</i></p> <p><i>Treating this is v difficult.</i></p> <p><i>But there are ways. Many of the private protocols are on the right lines, as is the PACE study. But they are only a 5% improvement for many, due to the extent of injury. There are further more powerful and direct options, but no one is looking in the right place. Please please someone with influence email me [email redacted] for more information, I am half way out of this nightmare and convinced I have an answer. But there's no one to tell.....</i></p>
412	Not listed	Be closed and a new service rebuilt with patient input	<p><i>It has already been closed</i></p>
413	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<p><i>Need long term support and advice. Access to more tests needed so there is less guess work.</i></p>
414	Not listed	Be closed and a new service rebuilt with patient input	<p><i>My illness was trivialised and I was left feeling like my illness was my fault. One comment being 'you have to want to get better'.</i></p>
415	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<p><i>There was no help only minimal advice (a pamphlet)</i></p>
416	Sheffield CFS/ME Service for South	Be adapted to provide	<p><i>A wider variety of services/help available would of been of more help to me than any of the 4 available.</i></p>

	Yorkshire and North Derbyshire	different services	
<b>417</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>My clinic was in fact held in the infectious diseases out patient clinic which I think is just terrible in itself. I was given no help and told I would get better as it only lasts a couple of years.</i>
<b>418</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I think the whole approach to the treatment of the condition should be reviewed to mainly focus on the physical side of the condition, and not try to tackle it from a "mind over matter" psychological angle.</i>
<b>419</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be closed and a new service rebuilt with patient input	<i>Because I was severe there was no support or guidance offered. No follow up. Nothing. Just oh well you are too severe nothing more we can do to help...Bye</i>
<b>420</b>	Torquay - Torbay and South Devon CFS/ME	Continue to provide current services	<i>Because it was excellent</i>
<b>421</b>	Not listed	Be adapted to provide different services	<i>It was very psychologically based</i>
<b>422</b>	Private clinic	Be closed and a new service rebuilt with patient input	<i>It was 26 years ago and not listed, so I assume it no longer exists. I was a teenager and not able to cope with day to day activities after being extremely active before becoming ill. I was given different advice from another patient who was also a friend, she went on to recover fairly well and I continued to worsen.</i>
<b>423</b>	Nottinghamshire PICS CFS/ME Service for Adults	Be adapted to provide different services	<i>I think it's a good basic starting point for people new to M.E. in terms of learning about pacing &amp; having someone to talk to who understands that condition more than most GPs but I dont think it really makes any difference to the illness.</i>
<b>424</b>	Preston - Lancashire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Patients with ME/CFS are NOT and DO NOT have involvement in the service. It needs a radical overhaul.</i>
<b>425</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>I found it useless but it was a long time ago now.</i>

<b>426</b>	Fareham - South Coast Fatigue	Be adapted to provide different services	<i>Not enough different types of care, support and treatments.</i>
<b>427</b>	Nuneaton - Warwickshire CFS Service	Be closed and a new service rebuilt with patient input	<i>the clinic is 20 years behind world research</i>
<b>428</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be adapted to provide different services	<i>I was only offered pacing then told that they couldn't do any more for me. Needs to offer a variety of different approaches and be more supportive.</i>
<b>429</b>	Leicester CFS Service	Be closed and a new service rebuilt with patient input	<i>The service is based within Psychiatry and is not focused on the complexity of symptoms and issues when a patient has ME. I live in Northampton the service is in Leicester so extremely difficult when very ill to attend. No real input to your daily living coping needs.</i>
<b>430</b>	Portsmouth Chronic Fatigue Syndrome Service	Be adapted to provide different services	<i>To support and understand what those with ME require. And not push us to do things we can't</i>
<b>431</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be adapted to provide different services	<i>The staff were very helpful and sympathetic but some of the NICE guidelines they had to follow are INAPPROPRIATE for cfs</i>
<b>432</b>	Not listed	Be adapted to provide different services	<i>More treatment options required.</i>
<b>433</b>	Not listed	Be adapted to provide different services	<i>The assumption was the condition was incurable. I had it for 8 years. I was recommended Progressive Exercise Therapy - but was too ill to do it at that time, and CBT. Which helped with the depression but not in the curing of symptoms. I have since attended private clinic - The Optimum Health Clinic - psychology and nutrition programmes and have had no symptoms for over 2 years.</i>
<b>434</b>	Not listed	Be adapted to provide different services	<i>The services it offered made me worse, if i had not been pushed to do more i may have not relapsed so often.</i>
<b>435</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide	<i>Initial leaflets included GET, which has been found to have a negative impact. Talking treatment only offered.</i>

		different services	
<b>436</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	Be closed and a new service rebuilt with patient input	<i>There was an utter lack of competence. They lost my file. They discharged me without a consultation, despite 2 being scheduled when the consultant suddenly decided he didn't do ME patients anymore. I wasn't able take the monitored Tai Chi class to evaluate effect of exertion as local health authority wouldn't pay and the hospital would not allow me to pay myself. Recommended alternative therapy at one point with medication that would have had serious implications as I was taking an incompatible other prescription. Truly horrendous experience.</i>
<b>437</b>	Birmingham and Solihull CFS Service	Be closed and a new service rebuilt with patient input	<i>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 conducted the internationally discredited and condemned - by internationally eminent clinical researchers/academics - study into Pacing and who continue to maintain that GET and CBT are helpful and effective 'treatments' contrary to current international research and; a new service should be set up staffed by medical people who are not primarily psychiatrists and/or psychologists.</i>
<b>438</b>	Nuneaton - Warwickshire CFS Service	Be adapted to provide different services	<i>Too specialised in endocrinology. Was not equipped to advised with sleep disturbances and neurological symptoms.</i>
<b>439</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	Be closed and a new service rebuilt with patient input	<i>I felt badly treated at this clinic</i>
<b>440</b>	Preston - Lancashire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Not fit for purpose as it is</i>
<b>441</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	Be adapted to provide different services	<i>There was no real true understanding of the root causes of M.E. so the service seemed to be based on improvising at least something formal to give sufferers a legitimate base of administrative help while we are all waiting for definite answers.</i>

<b>442</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>CBT can help anyone with any type of chronic illness as it can help deal with stressors and anxiety and keeps the nervous system calm. Stress can exacerbate any symptoms of any health condition. It does not explain the pathway to M.E or resolve what is causing the brain inflammation. GET also is very harmful for those in the preliminary stages of M.E. I was told to rest initially by my GP and didn't. And got worse. I was told to increase my activity by the M.E clinic and still got much worse. Had I rested it out. And cut out any sensory overload such as TV watching etc and changed my diet to calm down the inflammation caused by the virus which was the genesis of my M.E I think I could have been much much better in health now.</i>
<b>443</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>Better training of staff - more awareness of patients needs. More empathy.</i>
<b>444</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>The clinic needs to adapt to new findings regarding the treatment of ME and treat it more like a neurological illness than a psychological one</i>
<b>445</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>there needs to be an ME service but it needs improving</i>
<b>446</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>i found pacing taught useful, for a while I improved a little but was told to decrease activity to a baseline when worse and not to rest. In light of no other treatment I kept pushing myself. I was moderately affected now severely I became totally bedbound for two years and now semi bedbound- and totally wheelchair bound. Their model of graded activities made me worse</i>
<b>447</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Continue to provide current services	<i>Helpful OT. Taught me things I didn't know about the condition.</i>
<b>448</b>	Stockport CFS/ME Service	Be adapted to provide different services	<i>I think cfs/m.e is misunderstood by most health professionals they need to have more input from people with it.</i>
<b>449</b>	Not listed	Be adapted to provide different services	<i>A broader approach needed</i>

<b>450</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	Be adapted to provide different services	<i>I don't think closing is the answer, but I do think patient input is a good idea.</i>
<b>451</b>	Stockport CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>It is 4 or 5 years since I attended, so I don't know how it is presently being run. I chose the option of a new service so that invaluable patient input is taken into account.</i>
<b>452</b>	Suffolk Specialist ME and CFS Service	Continue to provide current services	<i>Although I haven't improved what they said made sense and made me feel not so alone</i>
<b>453</b>	Salford CFS/ME Service	Be adapted to provide different services	<i>The service only provided me with a diagnosis and discharged me back to my GP following the single appointment</i>
<b>454</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>The people I saw had no understanding of m.e, refused to listen to any research I had done and belittled me the entire time. I would never go back to the clinic if the same people continued to work there.</i>
<b>455</b>	Not listed	Continue to provide current services	<i>I was helped with home visits but it has been closed some years back.</i>
<b>456</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>I was discharged after a few months even though I was, and am, still ill. I don't think they provide the same service now. I have not been offered this by my GP</i>
<b>457</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>Everyone is at different levels</i>
<b>458</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>The emphasis on GET as part of treatment can be reduced.</i>

<b>459</b>	Private clinic	Be closed and a new service rebuilt with patient input	<p><i>I am sure that education about ME/CFS has not been up to standard for a long time. I still have faith that a patients journey can be a much improved. As a patient community, we have suffered enough don't you think?</i></p> <p><i>In fact the patient community has knowledge of the huge amount of educational resourses, and International Research Outcomes, and how sufferers need to be sub grouped. Doesn't it make you feel as though you need to listen and take action before someone sues...</i></p> <p><i>I feel sorry for all the well meaning Clinicians who really think that they are giving a great service, when in reality thay are not. They are making things worse. And getting the NHS a bad reputation.</i></p> <p><i>Patients have been miss lead by current NHS ME/CFS Centres. Which, I feel they are living in the dark ages. This is by the neglect from government to fund more research, and the lack of updated information on NICE behalf. The treatment education by NICE and the Guide Ways and Pathways for our NHS have lead Doctor's/Clinicians to miss trust patient's symptoms. This is and has making a our situation worse. And other Community and Government Departments a laughing stock.</i></p>
<b>460</b>	Not listed	Be closed and a new service rebuilt with patient input	<p><i>The clinic was not at all designed with fatigue in mind, being mainly responsible for pain management. The area itself was someone's office with no air flow, uncomfortable chairs and incredibly difficult to endure for 2.5 hours. The content was more common sense for general living and not really tailored to individual needs. Since going private I have had a much better and rewarding experience.</i></p>
<b>461</b>	London - University College Hospitals Children and young people's specialist adolescent services	Continue to provide current services	<p><i>They are a specialist clinic who understand and have written letters to schools</i></p>
<b>462</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<p><i>There has been some restructuring and the clinic is now under the psychiatric umbrella which is ludicrous</i></p>
<b>463</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	Be closed and a new service rebuilt with patient input	<p><i>There just aren't the services that would be beneficial. There should be an investigation into how the funding is spent.</i></p>

<b>464</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>Micheal Carlisle centre a waste of time and money!</i>
<b>465</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be closed and a new service rebuilt with patient input	<i>I've had ME for 28 years. I try to stay fit but this comes at cost, it is a balance. Only rest makes me feel better, but physical activity is essential for health, both physical and mental. I started taking antiretroviral drugs 2 years ago and have had a significant improvement in my energy levels and my recovery, though not really in other symptoms such as PEM, headaches, frequent infections, although perhaps the infections do not last as long and are not as severe. It's all subjective as I am doing this DIY with no tests. I think retroviral research and trials is a productive avenue. I've seen so many other ideas come and go over the years. I think this one will yield results, understanding and treatments</i>
<b>466</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Continue to provide current services	<i>I feel the clinic did it's best under the circumstances</i>
<b>467</b>	Harrogate CFS Service	Be closed and a new service rebuilt with patient input	<i>The knowledge within the NHS is so basic and they are ridiculously dismissive of other organisations.</i>
<b>468</b>	Edinburgh - Lothian CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>It's not geared toward moderate or severe ME and couldn't help so there's actually in reality no service for people who are beyond mild</i>
<b>469</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>They denied my illness and punished me for being ill</i>
<b>470</b>	York - Yorkshire Fatigue Clinic	Be adapted to provide different services	<i>Attending clinic/group activities caused relapses - did not achieve previous levels of ability</i>
<b>471</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>Therapists had no idea of ME or the impact of the symptoms</i>

<b>472</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>CBT doesn't work and GET can no longer help now that I am a mum and do more than my baseline every day. Every patient is different so treatment needs to be tailored to individuals. Dry needling, massage, physio, Pilates and light weights help me to manage the illness but not all are available on the NHS for a prolonged period of time if at all.</i>
<b>473</b>	Not listed	Continue to provide current services	<i>New patient may not have been offered all that is available yet.</i>
<b>474</b>	Middlesbrough - South Tees CFS/ME Service	Continue to provide current services	<i>Just needs more funding to ensure that we're offered treatment sooner</i>
<b>475</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>I was unable to attend they came to me. Good support but v little advice and stayed too long. Should have referred me to 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. But they had only limited budget so could not provide ongoing. I think There should b an inpatient hosp for patients with severe m.e. Thank god they understood I was too ill for cognitive therapy. They told me cognitive therapy was not a treatment for m.e. Instead it was to support adapting to life with a chronic illness. They understood it was not psychological thank god. However my general hosp discharged me with no help at home when I was first diagnosed as an inpatient even tho they said I needed to just rest. I asked them and social care for help and was refused. So all the improvement I made was lost and 8 actually became bedbound with carers instead of recovering.</i>
<b>476</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>There not listening to us patients</i>
<b>477</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>A clinic which is incapable of helping patients is clearly a waste of time and money.</i>
<b>478</b>	Liverpool CFS/ME Management Services	Continue to provide current services	<i>I found the information that I received was useful</i>

<b>479</b>	Not listed	Be adapted to provide different services	<i>I had excellent from an Occupational Therapist who helped me manage day to day issues that were arising from having CFS and returning to work. This was after my initial assessment in 2007. Subsequently revisited the clinic to ask for help to stay in work while reducing hours and duties with input from the clinic. they felt unable to help with that. Having worked as a careers adviser and supported adults with disabilities to start work and stay in work after being diagnosed with acquired disability, I feel this would be helpful. After undergoing medical capability at work in 2015-16 my part time job was deemed no longer possible. I have been self managing using mindfulness meditation and mindful movement since then.</i>
<b>480</b>	Not listed	Be adapted to provide different services	<i>Useful aspects of practice could be developed more easily than if starting fresh</i>
<b>481</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>M's illness was perceived as psychological, when it started with a virus. Exercise on a bike and a rowing machine at the clinic, made her very ill for months after.</i>
<b>482</b>	Nuneaton - Warwickshire CFS Service	Be adapted to provide different services	<i>It was at least useful to be given a diagnosis. I found the doctor and consultant I spoke to fairly unhelpful and arrogant. The only service provided was Graded Exercise Therapy and whilst the physiotherapist I spoke to was very kind and understanding, I chose not to go ahead with GET as I was aware it has a bad reputation. Also I didn't feel the treatment offered would be helpful to me at that time and logically it didn't make any sense to me.</i>
<b>483</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	Be adapted to provide different services	<i>Adjustments needed but clinic is vital for support</i>
<b>484</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be closed and a new service rebuilt with patient input	<i>We as patients know what we need</i>
<b>485</b>	Edinburgh - Lothian CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>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.</i>

<b>486</b>	Nottingham CityCare MOSAIC Service	Be closed and a new service rebuilt with patient input	<i>It was patronising, and not fit for purpose. I desperately needed care, understanding, advice about sustaining employment, benefits, more tests, medication. Not to be told to "think positive" and to exercise. People with equivalent illnesses are not patronised to the same extent.</i>
<b>487</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>No multi disciplinary services. Group sessions too long and not set up for home/bed bound patients. Telephone appts available but service stops too soon for a chronic illness.</i>
<b>488</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	Be adapted to provide different services	<i>The service was based purely on a Cognitive Behavioural Therapy approach</i>
<b>489</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>Everything is by skype</i>
<b>490</b>	Preston - Lancashire CFS/ME Service	Be adapted to provide different services	<i>The service was only just reinstated, there was no CFS group only fibromyalgia, it's was too brief and needed further development.</i>
<b>491</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	Be adapted to provide different services	<i>I've heard of others finding their treatment useful, but the treatment didn't suit my personal situation at all. They tried treating me for problems I don't have, and my input in the treatment was ignored. It felt like a waste of NHS resources and extremely 'one size fits all' in their approach. If they had further referral options for those for whom their treatment doesn't help, the clinic would be much improved.</i>
<b>492</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>I was given the option to choose either physio/GET or CBT, I'd like to see different options as well as the ability to choose more than just one treatment option.</i>
<b>493</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>Could incorporate different therapies such as nutrition, holistic, private testing etc</i>
<b>494</b>	Not listed		<i>None of these applicable</i>

<b>495</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>Having to travel such a distance when barely able to leave bed is unacceptable. I was discharged because I was physically unable to attend sessions frequently enough and when I did go, they used up all my energy for many days/weeks, while being bullied into increasing my activity levels even though it was making me more ill, then feeling like I was being shamed for not "meeting expectations".</i>
<b>496</b>	Essex Chronic Fatigue Service	Be adapted to provide different services	<i>The only option offered to me was Graded Exercise Therapy which did not improve my symptoms. When it became apparent this did not work for me, no other alternatives were explored or offered.</i>
<b>497</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Advice was limited and it was negative.</i>
<b>498</b>	Essex Chronic Fatigue Service	Be adapted to provide different services	<i>I was unlucky with the healthcare professional I saw as she spent a little over half the time in our sessions talking about herself, how her manager didn't understand her and how difficult some of her patients were! Because of my own professional background, I was able to pull out some helpful advice from our sessions. However, because I had lost much of my confidence at that stage I didn't feel able to challenge her and/or ask for different/more intervention.</i>
<b>499</b>	Salford CFS/ME Service	Be adapted to provide different services	<i>One on one counselling/therapy services alongside groups would have been most helpful for me</i>
<b>500</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>Whilst attending the clinic although the staff are wonderful it has been confirmed that the advice being provided by the NHS was not helping people to improve. Sadly they still had to teach a course with the outdated information. There Was one particular member of staff who basically said that your body will become weaker if you did not keep a level of exercise up. He advised against resting too much.</i>  <i>A larger problem for me is the fact that the staff are unable to keep you on their books in the same way that someone with diabetes is kept in the books. So it's very hard to gain more support if there is something that has changed. You Have to go to your GP and not all GPs are knowledgeable about M.E.</i>
<b>501</b>	Salford CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>It knew nothing, could offer nothing, wanted me off their books so they could 'take on another patient'</i>

<b>502</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because help is necessary, but currently v poor</i>
<b>503</b>	Not listed		<i>The service I attended has been closed for a number of years</i>
<b>504</b>	Nottinghamshire PICS CFS/ME Service for Adults	Continue to provide current services	<i>We need monitoring until well - after 6 months funding was up had it 15 years now</i>
<b>505</b>	Wells - Somerset CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Because there is not a good enough... (or for the severest, non existent!) service for patients with moderate or severe ME.</i>
<b>506</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Advice should be pacing, diet only</i>
<b>507</b>	Nuneaton - Warwickshire CFS Service	Be adapted to provide different services	<i>I went to get a formal diagnosis of ME. Only CBT and GET were offered, but not pushed</i>
<b>508</b>	Bath Centre for Fatigue Services	Be closed and a new service rebuilt with patient input	<i>Staff good but using outdated information, not being allowed to use current research which proves GET etc is harmful.</i>
<b>509</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>I haven't finished the treatment, but they seem very underfunded and underresourced, and it's very difficult to get any appointments, as such I don't think I've received adequate treatment, and any understanding I have of ME has been through my own research</i>
<b>510</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be adapted to provide different services	<i>There is no secondary care for severe case loads and need to keep severe cases open and on their books and contact patients who experience severe symptoms to offer further input and support and to attend tribunals for those experiencing problems with welfare benefits</i>
<b>511</b>	Bristol CFS/ME Service for Adults	Continue to provide current services	<i>The 6 week course I attended at Bristol helped me to understand the wide-ranging symptoms and how to manage daily activity, including setting a realistic baseline.</i>

<b>512</b>	Bath Centre for Fatigue Services	Be adapted to provide different services	<i>Needs more patient input and more info about range of alternative approaches that may help. not just suck it up rest and pace</i>
<b>513</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>Treatment based around m.e. being a psychological illness and it's not! Out dated way of thinking and treatments which can make people worse! People living with m.e. know more than the professionals do, listen to them! They have had to become the experts as the experts don't experience the illness.</i>
<b>514</b>	Bishop Auckland - Durham & Darlington CFS/ME Service	Continue to provide current services	<i>Ongoing support</i>
<b>515</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>CBT and GET therapy was used and should be scrapped immediately. Totally inappropriate. Some of the relaxation therapy was OK but nothing else was helpful.</i>
<b>516</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be adapted to provide different services	<i>trying medication didn't improve matters, no other alternatives</i>
<b>517</b>	Not listed	Continue to provide current services	<i>It was helpful for information/understanding the symptoms to a degree</i>
<b>518</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>It was run by a rheumatologist at Salisbury hospital. He said CFS wasn't his area so he could offer nothing but antidepressants</i>
<b>519</b>	Bath Centre for Fatigue Services	Continue to provide current services	<i>It was a 12 week programme I think you need to see someone on a regular basis</i>
<b>520</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be closed and a new service rebuilt with patient input	<i>I was told some patients with ME get better when they go on holiday. They had no understanding of severe neuroimmune Myalgic Encephalomyelitis</i>

<b>521</b>	Leeds and West Yorkshire CFS/ME Service	Continue to provide current services	<i>The Seacroft centre offered care over 14months (12 sessions) which gave me time to put into action what I'd learnt. My OT was lovely, thoughtful and knowledgable. I don't know what I could have done without her. I just wish there were more physical therapies she could have prescribed directly rather than needing to go back through my GP.</i>
<b>522</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>There is a gap between GP care and the ME service - this means some of the suggestions made from the service aren't offered by the GP. There should be more medical input in the service, learning to live with a chronic illness does not cure or alleviate, it only makes my life understanding better. There need to be more actual treatments offered, like vitamin B injections. Treatments that are researched and has shown good outcomes. This can then be audited for further research. CBT, graded exercise, breathing exercises and support groups work the same on ME patients as it would do on a cancer patient, someone who suffers with asthma or any other disease- yes, it gives you more understanding of yourself and your illness but you still need medicine! The absolute lack of medicine therapy from the ME care regime is disgrace for the NHS.</i>
<b>523</b>	Leeds and West Yorkshire CFS/ME Service	Continue to provide current services	<i>Group meetings were very useful but extremely mental exhausting.</i>
<b>524</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Continue to provide current services	<i>The team are good</i>
<b>525</b>	Not listed	Be adapted to provide different services	<i>The individual psychology and occupational therapy sessions as well the group CFS and mindfulness courses were helpful, but there should also be a dietary element. Many people with this condition often have deficiencies and intolerances which if addressed may have a positive effect. I have found it difficult to cope since the clinic support has stopped. I feel there needs to be a more ongoing support for patients who are dealing with this illness for such long periods of time.</i>
<b>526</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because the clinic was rheumatology</i>

<b>527</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>The service takes FAR too long to provide support. There is no feedback given to general healthcare practitioners in the meantime. My GP referred me in February this year, I was given NO advice on how to manage my activity or condition at this time. By the time I had my appointment with the specialist consultant through the service, in July, my symptoms had gone from Mild to Moderate. Then all I was given was a diagnosis for the condition I already knew from my own research I had. And I am now still waiting for an appointment at the end of October when I can expect to finally receive some advice from the service. I imagine this advice will be of the kind I have luckily been able to gather for myself online and through friends and therefore of little help. There are no affiliated support group or meetings as far as I can tell. And I am appalled at how neglected I have been.</i>
<b>528</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>There was no ongoing follow up after the sessions I attended &amp; no specialist consultant . Most chronic conditions have follow up clinics for specialist monitoring &amp; input as to continued management of the illness. This would have been appreciated.</i>
<b>529</b>	Stockport CFS/ME Service	Continue to provide current services	<i>In the year I attended, 1998, Stockport were very forward thinking in their treatment of M.E. and were one only two clinics in the UK at that time. If the clinic is still ongoing I would hope it is still providing a good service.</i>
<b>530</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Advice was based upon 'all in the mind' approach. To be asked questions like 'are you having enough fun in your life' whilst one was feeling so ill was a total insult. Only one clinical question asked in 40 mins which was 'have you had any blood tests?' My GP had written a full letter detailing tests undertaken but this was seemingly ignored. Not once was I asked about my symptoms and although I insisted on sharing these, they were not taken seriously.</i>
<b>531</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Continue to provide current services	<i>The treatment I have received from the Bath Clinic has been incredibly helpful and I have always felt supported by their service</i>
<b>532</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	Be adapted to provide different services	<i>I would have liked to have had access to Complementary Therapies because i know they are extremely beneficial. I would also like the course to be sympathetic to patients being unable to attend due to Flare ups and just simply being too poorly to attend. As i live a good distance from Connah's Quay it was impossible for me to attend all the dates of the Course, (which was not allowed).</i>
<b>533</b>	Grantham - Lincolnshire CFS/ME Service	Be adapted to provide different services	<i>More focus needed on understanding and managing post exertional malaise, pacing and heart rate monitoring to keep within individual limits.</i>

<b>534</b>	Suffolk Specialist ME and CFS Service	Be adapted to provide different services	<p><i>I was told I needed to manage my activity levels, when I asked for guidance I was told that the OT advising me couldn't 'tell me what to do as she wasn't my counsellor,' ~ not helpful. When I returned for the third of three appointments I reported no change, and was told I was a disappointment as the OT thought I was going to be one of their success stories. Despite me saying that being upright caused me huge difficulties, I was told that a perch stool would ease my symptoms; it didn't. Hardly surprising as it allowed me support, but only in an upright position, the same position that I had reported as causing me great problems; my lack of enthusiasm for trying this piece of equipment was not acknowledged as a reasonable response, but as a reluctance to try an effective strategy ~ effective perhaps for those who are unable to stand unaided, very ineffective for those with OI. The adviser offered no advice on dealing with the OI; I'm not sure she actually knew what it was.</i></p> <p><i>The centre itself was unsuited to ME patients; there was no parking, which necessitated walking from wherever we could find parking ~ I am unable to walk far and arrived at my appointments feeling very ill as a consequence. All the seating was upright, with no head or upper body support, both of which are areas of need for most ME patients, and exacerbated my symptoms.</i></p> <p><i>The intervention that has most eased my symptoms, has been the acquisition of a variety of powered wheelchairs which allow me to access the world in ways that my limited walking, and upright capacity, make impossible ~ there was never any mention of any kind of supportive seating/wheelchairs/ head support ~ all of which have hugely improved my quality of life.</i></p> <p><i>The OY seemed to have less knowledge of the symptoms of ME than I had at that time ~ and I was pretty ignorant ~ it seemed that whenever I mentioned a symptom that caused me grief, she would tell me that she didn't know 'that' was a symptom of ME.</i></p> <p><i>The only good outcome was that I received an official diagnostic check-list, letter, and a copy of the Canadian Consensus Criteria, which helped enormously in my understanding of my symptoms, and ways to ease them; it seems a shame that the ME/CFS service adviser hadn't availed herself of the information it contained!</i></p>
<b>535</b>	Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service	Be closed and a new service rebuilt with patient input	<p><i>There is no Consultant input only Psychologist led.</i></p>
<b>536</b>	Leeds - Yorkshire Centre for Psychological	Be adapted to provide different services	<p><i>More practical input not just booklets.</i></p>

	Medicine inpatient care		
<b>537</b>	Not listed	Be adapted to provide different services	<i>The service is good and healthcare professionals were understanding. Limited amount of actual support they can give as not enough evidence to be able to suggest more than limited advice.</i>
<b>538</b>	Nuneaton - Warwickshire CFS Service	Continue to provide current services	<i>It's the only one in this area and offers better advice and treatment than the gp.</i>
<b>539</b>	Leeds and West Yorkshire CFS/ME Service	Continue to provide current services	<i>Very good service and excellent professionals</i>
<b>540</b>	Hull and East Yorkshire CFS Service	Be closed and a new service rebuilt with patient input	<i>The course was focussed cognitive behaviour, which helped in accepting my limitations and using a wheelchair. However, the questionnaire at the end was completely inappropriate. I was quite shocked that the questionnaire was very much focussed on alleviation of symptoms and getting back to work. The course did NOT alleviate symptoms at all. I realised later that this course was a token service very much based on behavioural therapies, which certainly DO NOT alleviate symptoms.</i>
<b>541</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>As much as people try to understand what we go through until you have ME they can never appreciate the devastating impact and how it changes your life.</i>
<b>542</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>It was a nurse led service and it doesn't seem to exist any longer.</i>
<b>543</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>They had no idea about ME. I was severe and mainly bed bound and invited to a noisy/bright group meeting 45mins drive from my home.</i>

<b>544</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>I was referred to the Harold Wood Hospital, ME Clinic, about 1986? as my GP knew of no equivalent in Scotland. It has since closed I believe but the relief in having a diagnosis was immense; the kindness shown by the consultant after not being believed for several years was overwhelming to me then. I had already had to give up my teaching career while being told my illness was "all about anxiety and depression" or I was a silly women who thought she was ill. However, the ME Clinic only offered dietary advice and physio of a kind and although there was a follow up appointment both bouts of travelling from Edinburgh left me with relapses .</i>
<b>545</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Continue to provide current services	<i>The whole staff were brilliant - sympathetic and knowledgeable. Couldn't be better.</i>
<b>546</b>	Not listed	Be adapted to provide different services	<i>This service was provided for a year with a ten week initial course and a couple of check ins at six months and a year. I've had ME for much longer than that. A service needs to contain more than CBT and GET.</i>
<b>547</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>The advice and treatment offered was completely inappropriate and following it worsened my condition.</i>
<b>548</b>	Birmingham and Solihull CFS Service	Be closed and a new service rebuilt with patient input	<i>They were sympathetic and gave some very basic advice and did a couple of basic tests but that was that. I was only offered nortriptyline or amitriptyline (which I had previously tried and not got on with) and no effective bio medical treatment . I already did yoga stretches and breathing, etc which was all they could offer. 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).</i>
<b>549</b>	Not listed	Be adapted to provide different services	<i>Staff were not understanding of the problems patients with ME have.</i>
<b>550</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>Some aspects work others clearly do not</i>

<b>551</b>	Not listed	Continue to provide current services	<i>The Immunologist leading the clinic understood M.E. as did his colleague, but he retired and the clinic was closed. They gave listened to us, guided us and supported us. Since then there have been no further clinics in our area for patients who have had the M.E. for a long time (we were advised by a new clinic that it could not help such patients). So WE HAVE BEEN COMPLETELY ABANDONED FOR YEARS by the NHS with no support for severe M.E. - I am very very disabled by it and have no support for it AT ALL. I thus get very depressed because of this. ( I did a course of cbt since which made no difference at all - it does not help M.E.)</i>
<b>552</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because the current GET &amp; CBT "treatments" are harmful to ME patients and should not be recommended</i>
<b>553</b>	Salford CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Because we were told to find a base line for activity and to gradually increase the activity during the course at every session there was some form of exercise be it stretching ar movement . Run by a psychologist and physio it was tailored to ME being a psychological condition</i>
<b>554</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>If something is not working for someone then the advice needs to be adapted for that person there is no point in repeatedly being told the same thing if there are potential alternatives. I would describe the sessions more as counselling with someone trying to understand you whereas other doctors either don't believe in ME or they are rude and call you lazy.</i>
<b>555</b>	London - University College Hospitals Children and young people's specialist adolescent services	Continue to provide current services	<i>Obviously to have more options available would be good, but what they have currently is good</i>
<b>556</b>	Stockport CFS/ME Service	Be adapted to provide different services	<i>Would benefit from an extension of the service, more staff and more treatments and courses offered</i>

<b>557</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>The physio we saw at the Bath clinic seemed very naive about ME and didn't appear to understand the complexity of the illness. She said that if we followed their regime which was basic sleep hygiene and getting up in the morning and pacing activity then he would improve. We followed their advice to the letter and had 4 mo the of hell and he was no better. Basic sleep hygiene rules do not work with people with severe ME as there is someth8ng fundamentally wrong with their sleep. Once we ignored Bath's advice he stabilised and very gradually improved. The clinic would not prescribe melatonin when we asked, and said that we just had to move his wake/sleep routine by 15 mins a day - as if it were that simple - this was ridiculous advice and if they had ever live down with anyone with severe ME they would know this. I am also irritated that she promised he would get better if we followed her advice, as there is no clinical evidence for this claim and it gave us false hope. They also refused to do more than 2 phone calls nor Skype calls yet to get him to Bath gave him 3 months of payback - why on earth would an ME clinic not do Skype calls. They were also obsessed with him engag8ng with a home tutor when he was so ill he couldn't sit up in bed! He wanted, on line learning he could do from his bed as this would use much less energy than a visit from a tutor, but Bath felt that they knew best and told the Educational welfare officer that he should have a tutor. Where is the person centred ness in this?</i>
<b>558</b>	Not listed	Be adapted to provide different services	<i>It mainly treats Fibro and Chronic Fatigue which doesn't help people who have ME even though they have fatigue and pain - have 2 hour classes that one has to sign up for and be sure you can attend regularly in order to get a place.</i>
<b>559</b>	Not listed		<i>Clinic has been closed and should be opened again at City Hosp Belfast.No ME clinic in NI at the moment</i>
<b>560</b>	Oxfordshire CFS/ME Service	Continue to provide current services	<i>They were very patient focused. Didnt promise but offered options to help.</i>
<b>561</b>	Sunderland - South of Tyne Paediatric CFS Service	Be closed and a new service rebuilt with patient input	<i>Because I believe you have to have this illness to understand it.</i>
<b>562</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>Current input is not suitable to everyone</i>

<b>563</b>	Sunderland - South of Tyne CFS Service	Be closed and a new service rebuilt with patient input	<i>I feel the clinic had their agenda where what they offered and what was needed didn't match. I don't think they kept up to date in areas of research. When they could offer me no more despite being no better I was discharged.</i>
<b>564</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>CBT was fine I suppose, it is basically common sense, but graded exercise was a huge point of contention.</i>
<b>565</b>	Torquay - Torbay and South Devon CFS/ME	Continue to provide current services	<i>It had useful info</i>
<b>566</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	Be adapted to provide different services	<i>The clinic was initially nurse led and was excellent in helping me understand my condition when first diagnosed. However it changed to therapy led service. My physio lacked understanding of the condition and I deteriorated after I was put on a graded exercise program. I was rarely seen by a doctor so underlying health conditions were not picked up. They were only interested in increasing physical activity.</i>
<b>567</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I was assigned a physiotherapist who wasn't an expert</i>
<b>568</b>	Not listed	Be adapted to provide different services	<i>I was refused treatment at the St Albans CFS clinic because my BMI was over 40, and they would only treat people with a BMI under 40, I was told to go away and lose weight, not what you want to hear when you're desperate for treatment for your CFS/ME. They need to understand the needs of ME patients</i>
<b>569</b>	Portsmouth Chronic Fatigue Syndrome Service	Be adapted to provide different services	<i>I was not convinced by GET although the physio was really helpful and supportive. The activity management was the most important and the psychologist was interesting.</i>
<b>570</b>	Not listed	Be adapted to provide different services	<i>I didn't feel like going to the clinic benefited me in anyway nor did I come away with anything helpful</i>
<b>571</b>	Malvern - Worcestershire CFS/ME Service	Continue to provide current services	<i>The clinic has been very helpful and continues to find ways to help ME CFS patients.</i>

<b>572</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be adapted to provide different services	<i>As a patient I was told that I had taught them a thing or two. I think if you are running a clinic you should be at least one step ahead of your patient.</i>
<b>573</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>The service was emotionally abusive, an entirely new service based upon current, sound research should replace it entirely.</i>
<b>574</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	Continue to provide current services	<i>I have an excellent nurse who i see regularly and she has helped a lot</i>
<b>575</b>	Nottinghamshire PICS CFS/ME Service for Adults	Be adapted to provide different services	<i>There needs to be more research funded into CFS/ME to increase understanding in order to develop effective treatments, and outlaw the practice of potentially harming ones.</i>
<b>576</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Refer to world health organisations classification of m.e/cfs and up to date research on biomedical findings.</i>
<b>577</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>When I was extremely unwell, I attended what I thought was an appointment to provide a diagnosis but it was actually a presentation to many patients and was not what I needed. When I spoke to a nurse she was very understanding and supportive. But when I eventually got CBT I found it too focussed on activity and not enough on addressing core beliefs and working on finding a calm and healing state to live my life in and the benefit of attending was outweighed by the energy involved in getting there.</i>
<b>578</b>	Salford CFS/ME Service	Be adapted to provide different services	<i>Although it was many years ago since I attended, I believe that SOME of the staff now have a little more empathy with sufferers and are deeply embarrassed that the NHS &amp; NICE do not have up to date information or help available for us.</i>
<b>579</b>	Preston - Lancashire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>After I attended my initial appointment for diagnosis/confirmation of my illness, I was told that I would not be able to attend that clinic again, as the service/clinic was being decommissioned... I was then discharged back to my GP. It has had a detrimental effect on my health, as my GP is not up to date on the latest research..</i>

<b>580</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>More in depth service, I've since done the ANS Rewire course which I found far more helpful and more detailed than what was offered on the NHS</i>
<b>581</b>	Essex Chronic Fatigue Service	Be adapted to provide different services	<i>The advice and treatments offered should accord with up to date international research findings for ME/CFS and the WHO definition of ME/CFS. The clinic did not provide any advice on treating and managing migraines, muscle and joint pain, insomnia and other symptoms with medication or supplements and provided no dietary recommendations, which should be a cornerstone of treatment for ME. The occupational therapist mainly focussed on the psychological aspects of the disease, thus implying my symptoms were psychosomatic. While I wasn't forced to do Graded Exercise Therapy like some patients in other clinics, it was highly recommended - I would have found massage and/or advice on restorative yoga poses and meditation/mindfulness a lot more useful. I saw a second occupational therapist at the CFS service at Queen's Hospital in Romford who gave me advice that you would give someone with mild depression and encouraged me to push myself to do more physical activity and "have more fun". Taking her advice drove me into a 3-month long setback. When I quit the service I was told that trying to manage my condition on my own would lead me down "a slippery slope".</i>
<b>582</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be closed and a new service rebuilt with patient input	<i>I think a new consultant is needed to shape and lead the service coming from a bio-medical understanding of the illness. Although the staff were caring their model for understanding the illness was deeply flawed although tragically I didn't realise this at the time and strove diligently to follow their advice. I'm not sure much has changed in the 5 years since I was a patient at the clinic.</i>
<b>583</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>The first hcp I saw gave a very pessimistic view and I felt very low after my first appointment. However some information was useful. I changed practitioners on request and my new specialist physio is very helpful. Waiting lists are far too long and there are only 6 appointments offered over 2 years! This is not enough.</i>
<b>584</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	Be adapted to provide different services	<i>The services offered to me were only a telephone appointment, I am too poorly to attend the clinic for classroom work, but I don't use the telephone because of severe anxiety. So I haven't actually received any level of service.</i>
<b>585</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>There should be some consideration of how long people have had the diagnosis. Someone recently diagnosed has very different needs to someone whose lived with it for many years. Though I realise resources are limited.</i>

<b>586</b>	Not listed	Continue to provide current services	<i>I saw a private consultant who is involved in research on ME, so he provides up to date information.</i>
<b>587</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	Continue to provide current services	<i>It is the only thing the NHS could provide me with. They never claimed to cure me, they didn't belittle me, they understood and helped me manage my symptoms as well as help me deal with the mental side of living with a chronic, life changing illness. Without this service and level of support, I'd dread to think where I'd be now</i>
<b>588</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>there was no local service then: I was sectioned and wasted 3 1/2 years in psychiatric 'care' before they gave up and kicked me out and I've been on my back more or less ever since.</i>
<b>589</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>Because they said I was too ill to travel to the clinic and so I was left with nothing and nowhere else to go</i>
<b>590</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>Needs change to adapt to patient needs, to offer support at home OT and communications with other Professionals for POTS etc is very much lacking also information for biomedical research. NOT psychological problem so should NOT be treated as one and given empathy and understanding of complex illness.</i>
<b>591</b>	Penrith - Cumbria Persistent Physical Symptoms Service	Be closed and a new service rebuilt with patient input	<i>I was placed in a psychological rehabilitation group with others with ME/CFS, FND, fibromyalgia and what they termed any other 'medically unexplained symptoms!!' I did not require this. I needed 'treatment'.....and to understand the cause of my illness. I needed comprehensive tests to rule out any other conditions. Instead I got CBT! I was a Mental Health Nurse and I could not understand why I was sat in an 8 week psychological therapy group when I had a physical illness!</i>
<b>592</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>offering GET and CBT as treatment with some implication of mental health</i>
<b>593</b>	Bath Centre for Fatigue Services	Continue to provide current services	<i>Brilliant service very understanding</i>

<b>594</b>	Grantham - Lincolnshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Sessions were too close together not enough time for recovery between sessions. The most helpful part was meeting others with the same condition.</i>
<b>595</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be adapted to provide different services	<i>It was not possible to complete the course because I wasn't well enough to keep attending. It didn't take into account how hard the sessions were for anyone other than mild sufferers. The pacing advice was excellent. The graded exercise advice was not. The people were helpful and friendly but once you were finished the course that was it. No more help or on-going support, which I think it's vital. Instead we are left trying to support each other on social media.</i>
<b>596</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>They didn't understand the leg pain or believe in the pain in legs. No understanding of the exhaustion endured and too tired to even think.</i>
<b>597</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>The service is quite sparse. There are 3months between each 1hr session. Group sessions aren't very good for information. More like a tea n natter hour.</i>
<b>598</b>	Newcastle - North of Tyne CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Said I could not have ME as I had a history of mental illness, so they discharged me and I was not diagnosed until 2016.</i>
<b>599</b>	Not listed	Continue to provide current services	<i>It was the Keswick (Cumbria) clinic and it closed shortly after they cancelled my course after only two sessions.</i>

<b>600</b>	Not listed	Continue to provide current services	<i>Very sadly, the National ME Clinic where I was initially diagnosed and helped (I knew nothing about ME/CFS when I attended) was closed. I have since attended two others, neither of which provided the same standard as [the professional] and his specialist staff. Their treatments and the knowledge they gave me were far superior to anything I have experienced since. In fact, one of the mainstays of my treatment (regular B12 injections) enabled me, along with the rest of my treatment plan, to get back to full time employment. When these were stopped by NHS England (Capita) under threat of firing any consultant (another of which told me it helped 60% of their ME/CFS patients) who prescribed them, my condition deteriorated significantly. NICE should listen to experts and patients. I wonder how many people are now suffering and unable to contribute to society because NICE doesn't listen.</i>
<b>601</b>	Bristol CFS/ME Service for Adults	Continue to provide current services	<i>And add new services.</i>
<b>602</b>	Not listed	Be adapted to provide different services	<i>It was [the professional's] Falls and Syncope Unit in Newcastle. I was suffering from orthostatic intolerance and low BP. After I waited six months for an appointment they gave me an ECG and a tilt table test and told me they were discharging me as my HR did not increase by 30bpm on standing on the day in question.</i>
<b>603</b>	Private clinic	Continue to provide current services	<i>It was the Breakspear Clinic. At the time we suspected chronic Lyme disease so I took antibiotics but I also tried LDN in case it was ME. Unfortunately neither treatment was beneficial but I got an enormous psychological benefit from being asked for a clinical history and taken seriously by a medical practitioner for about the first time.</i>
<b>604</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	Be closed and a new service rebuilt with patient input	<i>GET made me worse!</i>
<b>605</b>	Not listed	Continue to provide current services	<i>I didn't see this clinic listed, so hope it is still active - St Hellier's Hospital, Carshalton. Although I only attended once, [the professional] helped me hugely in overcoming a severe relapse brought on by my current Line Manager at work. He altered meds, increased B12 injections and provided information to refresh my memory about the illness. As it was so far away, I couldn't attend the group sessions, but was assisted a few times by his lovely team over the phone. They got me back to work!</i>

<b>606</b>	Not listed	Be adapted to provide different services	<i>This is complicated, but: I saw [the professional] in Sutton twice, first on the NHS and then privately. When I tried to see him on the NHS I was told I wasn't allowed to see him, nor was he allowed to prescribe anything that would help. I went again privately and he was warm and friendly and prescribed B12 injections, which still seemed to be more or less all he was allowed to give me. Unfortunately they were not beneficial.</i>
<b>607</b>	Romford - Queens Hospital National CFS Diagnostic and Specialist Rehabilitation Service	Continue to provide current services	<i>Maybe the personnel could change. The consultant was rude, unhelpful and shouted at me. I was diagnosed a decade earlier and thank goodness had knowledge from previous excellent health professionals/consultants - this is the only thing that prevented a complete relapse.</i>
<b>608</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Continue to provide current services	<i>I found the service helpful</i>
<b>609</b>	Torquay - Torbay and South Devon CFS/ME	Be adapted to provide different services	<i>By "adapted" I mean the services all need way better funding. At the moment they have no admin staff etc.</i>
<b>610</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>No longer has a doctor, not wheelchair accessible, pushes CBT and GET. CFS/Fibro clinic is now Cumbria Partnership Persistent Phys Symptoms. Refuses home visits. Betrayal of Patients.</i>
<b>611</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>The people I saw were all awful, I would never attend the clinic again while they still worked there</i>
<b>612</b>	London - Uxbridge - Hillingdon CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>This is a facility based on psychological theory and does not address the biological aspects of the disease. I felt gaslighted.</i>
<b>613</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>Patient input is needed as we have a better understanding of what we need to get the right help and support</i>
<b>614</b>	Bristol CFS/ME Service for Adults	Be closed and a new service	<i>ME/CFS is a complex physical illness that should be treated by doctors instead of nurses and occupational health practitioners</i>

		rebuilt with patient input	
<b>615</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be adapted to provide different services	<i>pediatric services were good but not carried through to adult services</i>
<b>616</b>	Salford CFS/ME Service	Be adapted to provide different services	<i>Less psychological services, more practical help with daily living, social workers, occ health therapist, advice on diet</i>
<b>617</b>	Not listed	Be adapted to provide different services	<i>Nothing that was said was helpful, therefore different services are needed. For example, what supplements may be helpful or make symptoms more manageable</i>
<b>618</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>More advice on Pacing would be helpful. Graded exercise and CBT made my illness worse.</i>
<b>619</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>Pain, and management workshops were offered. Symptoms, new or existing was told to discuss with my GP.. would have thought any issues with my CFS/ me should have been discussed with the fatigue clinic, as well as blood tests etc..as my GP admitted he had no real knowledge or understanding of the condition, and had to research it.</i>
<b>620</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>When I first went to them (2014) I saw a medical doctor who provided practical advice on pacing and suggested supplements to try. When they retired, they were replaced by a psychiatrist and OTs who only seem to do GET and CBT. As I refused those (GET is dangerous, CBT isn't appropriate for me as I'm coping well with my condition overall) they had nothing to offer me. In about 2016 I was referred back to them for help to manage ME flare-ups linked to periods (due to possible menopause this had got worse). They had no suggestions for how to manage these flare-ups or (ideally) reduce their severity. Instead they told me I should give up work (I work 3hrs a day, mostly from home) because then I wouldn't be so bothered about the flare ups! I'm so lucky to have been able to see the proper doctor before they retired. If I'd only seen this new 'service' I'd be in a much worse place with my health and almost certainly unemployed.</i>

<b>621</b>	Salford CFS/ME Service	Be adapted to provide different services	<i>Self-managed pacing was offered, as well as specialist CBT and GET. I think the GET should be scrapped as I don't believe GET it appropriate for people with ME/CFS. I can't comment on how appropriate the specialist CBT is as I chose not to engage with the service. I wish I'd gotten more practical help (e.g. referrals to charities that could help with home adaptations) in order to best facilitate pacing.</i>
<b>622</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>The clinic provided appropriate management techniques for patients with chronic fatigue as a result of any condition. It was not tailored to specifically address the needs of those patients with M.E. As an example if the patient did not improve within two years the clinic removed the patient from all services, without referring the patient to other service providers.</i>
<b>623</b>	Fareham - South Coast Fatigue	Continue to provide current services	<i>The service provided was the only one in this area and we had to get trust funding as it was a private clinic. The staff had a great deal of understanding of fatigue and had good strategies and knowledge for teaching the management of the illness. They did not try and say they could cure it and never pushed but instead listen and worked with individual needs. Teaching pacing and resting. This was also done in the home not involving long trips to a centre. We did attend Bath once but it was a waste of time.[The professional at Fareham - South Coast Fatigue] team were far More help and support.</i>
<b>624</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Continue to provide current services	<i>The services they have support patients and are the best they can do at this stage</i>
<b>625</b>	Not listed	Be adapted to provide different services	<i>It was based heavily on pacing. And GET</i>
<b>626</b>	Bristol CFS/ME Service for Adults	Continue to provide current services	<i>To aid more to understand of pacing</i>
<b>627</b>	Essex Chronic Fatigue Service	Be adapted to provide different services	<i>The effort it took to attend the clinic far outweighed any benefits</i>
<b>628</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be adapted to provide different services	<i>Basically I was just asked how I was doing each time and told to keep up the 'good work,' rest, do graded exercise and reduce my stress levels and that eventually I should improve. Not very helpful when you are unable to work and don't know</i>

			<i>how you're going to pay the bills and exercising makes you worse.</i>
<b>629</b>	Not listed	Continue to provide current services	<i>Everyone who attended the clinic had different symptoms and problems. The clinic suited some people more than others.</i>
<b>630</b>	Manchester CFS/ME Service for Children and Young People	Be closed and a new service rebuilt with patient input	<i>Due to a lot of uncertainty about the condition, the patient or carer become the experts on the physical needs of the person diagnosed.</i>
<b>631</b>	Shrewsbury - Shropshire Community Neuro Rehabilitation Team	Be adapted to provide different services	<i>The service provided was very limited - a one-off series of workshops to help manage symptoms. There are no follow ups and long wait lists. I assume this is a funding issue more than anything.</i>
<b>632</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>I had monthly phone calls which explained pacing. No other input was given.</i>
<b>633</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>did not like been talked down to and pushed to do things i felt made me worse, also making me feel like it was in my head. Travel to service was 45 mins away.</i>
<b>634</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>Because it didn't help me I feel it needs to be changed</i>
<b>635</b>	Sunderland - South of Tyne CFS Service	Continue to provide current services	<i>I think services should continue I have used these services three times have had me for many years but recently deteriorated and had to give up job .as the disease is so complex it took me a long time many years to fully understand how my condition affected me as I have several co morbidities I had one to one sessions but enjoyed the group sessions at my third programme and was very supportive and nice to see your not the only person with this disease The staff give advice and tips on easier ways to do things relaxation letters of support for I'll health retirement and disability benefits</i>

<b>636</b>	Essex Chronic Fatigue Service	Be adapted to provide different services	<i>I found the CBT. I had there very helpful because my therapist understood my symptoms and the barriers I faced such as using a wheelchair for the first time . She help me to be able to make that first step in being seen outside in public . She also helped me to understand that there is no particular reason why and when each symptom appears. I had GET which made me become worse permanently. When my cbt therapist went off on long term sick the assessment I had afterwards was full of lies saying I was much better . I accepted my illness more because of it but I was actually worse . I felt completely 100% let down by the service after that .</i>
<b>637</b>	Bolton - Bury and Bolton CFS/ME Clinic	Be adapted to provide different services	<i>Please note: Regarding earlier question. Bolton ME doctor did not recommend I increase activity... another doctor did when I was first unwell.. in 1989.  I think all ME clients should have a review and support every 6-12 months. I have been to two different clinics and both discharged me. I have no ongoing support for the daily difficulties with this illness... which is so wrong... and cruel. Someone with MS gets great support.</i>
<b>638</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>Doesn' Understand illness</i>
<b>639</b>	Norfolk and Suffolk ME/CFS Service	Continue to provide current services	<i>Didn't go there long enough to form opinion- too far to travel in circumstances</i>
<b>640</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>I was already exercising a lot on my own, because my GP thought it might improve my mood and that this in turn would increase my energy. I was referred to physical therapy at a local hospital, where I did a course of Graded Exercise Therapy for a few weeks. It did not lead to any improvement, and I had a worsening of symptoms. Worse than that, I had no investigations, treatments or advice that could have helped me to better manage my symptoms.</i>
<b>641</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>The service offered cbt and GET. None of which work with ME</i>
<b>642</b>	Salford CFS/ME Service	Be adapted to provide different services	<i>The clinic I went to offered GET and CBT. I did not access the GET as I was attending another course at the time. The CBT was helpful for other issues I had but had no impact on the ME/CFS. I noticed that the handbook recommended 'pushing through' when you have symptoms which I totally disagree with.</i>

<b>643</b>	Oxfordshire CFS/ME Service	Be adapted to provide different services	<i>Need to move past the archaic understanding of ME</i>
<b>644</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>Touch wrong with service to be changed</i>
<b>645</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>Staff in clinic were excellent but they did follow NICE guidelines which are outdated, misleading and sometimes harmful. Staff tried to make some adjustments and often advised to "listen to your body" but advice was still about "increasing activity" which can cause me to relapse.</i>
<b>646</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>The service is severely hamstrung by NICE. The 'guidelines' are flawed, but medical practitioners are still bound by them. This is a ridiculous situation for both practitioners and patients and so the only course patients have is to fill gaps in advice with their own research and self-diagnosis. NICE are not carrying out the review fast enough or helping steer research to fill these gaps. NICE need to explain clearly to Government that greater levels of funding needs to go into research NOW.</i>
<b>647</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	Be adapted to provide different services	<i>This service was very oriented to psychological support, which was somewhat helpful, but it was very dismissive of any discussion of biological causes of ME/CFS. When I asked questions about specific symptoms e.g. vertigo and nausea, they would not answer. It left me completely in the dark if this was a symptom of the disease or something else I should be getting checked out. They appeared completely unaware of me/CFS research, medical advances and trials when I asked them about this. It felt like the unit was only interested in delivering CBT and there was no integrated approach to organising other care e.g. referring to other services to check for co-morbidities or mis-diagnosis, keeping patients informed about biomedical research and trials, helping patients access care services, etc.</i>
<b>648</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>No one listens to the patients</i>
<b>649</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be adapted to provide different services	<i>They must Move away from graded exercise</i>

650	Not listed	Be closed and a new service rebuilt with patient input	<i>This was the service at Great Ormond Street and it was based on pscyhological model of ME - being told that making my son empty the dishwasher would get him back to school was totally inappropriate</i>
651	Plymouth Sentinel CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I did telephone 'therapy' with OT. 6 or so sessions. Content was 60% good. 40% not good. Content did not reflect up to date biomedical science, therapists did not demonstrate understanding of the causes of symptoms. Therapists did not investigate how my physical functioning could be helped by environmental aids eg wheelchair, shower seat. Therapist mostly wanted to interpret PEM/crashes as the result of emotional stress, without ever asking about the duration of the activity, or whether I was standing or sitting - thus demonstrating her bias for psychological interpretation and lack of understanding of the quite fundamental physical causes of PEM. I would still support an Occupational Therapist led service, on the condition that their therapy is continually reviewed in the light of biomedical research. I don't think that the OTs in this specialist service know as much as I do about ME. I don't think they are up to date with biomedical research, and until they are, they have no authority to provide a specialist service. A specialist service should be built around understanding the principles of activity management and how they can be applied in daily life. Therefore it is essential that this is based on and continually adapted to patient experience. I believe that no specialist service for ME/CFS treatment has any right to exist unless it is created directly from the experience of patients. We are the evidence base, and we are the experts on living with and managing our condition. I believe that psychological therapy should be an option for patients. The problem with the NHS is that psychological therapy is prioritised over activity management, whereas pacing for ME/activity management is the only treatment strategy that works and is essential ie the primary intervention. Psychological therapy should be a secondary optional treatment where appropriate. One particularly bad example of the bias of this service is shown in the 1 hour assessment by the [professional at Plymouth Sentinel], where I was asked a few 'personality' questions, and the result of this was a line in my report which states 'Maintaining Factors' and notes 'Perfectionism'. ME/CFS is not maintained by a personality trait.</i>
652	Wells - Somerset CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Most of advice was just managing symptoms. There is no treatment, why?</i>

<b>653</b>	Private clinic	Be closed and a new service rebuilt with patient input	<i>Multifaceted condition requires a broader approach to 1. Prevent further decline 2. Get well. Current services are too narrow with insufficient research/experience/funding/positive outcomes</i>
<b>654</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>It has been closed no clinics are available now in Scotland</i>
<b>655</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be closed and a new service rebuilt with patient input	<i>Current understanding and treatment of ME/CFS within the NHS is largely based on female gender stereotypes and the outdated notion that the disease is psychological in nature. To discover that ME/CFS can last years, ruin lives and that the recovery rates are relatively low and then be offered a weekly planner as a treatment is frankly patronising and insulting. I was told at my first consultation (4 months after initial gp appointment) that I most likely had ME/CFS because I had been sexually abused as a child but did not remember (I have not been sexually abused) and that if I really wanted to get better I needed to see a £200 a week psychologist. I told the expert that I had been making some dietary changes that seemed to help, which he told me was a placebo and that I would soon feel worse again. I have since then found reputable private doctors who's free online advice I have followed to great success. The NHS consultants advice needs to match up with modern scientific findings and patient approved treatment programs. Treatment needs to be tailored to each individual patient and the success of the treatment measured for future patients. And instead of being offered 'fatigue management plans' once the patient is severally ill, the disease should be caught earlier (I visited the doctor several times with obvious early symptoms that were not highlighted as a concern). I cannot see any of this being achieved through adaptation, the service needs to be rebuilt from the ground up with the help from patients and reputable private practitioners.</i>
<b>656</b>	Birmingham and Solihull CFS Service	Be closed and a new service rebuilt with patient input	<i>These services need to be staffed with people who recognise ME is a physical illness &amp; by listening to patients tailor individual coping strategies.</i>
<b>657</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>It needs to be more personal as everyone has different reasons for getting cfs</i>

<b>658</b>	Edinburgh - Lothian CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>They dont understand that cbt and Get doesn't work for this condition</i>
<b>659</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>The treatment is based on CBT and GET which has been debunked as inappropriate for people with ME</i>
<b>660</b>	Norfolk and Suffolk ME/CFS Service	Be closed and a new service rebuilt with patient input	<i>Half an hour every 4 months is nowhere near enough support.</i>
<b>661</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>The service is solely focused on GET and CBT and is not open to the possibility that these do not work or open to the idea that other approaches might also be useful.</i>
<b>662</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Continue to provide current services	<i>Finally to have someone who believed me and showed compassion was worth it's weight gold</i>
<b>663</b>	Leicester CFS Service	Be adapted to provide different services	<i>Because it was nine years ago and I'm sure it has already adapted but there is always room for improvement over time.</i>
<b>664</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>I think the service needs to be more accessible to people that are house bound.</i>
<b>665</b>	Newcastle - North of Tyne CFS/ME Service	Be adapted to provide different services	<i>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</i>
<b>666</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>We the patient, know our illness better than any professional. We need to be asked what we think may help, or what we know will help. Patient input is the only way forward when existing with this lifestealing illness. Every time I've been to an appointment at an ME clinic, I've left with the feeling of wanting to kill myself. I have medical PTSD due to things that I was forced to do in the early stages of my illness.</i>

<b>667</b>	Hull and East Yorkshire CFS Service	Be closed and a new service rebuilt with patient input	<i>Only sufferers understand as such lack of appropriate training for staff as many doctors push cbt &amp; gets still</i>
<b>668</b>	Edinburgh - Lothian CFS/ME Service	Be adapted to provide different services	<i>Didn't help too much. Told you to change attitudes without helping. Handed out lots of sheets which was not useful. I could tell her more about certain areas. Spent a lot of time chatting about my family for some reason. didn't listen to my needs/concerns.</i>
<b>669</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because they don't listen to patients and use treatment which isn't proven to work. They expect us to follow their programme to the letter, much of which isn't proven to work and won't accept it if aspects of the programme are not helping or even worsening symptoms. If it doesn't work, no matter what reasons you give for it not working, you get condescendingly lectured and told you must follow it and that the only reason it's not working is because you're not following it properly, rather than the treatment itself not being proven to work. The therapist I was assigned to was not particularly understanding and often talked down to me and was patronising. I was scared of not doing it properly or it not working because of that. They also expect you to do some form of CBT and GET, which have been proven ineffective and potentially harmful. I refused the CBT, but they dressed up the GET in a way that I didn't recognise it until I'd started doing it (they didn't even call it GET).</i>
<b>670</b>	Exeter, East, Mid and North Devon CFS/ME Service	Continue to provide current services	<i>My symptoms have improved through pacing which they teach.</i>
<b>671</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>I think it would be difficult for the severely affected patients to access the service and the courses they run. It would be great if the service could reach out to those people who are house or bed bound.</i>
<b>672</b>	Not listed	Continue to provide current services	<i>My treatment was very helpful with [the professional] from the Wareham, Dorset clinic. I was making small improvement but unfortunately life took a turn for the worse as my husband left me and I had to move house... It set me right back. [The professional] was very supportive, but sadly I ran out of sessions before being able to get back on track. I now do less than I did before but still am not anything like well :(</i>
<b>673</b>	Fareham - South Coast Fatigue	Be adapted to provide different services	<i>Some of their advice was good. Although I crashed badly following one of their treatments, their general advice did help me to get more benefit out of my limited energy levels.</i>

<b>674</b>	Preston - Lancashire CFS/ME Service		<i>It closed before I finished the course</i>
<b>675</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>The service seemed to be provided by people with little experience or understanding of M.E, it focused too much on psychological approaches rather than dealing with M.E symptoms or improving quality of life.</i>
<b>676</b>	Penrith - Cumbria Persistent Physical Symptoms Service	Be adapted to provide different services	<i>The staff are restricted by the current NICE guidelines in the services they can offer. No medical professionals looking at treatment/ medication to reduce symptoms- only CBT and physio to help manage symptoms.</i>
<b>677</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>Because the way they are treating people now is hurting so many more people than helping yet they continue to carry on hurting people &amp; their family's.</i>
<b>678</b>	Salford CFS/ME Service	Be adapted to provide different services	<i>Make it more accessible with the fact in mind that the people travelling there have limited energy ie make it during the day not in the evening.</i>
<b>679</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Continue to provide current services	<i>I was referred to a clinical psychologist who was enormously helpful.</i>
<b>680</b>	Newcastle - North of Tyne CFS/ME Service	Continue to provide current services	<i>Through attending the clinic, I was able to better understand my illness and test out possible ways to improve my health within safe limits.</i>
<b>681</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>The building &amp; room were the furthest away from the entrance so it was a long walk. The sessions were too long and the chairs were not comfortable so I felt worse after attending the sessions.</i>
<b>682</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>The service I received was uninformed, unhelpful and condescending. At one point we were told to 'eat microwaveable ready meals and pre packed sandwiches to save energy'. Absolutely no knowledge of the importance of nutrition.</i>
<b>683</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>It is a very long time ago any I am sure that the service has changed greatly since my time. Their advice then was for graded exercise which damaged my recovery. I was ill for a total of 16 years</i>

<b>684</b>	Nottinghamshire PICS CFS/ME Service for Adults	Be adapted to provide different services	<i>They viewed us all as though we were at the same of of illness. There was no recognition of mild, moderate or severe.</i>
<b>685</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>I think they should continue to offer their services, but also add additional services</i>
<b>686</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	Be closed and a new service rebuilt with patient input	<i>I filled out endless psychological profile forms, which didn't address my symptoms, and just made me feel the real illness wasn't being understood at all. The CBT was sort of useful as it would be in any illness, but the exercise was a terrible treatment and I stopped and did my thing - resting, pacing, meditation, and loads of alternative therapies. None of these helped either so now I just live with it as best as I can.</i>
<b>687</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Service already closed.</i>
<b>688</b>	Portsmouth Chronic Fatigue Syndrome Service	Be adapted to provide different services	<i>Great team but offering Graded exercise therapy is crazy. The courses they offer for Pacing is great. The PACE trial should be stopped. OT service is fantastic. Activity course is a life changer.</i>
<b>689</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Needs to have continuous advise services not just a course then stop and left to fend for ourselves</i>
<b>690</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>They should take into account new ideas and research into the causes of ME/CFS and reflect that new understanding</i>
<b>691</b>	Grantham - Lincolnshire CFS/ME Service	Be adapted to provide different services	<i>They included some of the biomedical evidence in explaining what was wrong. But accompanied that with vague arguments that the brain was misinterpreting a fatigue signal and needed to be retrained by doing or increasing activities whilst feeling unwell as they said the fatigue would continue. They emphasised that you shouldn't lie down during the day as this would worsen sleep problems.</i>
<b>692</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>Support (sometimes) was fantastic but methods did not work</i>

<b>693</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>My appointments are every 3 months, which is not enough to help with the pacing recommended. The clinic is under-resourced so therefore cannot see patients more frequently. More contact with clinicians would make such a difference. Some other points of contact such as specific me/CFS counselling/support or help to access this, would be beneficial. The staff are kind and supportive but are limited in what they can do to help by lack of resources.</i>
<b>694</b>	Essex Chronic Fatigue Service	Be adapted to provide different services	<i>To expand on more services as well as current options</i>
<b>695</b>	Not listed		<i>Sutton clinic no longer there</i>
<b>696</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>Ineffective and inaccurate prognosis &amp; understanding of severe ME and PEM</i>
<b>697</b>	Salford CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Conflicting information on advice given for the condition, for example Pacing &amp; Graded Exercise which can often exacerbate the symptoms.</i>
<b>698</b>	Preston - Lancashire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>As one of the millions who have cfs/me. I think that its 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.</i>
<b>699</b>	Leicester CFS Service	Be closed and a new service rebuilt with patient input	<i>It is worse than useless.</i>
<b>700</b>	Preston - Lancashire CFS/ME Service	Be adapted to provide different services	<i>Keep updated with the research from abroad and apply it</i>
<b>701</b>	Not listed	Continue to provide current services	<i>I attended the Keswick ME clinic. It closed and became the Cumbria PPS Clinic</i>

<b>702</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>Better support with managing CFS/m.e, not give you pointless sessions to attend eg physio.</i>
<b>703</b>	Maidstone - Kent & Medway CFS/ME Service	Continue to provide current services	<i>My OT didn't believe graded exercise therapy helps, but did find pacing the best way to manage the condition.</i>
<b>704</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>They are still promoting graded exercise</i>
<b>705</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be adapted to provide different services	<i>I was put on a very brief, not very helpful short course about ME and immediately discharged back into the hands of my GP upon the course completion. I have not had any help since and I am extremely unwell with no help at all, not even any follow up, care plan or treatment. I am now housebound and in desperate need of help.</i>
<b>706</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because there is a complete lack of understanding of the illness/disease, inappropriate approaches in treatment i.e. GET/CBT, which cause further damage and harm.</i>
<b>707</b>	Birmingham and Solihull CFS Service	Be adapted to provide different services	<i>Their services were all geared towards people with mild ME.</i>
<b>708</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>A gross misunderstanding of the condition and what is required.</i>
<b>709</b>	Stockport CFS/ME Service	Be adapted to provide different services	<i>As the condition affects people in different ways it needs to be adapted and not be a one size fits all.</i>
<b>710</b>	Brighton - Sussex Paediatric CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The present treatment system is completely wrong, doesn't work and is potentially dangerous.</i>

<b>711</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	Be closed and a new service rebuilt with patient input	<i>In my experience you end up feeling let down and almost like it is all in your head. CBT therapy is a condescending therapy for those with CFS/ME</i>
<b>712</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Service already closed.</i>
<b>713</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>The service is excellent! The staff have great approach and understanding. They helped me so much! I just would have wanted more! I would have liked more ongoing support, perhaps a refresher 6m &amp; 12m after the end of the course.</i>
<b>714</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be adapted to provide different services	<i>The clinic I used to attend has had its only consultant reduced to part time. I was discharged as no treatments are currently available</i>
<b>715</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>It's clearly underfunded, and limited in what they can offer by the NICE guidelines. Until there there is proper biomedical research to find effective treatments then what they can offer is limited in its effectiveness.</i>
<b>716</b>	Salford CFS/ME Service	Be adapted to provide different services	<i>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</i>
<b>717</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Waste of resources. Pointless at best. Focus needs to be on biomedical issue.</i>
<b>718</b>	Stockport CFS/ME Service	Continue to provide current services	<i>I found the service excellent help in understanding my diagnosis</i>
<b>719</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be closed and a new service rebuilt with patient input	<i>The consultant showed a total disrespect and misunderstanding of how ME affects me</i>

<b>720</b>	Peterbrough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be adapted to provide different services	<i>To be honest I don't know. When I attended there wasn't really any treatment available just some support, advice on pacing and potential access to CBT. None of these helped me, but I can see that they could be helpful to other patients. What else could they do though, for a condition without so little known about it.</i>
<b>721</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>My clinic only provided talking therapy which in itself was okay but I expected to be able to see a doctor regarding things like meds.</i>
<b>722</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be closed and a new service rebuilt with patient input	<i>There was a checklist but no real help offered regarding all the complex needs I had such as heart problems I experienced, in fact I was told the heart isn't affected! Only thing that was offered was GET/CBT which were both an insult. Follow up appointments/reviews with consultant would be great but again not offered. Absolute failure to ME/CFS patients.</i>
<b>723</b>	Birmingham and Solihull CFS Service	Be closed and a new service rebuilt with patient input	<i>It was all based on CBT &amp; included graded exercise, which is of very little use.</i>
<b>724</b>	Wells - Somerset CFS/ME Service	Be adapted to provide different services	<i>Graded exercise is a terrible thing, causes more harm than good</i>
<b>725</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>To cover ME directly instead of tagging it on to Fibromyalgia and pain clinics</i>
<b>726</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>[Consultant] was amazing. [Clinical psychologist] gives the distinct impression she has no idea what she is talking about, that it's an anxiety disorder and her letter to GP was full of misquotes, inaccuracies and lies.</i>
<b>727</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>First they insist I must be depressed, they depress me but I can manage when I dont see people who depress me. Second I did not receive appropriate tests. Third their only remedy was more exercise or antidepressants - the first sends me to sleep for days, the second I dont need. NO ONE will investigate or treat the high levels of inflammation that mean I fall asleep after trying to undertake much activity.</i>

<b>728</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The staff have no understanding of the disease and promote GET and CBT and the hospital staff said to me ME is a label they give to people with a mental illness.</i>
<b>729</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Nothing helps currently</i>
<b>730</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>I found the ME clinic service to be not fit for purpose.</i>
<b>731</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	Be closed and a new service rebuilt with patient input	<i>The initial work to reduce my activity levels was both good and devastating. However, there was no acceptance that my symptoms were caused by anything other than deconditioning. The physio was unable to accept any information or research from sources other than the department. This failure to accept what I was saying was disgusting, demeaning and ultimately harmful.</i>
<b>732</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>Because it believes in GET and more exercise and this puts me into flares and makes me worse than ever. I feel they still don't understand how I am or how I feel</i>
<b>733</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>The service seemed to work to a prescribed idea that didn't really understand what living with moderately severe ME is like or how it should be treated. I was given 10 CBT sessions, the majority by telephone, and was released from the service despite still having the condition to the same level. The service should be available for as long as a patient has the condition.</i>

<b>734</b>	Malvern - Worcestershire CFS/ME Service	Be adapted to provide different services	<p><i>The staff are very understanding and want to be supportive. The information sessions were ok, they talked about what it is and then how to manage it with pacing. They also encouraged the use of mindfulness. There was a lot that was could also be discussed such as how to deal with the shock of the diagnosis and why it is a lengthy process of receiving a diagnosis, how to deal with the sadness of a long term illness. Facing the reality that it is life changing. What symptoms can be like, including physical and mental health. Discussing options for self management of the illness including hollistic, life style and medication.</i></p> <p><i>After the information sessions they had a group sessions to meet others with CFS/me, this was difficult as our clinic does not have a venue with access they can use. They used a local community room in a coffee shop which was lovely but it was difficult for some because of stairs. It was also fairly negative as people would share about lots of hard stuff they've been through. It felt like perhaps a few of the patients needed to see a counselor or therapist first before the group meetings.</i></p> <p><i>It would also be helpful if the clinic has a list of connections to other professions they can offer locally. Such as counseling services. Nutritional advice. Art therapy. Social groups that are appropriate for CFS/me needs. Massage professionals. Meditation groups. Medication management. Help with filling out forms for benifits and futher benifits advance. Housing support. Suggestions for vocational and vounteering options. Gentle exercise classes. Recommended Apps and websites. Cleaning services. Connection with community support, like help to go shopping and help to get out of the house.</i></p>
<b>735</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Continue to provide current services	<p><i>Much needed info sessions and the wait to have this service should be shortened</i></p>
<b>736</b>	Not listed	Be adapted to provide different services	<p><i>I was sent to a pain management clinic, and their understanding of mecfs was that it was a mental condition!</i></p>

<b>737</b>	York - Yorkshire Fatigue Clinic	Be closed and a new service rebuilt with patient input	<p><i>It is completely unacceptable for patients to become far more ill when undergoing treatment which claims to help them. Treatment should be EVIDENCE BASED.</i></p> <p><i>The treatment I received at Yorkshire Fatigue Clinic was well meaning, kind and perhaps based on their idea of a 'common sense approach', but it was not evidence based and this is not appropriate or adequate.</i></p> <p><i>At the very least, patients should be warned that treatment may make them worse - this is in line with treatments for other illnesses eg. medications carry warnings of side effects, patients are warned of the risks of surgery etc. Patients should be able to make an informed decision of whether to take on the risks of any treatment.</i></p> <p><i>Can you imagine if cancer patients were routinely exposed to non-evidence based experimental treatment they were told would benefit them, and they became far more ill? There would be outrage. But my life has been destroyed by this illness, and my subsequent engagement with so-called treatment - my mum has cancer and has a considerably better quality of life than I do.</i></p> <p><i>Furthermore, this kind of treatment should not be advocated by the NHS. The Yorkshire Fatigue Clinic assess themselves when bidding for funding - how can they possibly be seen as objective or independent?? My own personal experience was never assessed by any third party, or any NHS employee or doctor.</i></p>
<b>738</b>	Birmingham and Solihull CFS Service	Be closed and a new service rebuilt with patient input	<p><i>The whole day was boring. No useful practical information was given and the HCP had no understanding of ME. They were condescending and non genuine.</i></p>
<b>739</b>	Not listed	Be adapted to provide different services	<p><i>It felt like I was being used for information gathering rather than there to be helped.</i></p>
<b>740</b>	Suffolk Specialist ME and CFS Service	Be closed and a new service rebuilt with patient input	<p><i>A new approach is needed, based on current research and with more focus on patients and their experiences. I do not feel patient groups are listened to. In fact I know they are not. Doctors with special interest in M.E should be involved, I've only ever seen O.Ts at the Lowestoft clinic. The current service does nothing at all that actually helps. I see a private practitioner for treatment options.</i></p>

<b>741</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>Because it is not fit for purpose and a lot of patients are being harmed</i>
<b>742</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>I was laughed at by the doctor and told I was the reason I was still ill. I only went once, since then I have paid for private treatment as I have no faith in NHS services for ME. My GP surgery have made things very difficult, it is a constant battle to find basic understanding.</i>

<p><b>743</b></p> <p>Not listed</p>		<p>Be closed and a new service rebuilt with patient input</p>	<p><i>The specialist, psychotherapist or physiotherapist did not read any research out side of the psych field and treated the neuro-immune condition as psychosomatic &amp; deconditioning, which is an incorrect hypothesis not supported by biomedical evidence. The whole system needs a totally different approach. By using a psychosocial approach I got not only ineffective treatment, but treatment that actually harmed me and pushed me into long term disability. Harms are ignored. Other conditions are not ruled out, there is no investigation in to sleep disorders, vitamin deficiencies, gut issues, POTs screening or monitoring of high heart rate, low blood pressure, 2 day cpet, MS ruled out, monitoring PENE. No advice about envelope pacing, diet, sleep, pain management, no help tackling physical issues. Better Thyroid testing.</i></p> <p><i>I went from being able to work part time and having functionality to being completely bedbound, unable to move, listen to music, read, write, use a computer. This lasted years. I'm still housebound and unable to work a decade later! This services are not just useless but harmful. GET/CBT approach destroyed what little functionality I had. It does not work, it harms patients.</i></p> <p><i>I only discovered later when I was able to use a computer again I was not alone. Many patients are harmed and yet the harms are completely ignored, brushed under the carpet. I trusted the NHS, I trusted the doctors did everything they asked of me only to find these treatments are based on shoddy research.</i></p> <p><i>I only started to make improvements after talking to other patients. Envelope pacing, hr pacing, Dietary changes and testing from the optimum health clinic and the advice in Dr Myhills web page on pacing, diet and supplements. Finally after years of bad of advice in the NHS which steadily made me worse and worse, I do believe if I had the correct advice from the likes of Dr Myhill and followed her protocols right from the beginning, the ME would never had got so severe and I may have even recovered.</i></p> <p><i>NICE/ NHS must immediately drop harmful GET/CBT and retrain all doctors with the current scientific understanding of ME cfs. Adopt the ME ICC immediately to stop the great harm to patients and recreate a service that works to improve patient health based on good science that uses objective outcomes. Patients have died due to neglect and mistreatment. Patients have been left severely disabled to neglect and mistreatment. This must end. The current system needs to be torn down and rebuilt. The psychosocial model is defunct and harming patients. This needs to be recognised immediately and a new path taken. Adopting the ME ICC is a good start. First do no harm.</i></p>
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<b>744</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>I had no help or advice at all, it was simply a group telling us what we already know 😞</i>
<b>745</b>	London - Uxbridge - Hillingdon CFS/ME Service	Be adapted to provide different services	<i>They acknowledge that GET is being reviewed but haven't changed the way they encourage patients to pursue it.</i>
<b>746</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>Signposting to other treatment approaches especially functional medicine</i>
<b>747</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>The service offers no medical testing or treatment, but rather lots of rather inept courses about how to pace and keep your mood up.</i>
<b>748</b>	Aylesbury - Buckinghamshire Chronic Pain and Fatigue Management Services	Be closed and a new service rebuilt with patient input	<i>I knew quite a lot about ME when I attended the clinic, (being a private patient of) [the professional], and I did not think explanations at the clinic were very good. Eg, two of us, who had previously been taught pacing, explained it to some of the participants, as they had not understood the clinic teaching. They made incorrect assumptions about how I thought in a session on CBT; and made us do gym activities at the end of the morning, with no advice as to how much we should do. This gym work made my symptoms worse.</i>
<b>749</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Continue to provide current services	<i>Because there's no more money. They need an ME specialist doctor full time. Currently half a day a week. Not sure there are any specialists to recruit.</i>
<b>750</b>	London - Uxbridge - Hillingdon CFS/ME Service	Be adapted to provide different services	<i>I went to the clinic and for the first 5 years didn't receive any useful help apart from the initial diagnosis, disheartened most people would have probably let themselves be discharged but I continued and managed to see a different member of the team (CBT psychologist) after a 2 year waitlist and I found this very beneficial. They definitely need to change their initial approach as I would come away from my appointments feeling upset and more hopeless than I did before until I saw the psychologist and then I felt much better and that I was actually getting help from the service finally.</i>

<b>751</b>	Gillingham - Kent CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Because it is not fit for purpose. I had to wait months in between appointments and when I did have an appointment (when I was well enough to get there, it was quite far for me to travel) the best I got was positive thinking advice. I was told to watch my words and thoughts and to go for walks. At this point I was almost in a wheel chair, I was very unwell and struggling to walk. The M.E. professional was a physical therapist who knew absolutely nothing about the biochemistry of M.E. It was completely worthless to me. Further more it lowered my confidence in my abilities, in my hopes to get medical help and left me in a deep depression feeling that it was hopeless.</i>
<b>752</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>Discharged too quickly</i>
<b>753</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be adapted to provide different services	<i>They did not appear to have any knowledge of any tests which should be made.</i>
<b>754</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be adapted to provide different services	<i>Pain management is a small part, occupational therapy is too. This is an ever moving target, it does not stay the same. It has so many different symptoms not looked at. Total body dryness (everything internal and external) skin, hair eyes, ears, nails, mouth. Gut bacterial overgrowth, memory loss. concentration, locking limbs. Temperatures, Sounds and light sensitivity, sun burns skin instantly. (The list goes on).</i>
<b>755</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	Be closed and a new service rebuilt with patient input	<i>The location in a psych unit - although the trust claim it's not, and the attitude of the staff hiding behind nice guidance claiming they know best is at best negligence. They are not socialists and don't listen to the patient groups. They have caused harm</i>
<b>756</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>Get and cbt need abolishing to give better help</i>
<b>757</b>	Bristol CFS/ME Service for Adults	Continue to provide current services	<i>It's a very good clinic. The woman who runs it is excellent.</i>
<b>758</b>	Stockport CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>to be told to go home and deal with it is not what I expected from a doctor.</i>

<b>759</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>referred again due to much worsening symptoms 3 years ago still waiting! Mainly group pacing sessions offered in past but can't face groups because of extreme depression anxiety caused by CFS/ME</i>
<b>760</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>The clinic was part time and also very hard to get to, a long way from home. A specialist service should be available at a main hospital. I was not happy to have to do a psychological questionnaire beforehand. The only treatment that would have been offered would have been I believe a form of GET which thankfully was ruled out. Therefore all I had was a confirmation of the diagnosis pretty much. The psychologist made a lot of assumptions about me and was very confused because I apparently didn't fit the profile. This clinic was in Llanfairfechan North Wales.</i>
<b>761</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>CFS is not helped by GET. Clinic needs to recognise new research on CFS shows it is not deconditioning perpetuating the illness</i>
<b>762</b>	Essex Chronic Fatigue Service	Be adapted to provide different services	<i>I was offered graded exercise therapy, but it turned into fatigue activity management which was actually more useful as it really helped me to pace properly.</i>
<b>763</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be adapted to provide different services	<i>I needed to consult someone with biomedical knowledge of ME</i>
<b>764</b>	Essex Chronic Fatigue Service	Be adapted to provide different services	<i>Only provided CBT</i>
<b>765</b>	Nottinghamshire PICS CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>It's so old it's a shipping container and they admit they don't know anything about the condition</i>
<b>766</b>		Be adapted to provide different services	<i>Services should be flexible around different patient situations</i>
<b>767</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>I don't think you can understand how the illness impacts your life unless you have experienced the symptoms. The best advice and support I've had is from other sufferers and online support groups</i>

<b>768</b>	Edinburgh - Lothian CFS/ME Service	Continue to provide current services	<i>It's mostly CBT...I saw an ME specialist then a clinical psychologist, they were lovely getting you to talk about things and how you can conserve energy, showing me examples of how my energy gets low and how it takes longer to fill up my energy..they did it with a water bottle, which was good as you could actually imagine the water pouring out and the tiny drips going back in to fill it up, I know what I should be doing, in theory it works but in practice in everyday life it doesn't...we need a cure, which these clinics don't have, through no fault of there's.. they're doing the best they can of a bad job, and if it helps some people then it's better than having nothing</i>
<b>769</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Healthcare professionals have to listen to us. We are shunned and mocked .</i>
<b>770</b>	Birmingham and Solihull CFS Service		<i>I understand that services have changed since I attended</i>
<b>771</b>	Not listed	Be adapted to provide different services	<i>It feels like you're just on a conveyor belt. My marriage broke down and I needed their help and advice but they discharged me for 6 months as "I had enough to deal with". I've now had a major deterioration in the illness. It's 10 months since discharge with no contact from them including me asking them to ring me back. Not helpful at all</i>
<b>772</b>	Not listed	Be adapted to provide different services	<i>The Service I attend is my local NHS Neuro Rehab Service, if the staff had proper training and information on ME they could manage my condition</i>
<b>773</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Stop prescribing GET and CBT</i>
<b>774</b>	Middlesborough - South Tees CFS/ME Service	Be adapted to provide different services	<i>The lady who was working at the clinic at my first appointment was really helpful and really understood ME. It was that one session that helped me a lot. Unfortunately she left and for months there was noone else to see. She was finally replaced by a woman who was worse than useless. Made mistakes in my notes and seemingly knew very little about ME/CFS.</i>
<b>775</b>	Oxfordshire CFS/ME Service	Be adapted to provide different services	<i>There was a very limited number of times you could use the service after you had attended their very short course on managing ME.</i>

<b>776</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>At the moment the treatment is useless</i>
<b>777</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	Continue to provide current services	<i>Very professional</i>
<b>778</b>	Bristol CFS/ME Service for Adults	Continue to provide current services	<i>I doubt any changes would be funded</i>
<b>779</b>	Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service	Be closed and a new service rebuilt with patient input	<i>They were very dismissive of my symptoms. These should have been looked in to further as not all related to ME (dizzy spells, which turned out to be PoTS - the doctor was adamant it was blood pressure related and didn't bother checking to confirm). I think a new clinic is needed as the reputation of the current one will put patients off if it's just updated. It's also not easily accessible unless you have a car.</i>
<b>780</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be closed and a new service rebuilt with patient input	<i>When I discuss my symptoms with my specialist her advice is not relevant nor helpful. For example at times my muscles are overworked so much so that they keep me up at night with what I call fire muscles. Feels like fire &amp; painful pins and needles. This occurs when I have used them more than my body can handle. Her advice was to not watch scary movies, no technology in the bedroom. So my cry for help wasn't listened to &amp; im given 'tick the box' methods which really do not try to tackle or explore the issue.</i>
<b>781</b>	Not listed	Be adapted to provide different services	<i>There is no provision or funding for long term follow-up or monitoring. There is no recognition of M.E. as a long term condition.</i>
<b>782</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>because there are very few MS/CFS consultants. This was at the Sutton hospital and he has now retired. The fact is that the medical profession in the UK have still not accepted MS/CFS as a serious illness</i>
<b>783</b>	Not listed	Be adapted to provide different services	<i>I feel that still recommending GET and CBT are not helpful and are in many cases actually harmful to patients</i>

<b>784</b>	Brighton - Sussex Paediatric CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The service did not have a proper understanding of ME and was providing harmful advice and treatment.</i>
<b>785</b>	Bishop Auckland - Durham & Darlington CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>They follow outdated advice and are unresponsive to your concerns.</i>
<b>786</b>	Not listed	Continue to provide current services	<i>I feel they do their best and give much needed support</i>
<b>787</b>	Exeter, East, Mid and North Devon CFS/ME Service	Continue to provide current services	<i>Helped me come to terms with the illness and ways to manage it</i>
<b>788</b>	Birmingham and Solihull CFS Service	Be closed and a new service rebuilt with patient input	<i>The service is based in mental health services and deeply embedded in the biopsychosocial view - it isn't a psychological condition so it isn't appropriate or useful and the services view of the cause of the illness and it's treatment are unsalvageable. The staff were arrogant and dismissive of patient experience or any view or evidence that contradicted their own. They were inflexible in approach by design and blamed patients for their own symptoms and lack of improvement.</i>
<b>789</b>	Not listed	Be adapted to provide different services	<i>The course wasn't structured right.</i>
<b>790</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>I attended a few talks in a group scenario. I then was asked to attend meetings where I was expected to provide a plan to go forward - this without warning. I was told I would need to attend a monthly meeting for a short period with fellow patients. I never heard anything about location or dates. I could not get a response from the clinic. I've had no interaction/contact for two years. I am on my own with this.</i>
<b>791</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be adapted to provide different services	<i>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. I often wasn't well enough to attend so I feel that home visits or video calls would initially have been helpful.</i>

<b>792</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Sutton Hospital is closing and the consultant, who was an immunologist, has retired. My GP would not refer me to a proper ME/CFS clinic. The Nelson Medical Centre SW20 does not appear to believe in ME. I have felt totally unsupported. I am moving to another surgery. GP's are not interested in helping and we should have surgeries that are not small minded and just interested in making money.</i>
<b>793</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>Most healthcare professionals under Bath clinic are physiologists and so can't understand people who are physically sick. No input from patients who know ME more than doctors can when they live with it. No help with symptoms and no investigation into over co-existing possible conditions like POTS. I was left 2 and a half years with extreme knee pain and very obvious symptoms for dysautonomia and no help from Bath or my consultant with this.</i>
<b>794</b>	Not listed	Be adapted to provide different services	<i>The OT was excellent in her knowledge &amp; understanding but the program was 2hrs long with a comfort break in between for 8wks. While this might be the best use of the OT's time to deliver the program it is detrimental to the health of the majority of ME patients who attend. It is too long and each week causes patients to relapse only in time yo recover for the next week. The OT knew I wanted to meet other ME patients but didn't suggest I might not be well enough to attend. I was housebound &amp; deteriorating before I went to the first session. I totally crashed after it and have been 100% bedbound since which is 6mths ago.</i>
<b>795</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>After being unsuccessfully treated for hypothyroidism It took me 8 years of visits to my GP to gain a diagnosis - which meant there was no treatment other than mindfulness and pacing to cope with an illness that is treatable.</i>
<b>796</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>I am housebound and treatment was refused as I could not physically attend the service. This enables the most gravely ill to be left with so support when they need it the most. This would be shameful with any other condition where as this is deemed to be okay with ME/CFS. I am disgusted and afraid that it has effected my life so badly and I have had no support at all.</i>
<b>797</b>	Leicester CFS Service	Be adapted to provide different services	<i>Too broad a spectrum of people attending clinic</i>

<b>798</b>	Plymouth Sentinel CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The offer me diet advice and to attend a self help group</i>
<b>799</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>My clinic advocate CBT and GET which is so detrimental. They dont offer a counselling service and their waiting lists for services are ridiculously long.</i>
<b>800</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>The advice was extremely basic to the point it was almost insulting</i>
<b>801</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Continue to provide current services	<i>They worked around my needs and supported me</i>
<b>802</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>I was given the impression that there was nothing they could do for me.</i>
<b>803</b>	Not listed	Be adapted to provide different services	<i>Research has improved since 2012 into cfs/me</i>

<p><b>804</b></p>	<p>Not listed</p>	<p>Be adapted to provide different services</p>	<p><i>Firstly, I have to remember back to how grateful I am for what I received at the time when no one else could provide answers or compassionate support. The staff were absolutely committed.</i></p> <p><i>Some things have moved on but services in some other countries seem to offer more alternatives to CBT and GET.</i></p> <p><i>See <a href="https://youtu.be/KuIRDzUDO3o">https://youtu.be/KuIRDzUDO3o</a> for example.</i></p> <p><i>A far greater holistic balance. When I listen to this presentation for example I don't feel I want to blame myself, the latter being one of the most demoralising and damaging feelings we can be made to feel.</i></p> <p><i>Those professionals who are always in the course and remedy lying in the psychological only camp usually because of their own beliefs and I have to say preconceived and prejudiced ideas about CFS M.E are the most damaging. This includes those who apportion making the patient feels it's their fault. The word functional is often used and poorly explained by clinical staff outside the specialist service.</i></p> <p><i>What went wrong for me was the limited ongoing support and access to doctors, the CBT message of pushing through which was playing like a destructive script in my head which reinforced a cycle of push and failure, push and failure. My self esteem was in tatters and it added a layer of stress on top. I know there are private services stating I recovered and so on yet this is isn't always possible for some I conclude. I'm certainly not lazy, I just can't do it.</i></p> <p><i>Additionally, given the sheer exhaustion and other symptoms I was feeling at the time, I have never experienced so much paperwork, recording and mental processing in any other medical condition than I experienced in this treatment programme.</i></p> <p><i>This said, I realise how difficult it is to try to t a condition that it is difficult to fully understand.</i></p>
<p><b>805</b></p>	<p>Suffolk Specialist ME and CFS Service</p>	<p>Be closed and a new service rebuilt with patient input</p>	<p><i>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</i></p>
<p><b>806</b></p>	<p>Exeter, East, Mid and North Devon CFS/ME Service</p>	<p>Continue to provide current services</p>	<p><i>Continued support</i></p>

<b>807</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>I felt the onus was upon me to keep increasing activity - having been encouraged to do GET regime - I attempted to do this for over a year &amp; felt a failure when it was impossible to increase activity without crashing &amp; was unable to find a balance. Group CBT &amp; Pacing was very helpful - I learned a lot from others sharing their experience &amp; just meeting others who were going through the same illness. It was always therapists that were seen never a doctor- didn't feel like a multi disciplinary team just an individuals approach.</i>
<b>808</b>	Edinburgh - Lothian CFS/ME Service	Be adapted to provide different services	<i>The service was based on management of health with use of cbt and psychological services it did not address the physical symptoms of my illness</i>
<b>809</b>	Leicester CFS Service	Be closed and a new service rebuilt with patient input	<i>There not suffering through ignorance and every case is different x</i>
<b>810</b>	Preston - Lancashire CFS/ME Service	Be adapted to provide different services	<i>NICE current guidelines do not work regarding GET and CBT as it is based on M.E being psychological illness. I believe it not to be as I am usually a positive person and before I became ill I was highly active.</i>
<b>811</b>	Birmingham and Solihull CFS Service	Be adapted to provide different services	<i>I saw a head doctor, ME is not a mental illness</i>
<b>812</b>	Essex Chronic Fatigue Service	Be adapted to provide different services	<i>My needs are met by the service. I have attended acupuncture privately and would like the treatment to be included in my healthcare plan.</i>

<b>813</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be adapted to provide different services	<p><i>Post diagnosis of ME, the clinic offered a useful weekly group session for learning how better to self manage ME. However, when this finished, there was no follow up support and you are referred back to care of the GP. The GP has no training/treatment options/resources for this, so you are effectively abandoned. All they do now is to see me every three months to provide a fit note so that I can claim benefits, as I am unable to work following a substantial relapse last year. There is no ongoing support provision within healthcare services. This is one issue, but a second and indeed fundamental issue for me was the inability of the healthcare system to be able to identify ME. I spent five years returning to GP surgeries with the same symptoms, but a referral to a specialist ME service for assessment was not progressed. I underwent multiple tests on each occasion and was given varying advice eg 'go away and rest, stop worrying and take up a hobby' etc, with the GP assuming that my problem was psychosomatic as the tests were persistently negative. I was belittled and ignored due to such ignorance. I was referred to cardiac and gastro specialists (due to symptoms associated with ME) and despite again stating all of my symptoms, they did not consider ME at any stage, despite a clear set of primary and secondary symptoms being present. It was only after a friend informed me of ME and its associated symptoms that I looked into this and requested a referral to the area specialist ME service for assessment. Even then the GP was reluctant, despite me presenting with most of the ME symptoms and tried to dissuade me. I attended the specialist service for assessment and was diagnosed with ME, five years after originally approaching healthcare services with these symptoms.</i></p> <p><i>In summarising, generic healthcare services fail to identify the core ME symptoms and then to refer onto specialist services for assessment. The specialist service provided a good coping mechanisms course to help to reduce the impact of the disability, but then returned us to the care of the GP where support services do not exist. Hidden, forgotten, ignored, fobbed off.</i></p>
<b>814</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<p><i>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.</i></p>
<b>815</b>	Shrewsbury - Shropshire Community Neuro Rehabilitation Team	Continue to provide current services	<p><i>Pace was the main focus, yes it's hard, yes it hurts but it works in the long run.</i></p>
<b>816</b>	Nuneaton - Warwickshire CFS Service	Be adapted to provide different services	<p><i>Services are needed, partially it was underfunded &amp; rushed. Partially the Dr i saw had a rigid view which justified the Graded Exercise NICE approach &amp; the clinic didnt allow time to discuss my experiences.</i></p>

<b>817</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>Waste of time and energy and too long to wait</i>
<b>818</b>	Gillingham - Kent CFS/ME Service	Continue to provide current services	<i>As little is known about the illness, I felt that they did the best they could with what is known.</i>
<b>819</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>I think the clinic really has a lot of potential but the waiting times are extremely long, even after you get seen you wait months/year for any specialised services which is not helpful. I also think they should offer more therapies, more acupuncture, oxygen therapy, etc.</i>
<b>820</b>	Not listed	Be adapted to provide different services	<i>Answer is academic as service (East London) is now closed</i>
<b>821</b>	Bolton - Bury and Bolton CFS/ME Clinic	Be adapted to provide different services	<i>I attended fortnightly meetings but you are discharged if you miss 2 appts. Considering my diagnosis this doesn't work well.</i>
<b>822</b>	Middlesborough - South Tees CFS/ME Service	Be adapted to provide different services	<i>Waiting times too long. Needs a revamp. Not as helpful as i had hoped.</i>
<b>823</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>needs to have a biomedical thread alongside experience of quality of life approaches</i>
<b>824</b>	Leeds and West Yorkshire CFS/ME Service	Continue to provide current services	<i>Because the service is good and needed</i>
<b>825</b>	Nuneaton - Warwickshire CFS Service	Be adapted to provide different services	<i>When visiting. I felt although nothing was achieved. I felt like something was missing but because my foggy mind I cant remember much.</i>
<b>826</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>As my clinic wasn't just for ME/CFS it a basic Holistic clinic which offers day services.</i>

<b>827</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>I went to Bart's and the Royal London service. Took the view it was deconditioning, primary focus on physio, graded exercise and psychological assessment/sessions. I wasn't properly listened to. Ignored fact I had continuing symptoms of original infection. Didn't run many blood tests other than bog standard ones. I was treated as a personality type, rather than as someone very ill physically. The neck spasms and pain was helped a little by an exceptional nurse who gave me extra acupuncture sessions and believed I was physically ill. My partner was sent out of the room at one point while the doctors and head physio purported to examine the rash on the back of my neck that I reported I was repeatedly suffering since falling ill. This rash was glossed over. I have recently received news that I have a very high level of auto antibodies to part of my immune system and am awaiting a return appointment to a rheumatologist to discuss this .</i>
<b>828</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	Be adapted to provide different services	<i>Ultimately the focus of these services at the time, and to an extent is still now from others who have been through the Peterborough clinic much more recently I have spoken with, is on CBT and graded exercise, rather than a sensible framework that helps with understanding and learning to manage your own condition where possible. It also doesn't look at any under lying causes or contributing health factors, either those already investigated or those that may yet to be investigated or could be unknown. The service was new when I visited some 18 years ago and has improved greatly, but is still focusing on things that often hinder recovery, and do not help people learn to manage their condition as effectively as possible.</i>
<b>829</b>	Fareham - South Coast Fatigue	Be adapted to provide different services	<i>Have more centres which are more locally. Give longer courses</i>
<b>830</b>	Not listed	Be adapted to provide different services	<i>Was more of a chat and saying nothing we can do( at time I was unable to walk,swallow or talk well)</i>
<b>831</b>	Shrewsbury - Shropshire Community Neuro Rehabilitation Team	Be adapted to provide different services	<i>NICE guidelines need to change</i>

<b>832</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be adapted to provide different services	<i>The general information provided is adequate but more up to date information and personalised input is required. It also needs to be more accessible. Two hours of group therapy a week is not suitable nor accessible for everyone, and is not personalised to support individuals. Repeated recommendations of Graded Exercise were made with no mention of risks and studies that have disproved it.</i>
<b>833</b>	Nottinghamshire PICS CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>the clinician was patronising and ill-informed on the condition.</i>
<b>834</b>	Oxfordshire CFS/ME Service	Be adapted to provide different services	<i>As, I was referred to the clinic, it made me feel, the doctor , knew I was very ill. I would of liked to have been referred as , soon as I became ill. Not years afterwards. I only got to know aboutThe clinic from my local M.E group. It would of been good if the doctor, had informed meThe distance, was a track for me, 60 mile round journey, hubby had to take time off work to take me. The nurse told me I had to walk more &amp; exercise more, even if I felt worse. My husband, hearing, this used to push me, to walk, as he was told by a health professional, this was how I would get better, it made me worse,plus the stress of trying to 're educate him, made me worse, as he bel strongly, I would be better, if I just exercised more. I ended up with a six month relaspe.</i>
<b>835</b>	Hull and East Yorkshire CFS Service	Continue to provide current services	<i>MY THERAPIST IS UNDERSTANDING AND HELPFUL</i>
<b>836</b>	Not listed	Be adapted to provide different services	<i>some aspects of the service (e.g. occupational therapy) are very useful when applied correctly, but change needs to be made in other areas in light of new information</i>
<b>837</b>	Peterbrough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be adapted to provide different services	<i>The condition is not researched enough. So much is being done to try and "fix" the patient's mentality towards the condition when no professional you see ever has a clue WHY this is happening to you.</i>
<b>838</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>They are still working with a very outdated psychological approach</i>

<b>839</b>	Essex Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>The ME Clinic I attended was damaging, both physically and mentally, and I would go as far to say abusive too!</i>
<b>840</b>	Not listed	Continue to provide current services	<i>They had good advice about pacing, but otherwise could not provide much support. Good for someone new to the disease, not so much for someone who has been ill for decades.</i>
<b>841</b>	Dorchester - Dorset Children and Young People's Chronic Fatigue Service	Be adapted to provide different services	<i>Wareham Hospital Clinic. More should be offered than CBT</i>
<b>842</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Continue to provide current services	<i>My cfs doesn't follow conventional patterns due to other issues that sometimes conflicted with advice. So although clinic couldn't help completely it offers a good service</i>
<b>843</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>At the time they were advising exercise as treatment for ME, which has been proven to be totally inappropriate if not harmful to patients with ME. It is important for professionals to listen to patients' experiences and difficulties whilst suffering around ME and built a service around that.</i>
<b>844</b>	Not listed	Be adapted to provide different services	<i>All that is currently offered is advice on pacing. Some other treatment options would be appreciated</i>
<b>845</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	Be adapted to provide different services	<i>I don't think the service can be all that is available for sufferers, so much more needs to be done to help those living with this hurrendous disease</i>
<b>846</b>	Not listed	Continue to provide current services	<i>Belfast, was closed due to funding</i>

<b>847</b>	Birmingham and Solihull CFS Service	Be closed and a new service rebuilt with patient input	<i>I only attended once and they said I didn't need to attend again. They showed no understanding of the disease and it was mainly a waste of time. However my local support group have held meetings with people from the clinic after many patient's were reporting problems with the clinic. The clinic has denied these problems and the understanding shown by the people representing the clinic was woeful. I also consider it highly inappropriate that the clinic is based in the Psychiatry section and run by a psychiatrist because ME is classed as neurological and the Dr had no knowledge, ability or interest in my symptoms (myoclonic jerks, POTS etc) that could have been treated by someone in the correct field.</i>
<b>848</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>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</i>
<b>849</b>		Be closed and a new service rebuilt with patient input	<i>The service is basically non functional at the moment due to lack of staff (apparently). GET was the only option for treatment and it caused me more harm than good.</i>
<b>850</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be adapted to provide different services	<i>I never saw a consultant, never had the chance to ask questions. I am currently in the middle of a fatigue management course. It was made clear that this was the only service on offer, and if I declined I would receive no help at all.</i>
<b>851</b>	Liverpool Children's CFS/ME service	Be closed and a new service rebuilt with patient input	<i>Felt bullied, humiliated, disbelieved</i>
<b>852</b>	Sunderland - South of Tyne CFS Service	Be adapted to provide different services	<i>I was offered CBT &amp; PACE which didn't change anything as I couldn't stick to advice</i>
<b>853</b>	Dunstable - Bedfordshire Chronic Fatigue Service	Be adapted to provide different services	<i>Other than CBT and GET there is nothing offered of any substance to help with the many symptoms of ME, e.g. sleep disturbance, pain management, etc</i>
<b>854</b>	London - Uxbridge - Hillingdon CFS/ME Service	Be adapted to provide different services	<i>There needs to be one to one treatment with a physio who can help you set a realistic baseline. Group therapy does not work.</i>

<b>855</b>	Not listed	Continue to provide current services	<i>The service I receive is important in understanding my condition.</i>
<b>856</b>	Not listed	Be adapted to provide different services	<i>As advice given but no treatment</i>
<b>857</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>Needs to remain open to support kids through school years. Needs to adapt to individuals rather than sheepdip approach</i>
<b>858</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>Too much emphasis on CBT and GET at not physiological reasons.</i>
<b>859</b>	Suffolk Specialist ME and CFS Service	Be closed and a new service rebuilt with patient input	<i>The staff were arrogant, gave contradictory advice and were sure that their way was the only way, even when confronted with evidence to the contrary. Their offering was extremely narrow, and completely inflexible. They were absolutely convinced that I had a mental health issue, and refused to contemplate anything else, despite being told that I had, in the past, had extensive experience of depression, and that this was not depression related.</i>
<b>860</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>It wasn't really for cfs/me sufferers. It was a rehabilitation clinic for stroke/brain injuries.</i>
<b>861</b>	Hull and East Yorkshire CFS Service	Continue to provide current services	<i>Having professionals that understand the need for help is life savings when you can feel all alone .</i>
<b>862</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Accused of Fii</i>
<b>863</b>	Sunderland - South of Tyne CFS Service	Be closed and a new service rebuilt with patient input	<i>No Dr or nurse only psychologist physio only mental health help not physical ie pain management no help with benefits as psychologist input only and gp will not write support with benefits. Need a person knowledgeable with your history to support benefit applications and renewals</i>

<b>864</b>	Newcastle - North of Tyne CFS/ME Service	Be adapted to provide different services	<i>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.</i>
<b>865</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>We need new staff with biomedical training whose mindset is not coloured by a psychosomatic view of M.e and who use strict M.e diagnostic criteria so as not to conflate M.e with depression-related 'tiredness'. We will then have a service that has a proper understanding of our illness and therefore not use the harmful 'treatments' of G.e.T and the potentially harmful form of coercive CBT.</i>
<b>866</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>More patient knowledge should be taken on board</i>
<b>867</b>	Not listed	Be closed and a new service rebuilt with patient input	<p><i>In the clinic I attended, quality of life did not seem to be important. I was told to decrease my physical activity with no concern for my mental health whatsoever. When I went with new symptoms, the clinicians didn't seem to be interested and told me to go to A+E if I was concerned. I also asked for CBT or something similar to help me come to terms with, and manage the diagnosis- they told me this wasn't offered for M.E. despite it being advised I the guidelines.</i></p> <p><i>I was discharged from the service and I am still unwell, I manage but I am very dissatisfied with the care I've received. PPI is such an important aspect of any research and service planning- whether the service is closed and rebuilt, or whether the services are adapted- we need research that is built on patient input and experiences to find out what they need help with, how they can be best supported, what they think is missing from current services.</i></p> <p><i>A collaborative approach between practitioners and patients is so important for any chronic illness, particularly where there isn't a cure or known cause. People with ME/CFS need to feel supported not abandoned- facilitating patient/professional collaborative care might be a way to start to change this</i></p>
<b>868</b>	Private clinic	Continue to provide current services	<i>More access to services are needed. The private clinics are swamped.</i>

<b>869</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Clinic didn't do any healthcare checks or even discuss symptoms. Seemed to consist of physio I couldn't do as too severe and 'mindfulness' and breathing techniques. I was having seizures for heaven's sake!</i>
<b>870</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be adapted to provide different services	<i>I think a holistic approach to ME/CFS is required where practitioners look at the individual in terms of what their needs are based on their levels of activity, diet, mental and spiritual health. Telling someone to give up all exercise completely is detrimental in terms of this illness so is making a person over exhort themselves. Helping individuals to find their baseline and work from there is a better approach as is including all other areas and aspects of their life. Preparing the person for a lifestyle change and offering help regarding this. Toby Morrison and Dr Sarah Myhill are good examples of how to approach working with ME/CFS patients. It requires an all rounded holistic approach with GP's being educated on the disease and other medical professional staff. Working with ME/CFS action groups should be a must as is more funding.</i>
<b>871</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>I was given CBT. I was not listened to and in the end I did better managing it without medical help</i>
<b>872</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Continue to provide current services	<i>Excellent service probably saved my life</i>
<b>873</b>	Newcastle - North of Tyne CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I attended [the professional's] infectious disease clinic in the 1990s, I have no idea if it is still going, they didn't know much about ME. From what I hear specific ME clinic's are even worse because they are based on a pschological version of ME and/or have virtually zero doctor input anyway.</i>
<b>874</b>	Sunderland - South of Tyne CFS Service	Be closed and a new service rebuilt with patient input	<i>Patients know their bodies better than anyone</i>
<b>875</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I waited 18 months to go back to see a therapist even though I've been under the M.E. consultant for 5 then they forgot abt me for a years even tho I was ringing them weekly begging them for help</i>

<p><b>876</b></p>	<p>Aylesbury - Buckinghamshire Chronic Pain and Fatigue Management Services</p>	<p>Be closed and a new service rebuilt with patient input</p>	<p><i>They have no idea. They said that my mum was causing my tiredness by making me horse ride when in fact I would ride when I felt up to it as it was my only "treat" in life at that time. I lived to ride once a week but they would keep making it out my mum was the baddie so I lied to them and said I felt 100% better on the program to get them off my mums case. In hindsight it was the worst thing to do as now my data will be used as a success story for them, when in actual fact I was no "better". The way they treated us was by making it out to be in our head, every week we would have to do an extra 5 mins of walking, to push ourselves. It was ridiculous and extremely damaging.</i></p>
<p><b>877</b></p>	<p>London - King's College London and South London &amp; Maudsley Persistent Physical Symptoms Research and Treatment Unit</p>	<p>Be closed and a new service rebuilt with patient input</p>	<p><i>The service was not fit for purpose:</i></p> <ul style="list-style-type: none"> <li>• <i>poor record keeping (a draft report stated I had several diagnosis, both physical and mental, which were nothing to do with me and must have related to another patient);</i></li> <li>• <i>inappropriate time boundaries for someone fatigued (1:1 sessions varied randomly from 90 to 120 mins) ;</i></li> <li>• <i>the service was delivered according to a plan or hypothesis about the illness, it's cause and continuation which did not relate to my circumstances,</i></li> <li>• <i>reports were made from pre-prepared drop-down menus (the excuse made by the therapist for inaccuracies) &amp; were not tailored or responsive to my situation &amp; responses.</i></li> <li>• <i>The therapist said 'people worth your ... erm ... condition' but refused to explain what that meant, or give details of the theory of the illness, it's cause &amp; why the particular treatment was offered.</i></li> <li>• <i>The therapist stated that they were a specialist CBT trainer as well as a specialist practitioner in this clinic and private practice at The Priory.</i></li> </ul> <p><i>Serious omissions were made: I was not told of Heart Rate monitoring, or cautioned as to the danger of exercise. I was positively encouraged to walk quickly between every third lamp post to gain energy &amp; strength. In fact this contributed to a severe &amp; long lasting relapse.</i></p> <ul style="list-style-type: none"> <li>• <i>When I raised issues or concerns, this was treated instead as a 'therapy session' rather than eg seriously understanding and responding to my concerns, offering an alternative practitioner or indeed the opportunity to speak to a manger.</i></li> <li>• <i>The Service felt manipulative and that anything I said would be twisted to fit a particular narrative, rather than honour my experience and understanding. Given the vast amounts of</i></li> </ul>

			<i>paperwork I had completed (and I am not sure was actually read or appropriately or quickly reviewed before session) I felt it was an exercise in futility.</i>
<b>878</b>	Bath Centre for Fatigue Services	Be closed and a new service rebuilt with patient input	<i>I attended the clinic while severely ill. My level of illness made me bedbound/horizontal 23 hours a day, but the clinic wanted me to sit up for 6 hours per day. They said I seemed healthier than I said I was. I told them that exertion made me sicker and they said that actually, exertion could cure me. There was almost nothing redeemable about this clinic.</i>
<b>879</b>	Torquay - Torbay and South Devon CFS/ME	Be adapted to provide different services	<i>Due to my ME/CFS being severe and that I was housebound at the time and now bedbound they couldn't do anything for me due to lack of funding preventing home visits apart from diagnosis, so they discharged me.</i>
<b>880</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I was an inpatient many many years ago and the ward I was on was a psychiatric ward ,also there was one admission where I was with people who had eating disorders</i>
<b>881</b>	Sunderland - South of Tyne CFS Service	Be adapted to provide different services	<i>I was very ill and instead of having the option of the professionals coming to my home. I had to travel to them. When you can barely stand, and are sleeping up to 22 hours a day. I think they should come to you</i>
<b>882</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>There is no specialist medical advice to manage symptoms, only physio advice on pacing</i>
<b>883</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Specialist medical services for management of symptoms and related conditions eg MCAS, POTS</i>
<b>884</b>	Birmingham and Solihull CFS Service	Be closed and a new service rebuilt with patient input	<i>I think a whole new perspective on ME as a biological illness. We need bio research so the clinic should be taking a proper health history, a proper list of all symptoms, tissue samples, blood tests, properly trained consultants, properly trained nurse etc. Real progress on re-education all staff and Gp especially on ME as a bio illness. A cure focused service not just a plattuide service with mindfulness</i>
<b>885</b>	Newcastle - North of Tyne CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The current offerings are not fit for purpose. Whilst cognitive behavioural therapy can be beneficial to anyone, sick or not, it should not be at the top of services offered to manage such a multi systemic illness such as ME. The Graded excersise is in my eyes abusive to such vulnerable patients. We need need more physical medicine rather than psychological.</i>

<b>886</b>	Bath Centre for Fatigue Services	Be closed and a new service rebuilt with patient input	<i>Still treating according to NICE current guidelines, following which made me much worse. This time all I wanted was support with return to work. Only had phone appointments with OT. My condition only improved (I'm still sick, not quite so sick as I was) because I followed Dr Myhill's protocol. No treatment from Bath, just tried to force CBT on me. I was too sick for GET!</i>
<b>887</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>More individualized... less waiting times</i>
<b>888</b>	Bath Centre for Fatigue Services	Be adapted to provide different services	<i>After the 6 week course we were just 'signed off and out of the Bath CFS unit '. No other help offered, no further advice. I guess because they don't know how to help really. Mental health is a huge issue with all of us as there is no help, no cure, no real knowledge. Ongoing mental health counselling sessions should be offered if there is nothing else they can do to help!!!</i>
<b>889</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be closed and a new service rebuilt with patient input	<i>The clinic was there for my mental health rather than for ME. If the service is there for ME. It needs to be completely re designed using all information available, not just what's cheapest. Nothing discussed has actually helped my ME or relapses.</i>
<b>890</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>The clinic means well but it felt like a data gathering exercise rather than any real help. The pacing talks were drawn out, tiring and unnecessarily long.</i>
<b>891</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be closed and a new service rebuilt with patient input	<i>Totally irrelevant help offered, hospital was miles away and I was unable to get there for many of my appointments</i>
<b>892</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>They meant well but were shackled by NICE guidelines</i>
<b>893</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>Psychological basis for previous input...and pace....not suitable for me and caused much distress. Needs clinicians that don't follow this rubbish</i>
<b>894</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>It's not always possible to attend the appointment</i>

<b>895</b>	Not listed	Be adapted to provide different services	<i>I am often unable to attend appointments due to being too unwell. Support should be available when you don't have the ability to leave the house. I have been able to attend the appointments after months of trying but it would have helped had I have been seen whilst bed bound.</i>
<b>896</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	Be adapted to provide different services	<i>Not everyone's experience of ME is the same and their needs don't fit in one box</i>
<b>897</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be closed and a new service rebuilt with patient input	<i>Because from my experience patient vary so much and seem to know more</i>
<b>898</b>	Bath Centre for Fatigue Services	Be adapted to provide different services	<i>I attended the clinic before CBT/GET was introduced. I received good advice on pacing and ACT (Acceptance and Commitment therapy). If they're now offering GET it should be stopped.</i>
<b>899</b>	Middlesborough - South Tees CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>It might have changed in the last 8 years so difficult to say</i>
<b>900</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>The only recommended treatment for me was graded exercise and CBT. There is far more that could be offered. Such as dietary plans, physical therapy, emotional support, guidance on things that can make the condition worse.</i>
<b>901</b>	Sunderland - South of Tyne Paediatric CFS Service	Be adapted to provide different services	<i>Need better awareness training</i>
<b>902</b>	Not listed	Be adapted to provide different services	<i>Graded exercise therapy was used I feel that did me great harm previously so I refused it get need to be banned in my opinion</i>

<b>903</b>	London - University College Hospitals Children and young people's specialist adolescent services	Be adapted to provide different services	<i>Travel to London caused PEM and this seemed pointless as there was no real treatment given when I got there. Advice given on reversing sleep reversal proved impossible to follow and trying to follow it made me much worse. I was made to feel as if this was my fault; my mother was also made to feel as if it was her fault. Trying to increase activity had the same effect and again we were made to feel it was our fault. There were no local services available other than a physio and I rapidly became much too ill to engage with him and was discharged. The clinic were good at providing letters for school only.</i>
<b>904</b>	Newcastle - North of Tyne CFS/ME Service	Be adapted to provide different services	<i>Staff showed more understanding and tried within the knowledge available to give appropriate services. Manager believed CFS was fully psychological which combined with NICE guidelines meant services were heavily weighted to thinking yourself better and pushing yourself physically. With different guidelines and management staff can deliver appropriate services</i>
<b>905</b>	Brighton - Sussex Paediatric CFS/ME Service	Be adapted to provide different services	<i>It was very vague and unspecific. Mostly I was taught about pacing and nothing else.</i>
<b>906</b>	Portsmouth Chronic Fatigue Syndrome Service	Be adapted to provide different services	<i>I already knew most of the information offered as I had had the illness for 13 years by the time I was referred (I was 24) so the service could offer nothing for someone who had experience, it was all for people new to the illness. As they could not offer me any courses I was discharged and sent back to my doctor, no ongoing support was offered. I had improved somewhat and this was enough for the clinic, but with a variable illness this improvement was temporary, more to do with the time of year than the clinic itself</i>
<b>907</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>It was a while ago I attended and it was more like therapy then. Basically saying it's in my head. They did however give me information on pacing which was very helpful.</i>
<b>908</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>It should continue with what it's currently providing but also sign post other areas of support going forwards in addition to the GP once you're discharged from the service.</i>
<b>909</b>	Plymouth Sentinel CFS/ME Service	Continue to provide current services	<i>The service is very informative and provides a safe environment to share experiences with others who have the same diagnosis for</i>

910	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>I have a 70 mile round trip to attend which sets me back for days afterwards ironic really! It's the only help on offer for my geographic area.</i>
911	Not listed	Be adapted to provide different services	<i>The staff Manchester clinic at Delauneys Hospital knew less than I did re: latest research , causes etc and gave me no advice that I hadn't already been following for years. However, for patients who know nothing their input would probably be useful.</i>
912	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>It is essential that a paediatric service stays open for those in the SW however [the professional at Bath Specialist Paediatric CFS/ME Treatment Service] approach should be shut down. It was pushy, highly degrading, harmful and ineffective. Her 'mind over matter' &amp; 'training the brain to believe you're not in pain' therefore telling children that they can control and overcome their physical illness with mindful thoughts not only didn't work, it cost me my teenage years and (because the team would not take my. They withdrew me from the service with no explanation but my mum &amp; I believe it's because I stood up for myself, questioned their techniques, refused to nod my head in agreement and proved to them that CBT/GET didn't work. Their outpatient program made me much worse- resulting in collapses, paralysis and ignored GI/nutritional &amp; heart issues that gradually deteriorated &amp; almost cost me my life. They advised me to attend their 'rehabilitation' program which would "be fun.. successful and a great opportunity to make friends" on an impatient basis . It was made out to be like some kind of summer camp, where the parents aren't allowed contact for most of the day unless a session on the strict timetable said so but it was more like the opportunity to speak to &amp; psychoanalyse the patients without their guardian(s) being there whilst attempting to distract kids from their illness with interactive party like games with rewards for those that cooperate. (one hour off the timetable was one example). They said they would offer family sessions at the weekend too. But they seemed to have missed the memo... I couldn't even manage 2 hours at school or ANY physical activity without crashing or relapsing. I loved school and was a dancer/athlete and had to drop out of clubs &amp; classes. Yet the team expected me to attend a 9-5 course-6 day week- and said I'd have to climb a flight of stairs every time I needed to access the room they would set my mum &amp; me up in for free if we agreed. I declined. They refused to see me again, did not refer me elsewhere; leaving that job to my GP's which had/still have little to no understanding of ME. This service should be restructured with patient input: from both those who require the service (under 16's) and those who have previously attended this program (over 18's) so it can be rebuilt from those newly diagnosed- those who (like me) initially believed Bath Clinic was helpful as that's the only help they've had</i>

			<i>access too, whilst taking the perspective on those who have had experience- people who have been sick for 3+ years or have witnessed polar opposite sides of what I call the 'ME Management spectrum'.</i>
<b>913</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	Be adapted to provide different services	<i>They need to provide advice on symptom management. I have a lot of scary symptoms, that I would be more accepting of if I understood why and how they were happening. I'm just left to deal with them.</i>
<b>914</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>They use outdated information which had a negative impact on me and discharged me when they felt they could no longer help me.</i>
<b>915</b>	Not listed	Be adapted to provide different services	<i>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.</i>
<b>916</b>	London - Uxbridge - Hillingdon CFS/ME Service	Be adapted to provide different services	<i>It should be adapted as there is only a focus on cbt, the service doesn't focus on neurological/physical illness. Also the cbt sessions are limited and are limited in what is addressed.</i>
<b>917</b>	Norfolk and Suffolk ME/CFS Service	Continue to provide current services	<i>In my experience, the Norfolk and Suffolk ME/CFS Service provides an excellent and appropriate service and should continue to provide current services. It's resources are extremely stretched, however. I would like to see it provide more services, including consultant input, of which is none, and see patients more regularly.</i>
<b>918</b>	Newcastle - North of Tyne CFS/ME Service	Continue to provide current services	<i>The physiotherapist has been replaced.excellent reports of new physio</i>
<b>919</b>	York - Yorkshire Fatigue Clinic	Be closed and a new service rebuilt with patient input	<i>there were no physiological treatment or tests. No test for POTS.</i>
<b>920</b>	Bishop Aukland - Durham & Darlington CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>It was as if the "professional" was reciting a script. Not one box fits all!!!</i>
<b>921</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Continue to provide current services	<i>I was almost suicidal beforehand. I understood what I was facing and learnt strategies to cope. It's still not easy and it is ruining my life.</i>

<b>922</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>Adapted to individuals needs</i>
<b>923</b>	Dunstable - Bedfordshire Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>The current treatment options offered (CBT and GET) are at best ineffective and at worst severely damaging</i>
<b>924</b>	Nuneaton - Warwickshire CFS Service	Be adapted to provide different services	<i>It was combined with other endocrine conditions and was extremely busy</i>
<b>925</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>They diagnosed me but did not offer any treatment or support. They did take me seriously though.</i>
<b>926</b>	Nuneaton - Warwickshire CFS Service	Be closed and a new service rebuilt with patient input	<i>Its not simply that it has not been helpful but the experience that I have had has been actively harmful on at least one occasion. The consultant that I saw berated me, was completely inappropriate and left me traumatised. I have not gained anything helpful from attending and usually end up feeling worse. The clinic seems mainly focused on ruling out any conditions which could be causing fatigue, once these are ruled out they seem to have nothing to offer.</i>
<b>927</b>	Middlesborough - South Tees CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Treated as though positive thinking would improve health. Kept being told health was improvising when it was deteriorating</i>
<b>928</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>I attended 4 group sessions (approx 15 attendees) while we wait for actual treatment. Been advised up to a year waiting list.</i>
<b>929</b>	Liverpool CFS/ME Management Services	Continue to provide current services	<i>I am new to the service and only had 2 appointments but both have been professional , informative and compassionate</i>
<b>930</b>	Not listed	Be adapted to provide different services	<i>Help needs to be offered for the long term disabled in getting their lives in order once a diagnosis has been made. They also need help to rebuild their confidence after the constant "it's all in your head", "just exercise and eat better", "you're just depressed" comments from GPs before getting said diagnosis.</i>

<b>931</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Because of inappropriate treatment that made me significantly sicker.</i>
<b>932</b>	Newcastle - North of Tyne CFS/ME Service	Be adapted to provide different services	<i>Advised GET - proven to harm ME/CFS patients</i>
<b>933</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>The Service is extremely limited, only really advising on pacing.</i>
<b>934</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>There needs to be better treatment and understanding</i>
<b>935</b>	Bishop Auckland - Durham & Darlington CFS/ME Service	Be adapted to provide different services	<i>The only 'treatment' I received was talking about how I was feeling that month compared to last month, and how much activity I had been doing. I didn't actually receive much advice or an activity plan, just talking with a doctor. We asked about new drugs/vitamins, and tests dlbeing developed, and if so would be eligible for them, but it never went anywhere.</i>
<b>936</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>I encountered three professionals at the service - one who was excellent and I believe could provide a good service, but the other two were not helpful and possibly harmful. So it wasn't totally bad but it should be centred around the beliefs and advice of the one helpful professional.</i>
<b>937</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>Provide real services and stop telling people it's all in their minds.</i>
<b>938</b>	Middlesborough - South Tees CFS/ME Service	Continue to provide current services	<i>It is very thorough. However, they have to refer out for certain things and it would be useful if it was all on house</i>
<b>939</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>A consultant psychiatrist told me he knew nothing about the physical symptoms, I had no psychological element to my illness and should ask my GP if I needed medical advice!  Group sessions are long and exhausting, I only managed one. This involved discussing your health symptoms in front of a room full of strangers. The first session was so exhausting I never made it back.</i>

<b>940</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>The clinic provides excellent support and advice and the staff were brilliant</i>
<b>941</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>CBT is not the answer for ME</i>
<b>942</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	Be closed and a new service rebuilt with patient input	<i>Currently ran by Psychiatric Dept</i>
<b>943</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>The only offer for my son is CBT. This has limited effectiveness.</i>
<b>944</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>If you don't get better you're discharged as you spoil their efficiency/improvement figures</i>
<b>945</b>	Norfolk and Suffolk ME/CFS Service	Be closed and a new service rebuilt with patient input	<i>Not that I've been for a while but they issued massive questionnaires to develop a baseline and told not to come back until I'd filled it in. Without help there is no way to fill them in.</i>

<b>946</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<p><i>I am currently severely ill and the team at the Royal Free are supporting me to avoid crashes and frustration which would make me worse through a cycle of boom and bust. They do not push me to 'exercise' which my GP has done previously leading to post exertional crashes, confusion and counterproductive distress. The clinic offers cbt, graded exercise and educational groups. The cbt is geared to managing the impact of me/cfs and obstacles to self-compassionate pacing and is sensitive and respectful. I think the graded exercise needs to be reframed as graded activity. I think it would be more helpful to also have occupational therapists, not only physiotherapists at the clinic. At my level of health, occupational therapy advice around mobility and pacing would be very helpful. In my experience, some physiotherapists can tend to view m.e/cfs as a result of deconditioning and in the past I have followed advice around countering supposed deconditioning via exercise. I got progressively worse after exercising. The specialists at the Royal Free clinic clearly have greater knowledge and understanding than my GP and are managing to use the cbt/graded activity programme supportively. Unfortunately they have a very long waiting list during which time I imagine people may (like me) risk following uninformed advice which could exacerbate fatigue. I think one risk of calling what is actually graded activity 'graded exercise' is that for people too busy to read deeply into the subject, this term perpetuates the myth of m.e/cfs as a deconditioning or depressive phenomenon.</i></p>
<b>947</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<p><i>it was appalling, dangerous, caused harm, wouldn't listen or accept any information about the biological physical nature of ME. i don't think they have any idea of what ME actually is, only about "fatigue".</i></p>
<b>948</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<p><i>no real advice on treatments. Just Pacing.</i></p>
<b>949</b>	Manchester CFS/ME Service for Children and Young People	Be closed and a new service rebuilt with patient input	<p><i>They had no understanding of ME or ME symptoms at all. They said my daughter did not have ME, she was later diagnosed by both a private ME specialist and an NHS specialist. My daughter had Very Severe ME and died as a result of ME. An inquest found her death was caused by Severe ME due to the post mortem findings.</i></p>
<b>950</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<p><i>Unhelpful and useless service</i></p>

<b>951</b>	Not listed	Be adapted to provide different services	<i>Needed more focussed advice, techniques etc</i>
<b>952</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>The service about giving information about CFS/ME is really good and the group sessions are good as you don't feel alone. Other than that the service is very limited and pacing does not work</i>
<b>953</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	Be adapted to provide different services	<i>Reduce insistence on GET. Investigate alternative options.</i>
<b>954</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>It is closed now as no funding. We are in desperate need of help and not be left abandoned. Every patient is unique so should be based on patient input. There is no known cause for ME... maybe there are many causes... so solutions should be as varied... and tailored to individual. Patients know their bodies best ... listen and support not ignore, denigrate and belittle.</i>
<b>955</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be closed and a new service rebuilt with patient input	<i>I did not get a certain diagnosis and never saw a dr most was done by questionnaires.</i>
<b>956</b>	Malvern - Worcestershire CFS/ME Service	Continue to provide current services	<i>Too many people are left alone to deal with this condition. More services are required.</i>
<b>957</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>Entirely psychological explanation and told to walk 25% further every few days. Nearly finished me</i>
<b>958</b>	Not listed	Be adapted to provide different services	<i>I was given a diagnosis but no further advice and then discharged. I have no idea whatsoever how to manage this condition.</i>
<b>959</b>	Aylesbury - Buckinghamshire Chronic Pain and Fatigue Management Services	Be adapted to provide different services	<i>It still advocated GET</i>

<b>960</b>	Leeds and West Yorkshire CFS/ME Service	Be adapted to provide different services	<i>I was given a lot of paperwork to read through and files to fill in, but we never came back to the topics or my answers to the questions in the files. I couldn't concentrate on the paperwork given to me to read because it was such a big amount</i>
<b>961</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>The Yorkshire Fatigue Clinic displayed excellent understanding of the biological mechanisms of ME/CFS and used this to explain why the techniques advised were important. I went from being mostly housebound to returning to work for 10 hours per week using their advice and have maintained this for the last 2 years.</i>
<b>962</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>The clinic only recommends pacing which is only suitable for those who are already managing their condition. Those with severe/very severe ME are not able to attend the clinic so are missing out on treatment.</i>
<b>963</b>	Wells - Somerset CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Their advice was good. Unfortunately they do not provide ongoing support</i>
<b>964</b>	Grantham - Lincolnshire CFS/ME Service	Be adapted to provide different services	<i>Need to have more emphasis on management of symptoms and less pressure to improve activity levels</i>
<b>965</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Old school mentality.</i>
<b>966</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>Staff need to be retrained in basic bedside manner, and not to give timescales promising recovery. There is also a tendency to throw prescription medication at every symptom- this caused more harm than good.</i>
<b>967</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be closed and a new service rebuilt with patient input	<i>Once [the professional at Truro - Cornwall &amp; Isles of Scilly CFS/ME Service] retired was only offered 20 minute phone consultation once a year after which GP was advised of different medication to try. After 2 yr tried to be re referred as symptoms worse but was told they are aware of my son's case but there is nothing they can do to support him now. So he now has no support.</i>

<b>968</b>	Not listed	Continue to provide current services	<i>Because the support group was amazing. Meeting people with CFS realising you weren't alone, sharing what helped and didn't. Each week we had a different topic, with two very support Occupational therapists. Which was thought provoking but for me meeting other people of all ages really helped me to accept. There is no cure or medicine, but I had completely underestimated the positive impact of going to a group would have.</i>
<b>969</b>	Fareham - South Coast Fatigue	Continue to provide current services	<i>Their advice and support was invaluable but I wish I could continue to use it beyond 6 months</i>
<b>970</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be closed and a new service rebuilt with patient input	<i>I've only ever seen a nurse once and when I tried to get help they told me to go to my g.p and my g.p told me to contact them.</i>
<b>971</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Everyone is individual. Advice ( treatment) should be within the capacity if the individual.</i>
<b>972</b>	Wells - Somerset CFS/ME Service	Be adapted to provide different services	<i>Very good service, but could be better if there was more Intergrated with other services.</i>
<b>973</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be adapted to provide different services	<i>It provides a good service considering the lack of funding it receives but they could do with a physiotherapist etc. Waiting lists are long.</i>
<b>974</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Continue to provide current services	<i>Cornwall &amp; IoScilly services are excellent. I am fortunate to have access to them &amp; their expertise</i>
<b>975</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>It's better to update the treatments than to close clinics and cause more delays in mine and others treatment</i>
<b>976</b>	Nuneaton - Warwickshire CFS Service	Be adapted to provide different services	<i>There was a slight emphasis on graded exercise although I wasn't told to exercise too much, just find a baseline and increase very gradually. It wouldn't be a huge leap for this clinic to promote pacing. I was recommended a book which wasn't useful. I was given unrealistic expectations regarding prognosis, so I expected t make a full recovery. I feel they could have been optimistic without being unrealistic.</i>

<b>977</b>	Portsmouth Chronic Fatigue Syndrome Service	Be adapted to provide different services	<i>I attended the clinic in Southampton which has since been closed and is now in Portsmouth which is too far for me</i>
<b>978</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>Systemic incompetence</i>
<b>979</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Because it works on the NICE guidelines which mainly focus mental health services. CBT is no good for this illness. Also the practitioners are lovely but there is no long term care..I have been ill for 10 years, and mainly had to deal on my own. Only be getting re-referred did I get more help. ME/CFS is the only long term major debilitating illness where we get left to just deal on our own. We need physical support and not just "pacing" and CBT.</i>
<b>980</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>No Medical Drs involved. Psychiatrist running the service had little to no knowledge about any of the issues related to PEM. And did not seem to have read widely upon the subject of ME (Having no knowledge of a) what the PACE trial was; nor why it was considered controversial...)</i>
<b>981</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	Be closed and a new service rebuilt with patient input	<i>Treatment based on disproven CBT GET nonsense is not helpful. Asking people with severe ME to travel to 2 1/2 hour sessions that will leave them suffering PEM for a week is counter productive.</i>
<b>982</b>	Not listed	Be adapted to provide different services	<i>The clinic has closed down due to lack of funding and loss of doctor, didn't see a consultant at all and we didn't test any drug therapy it was just training session on pacing, keeping diary, relaxation exercises understanding how affects sympathetic and parasympathetic nervous system</i>
<b>983</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be adapted to provide different services	<i>GET &amp; CBT isn't good for the condition</i>
<b>984</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>Specific treatment rather than general management.</i>

<b>985</b>	Essex Chronic Fatigue Service	Continue to provide current services	<i>At that time 1998, they had an in patient service as well as out patient and a team of neurologist, physiotherapists occupational therapists, management plans were individualised. Paced activity was used at a pace the patient could cope with along with medication to cope with symptoms that could be medicated for eg sleep, pain, secondary depression.</i>
<b>986</b>	Bridgwater - Somerset CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>First thing they said was they couldn't recommend pain relief. I went 3 times. Told them what had happened and they were no help at all. I felt the journey was wasted and would have been better off not making the 40 mile round trip. Nothing helpful or constructive was ever discussed.</i>
<b>987</b>	York - Yorkshire Fatigue Clinic	Be adapted to provide different services	<i>They still use pacing and graded exercise. Don't always listen to the whole picture. The location is too far and not near good transport links. Appointments are hard going and once you take travelling and appointment time into account I am normally bed bound for days.</i>
<b>988</b>	York - Yorkshire Fatigue Clinic	Be adapted to provide different services	<i>They need to stop providing GET/CBT</i>
<b>989</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>The clinic is very knowledgeable about cfs/me and very patient-oriented.</i>
<b>990</b>	Bath Centre for Fatigue Services	Be closed and a new service rebuilt with patient input	<i>They used the psychological model of ME which is terrible, and tried to teach psychological pathways to managing my ME, whereas I needed biomedical help. It was a complete waste of time. I also never even saw a Consultant. I found I could have got a very similar course under the Expert Patient Programme at my local hospital! I was fuming!</i>
<b>991</b>	Norfolk and Suffolk ME/CFS Service	Be closed and a new service rebuilt with patient input	<i>People with dubious, incorrect and uniformed medical knowledge, or lack of it, are putting forward potentially harmful 'treatments' that don't work for people with M. E.</i>
<b>992</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>pace and GET is considered harmful by most patients, but still heavilly pushed by CFS service</i>
<b>993</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service	<i>GET and CBT are useless. There should be biomedical advice rather than psychological.</i>

		rebuilt with patient input	
<b>994</b>	Manchester CFS/ME Service for Children and Young People	Be adapted to provide different services	<i>Because they pushed GET and when I deteriorated discharged me as there was "nothing more they could do"</i>
<b>995</b>	London - Uxbridge - Hillingdon CFS/ME Service	Be adapted to provide different services	<i>Activity and management of illness only useful session , of 10 , for me .</i>
<b>996</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>A service manned by psychiatrist and psychologists whose careers are dependent on the CBT/ GET paradigm cannot be adapted.</i>
<b>997</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>It's run by psychologists who stand to lose their position by accepting it as a physical/biomedical illness as research supports it to be. Conflict of interest. The service needs to support patients with real help and support and should be a community/home based service so that everyone can access it. It is t rocket science to understand that those most in need are bed and housebound and can't make the journey.</i>
<b>998</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Leaflets saying there is no disease process are unhelpful and highly insulting and outdated.</i>
<b>999</b>	Not listed		<i>Don't think clinic still exists</i>
<b>1000</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	Be closed and a new service rebuilt with patient input	<i>The clinic cause untold harm. Needs to be closed full stop. Why have a clinic when there's no cure. Symptoms can be helped by a GP. So much wasted money that could go into research, not triggering child protection investigations and failing to support what patients say</i>
<b>1001</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>Listen to the patients more</i>
<b>1002</b>	London - University College Hospitals Children and young people's specialist adolescent services	Continue to provide current services	<i>Although our experience is 11 years ago, UCLH gave us hope. WE travelled 150 miles there and back for the support they gave us</i>

<b>1003</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be closed and a new service rebuilt with patient input	<i>The service discharges patients who don't improve and will not endorse any investigations into other conditions that can be contributing to symptoms</i>
<b>1004</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be adapted to provide different services	<i>I've had useful telephone support, but after my diagnosis I was just offended group therapy, there was no ongoing support</i>
<b>1005</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<i>A lot of existing advice and support doesn't allow for employment support and advice and guidance.</i>
<b>1006</b>	Suffolk Specialist ME and CFS Service	Be adapted to provide different services	<i>I felt that all I got from this clinic was a diagnosis and that took a long time to get because they forgot about me</i>
<b>1007</b>	Bolton - Bury and Bolton CFS/ME Clinic	Continue to provide current services	<i>I feel that the clinic is good at what it does but there is a long waiting list and you have to go through the nurses and they see if they think you should see [the professional] which some are very of handed.</i>
<b>1008</b>	Portsmouth Chronic Fatigue Syndrome Service	Continue to provide current services	<i>They did home visits, they had originally OT, physiotherapist, psychologist, promoted exercise, which was declined, as hospital 2015 caused new symptoms being paranoia and severe anxiety both diagnosed... Rare somebody as severe is treated, more apt for mild cases.</i>
<b>1009</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>I was told to push myself when in fact I have now been informed that I have been overdoing as I have been having crashes where I am now bed bound.</i>
<b>1010</b>	Malvern - Worcestershire CFS/ME Service	Be adapted to provide different services	<i>A wider depth of offer. One PT and one Psychologist means 12month+ wait times for support. A nutritional offer would also benefit I believe.</i>
<b>1011</b>	Newcastle - North of Tyne CFS/ME Service	Continue to provide current services	<i>Whilst the clinic only operates part time, it provides the only contact that any patients I have met have with any health care professionals who are informed regarding ME and the only healthcare environment any of us ever encounter where we do not have to defend, justify and explain our diagnoses.</i>
<b>1012</b>	Middlesbrough - South Tees CFS/ME Service	Continue to provide current services	<i>Initially very good but once I had the allotted number of sessions I was on my own, luckily I had a very understanding GP.</i>

<b>1013</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be adapted to provide different services	<i>My doctor is kind and personable, happy to explain things to me in a way I understand. The other aspect is the specialist management (CBT and Pace) the women running it is dismissive and dangerous. "the diagnoses of ME is not useful for Miss..." and "if you tried harder you would get better, this method works for most people who do it properly"</i>
<b>1014</b>	Newcastle - North of Tyne CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The service is based on a false and unproven premise (biopsychosocial) and was dangerous to my Physical health. I also felt my mental health suffer as a result of the way I was treated by some of the people there, and due to the underlying approach. It was manipulative.</i>
<b>1015</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<i>Needs to be consultant/medically led not using bio psychosocial model of cbt led treatment. Patients shouldn't be discharged just because they've completed a cbt course but given regular opportunities to discuss their physical symptoms and medical treatment options.</i>
<b>1016</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>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.</i>
<b>1017</b>	Not listed	Be adapted to provide different services	<i>Some aspects were helpful like, relaxation techniques, learning to pace and manage illness better.</i>
<b>1018</b>	Harrogate CFS Service	Be adapted to provide different services	<i>little understanding of older people with this illness. didnt feel that they knew what to do with me</i>

<b>1019</b>	Edinburgh - Lothian CFS/ME Service	Be closed and a new service rebuilt with patient input	<p><i>The service is not fit for purpose. I was bullied, lied to and gaslighted by my physiotherapist. The physiotherapist acted outside of her professional expertise by proclaiming I had a psychological condition when I had a sick family member to look after. The physiotherapist actively ignored the fact I had deteriorated whilst seeing her. The physiotherapist lied by stating in her discharge letter that I had improved and was equipped with all the skills I needed to complete my recovery. Whilst I was given a set of questionnaires to fill out at the start, I have not been asked by the service to provide any feedback nor have they asked me to fill out post-attendance questionnaires to evaluate my progress. There is no way to independently and objectively track, monitor or audit patient's progress; the clinic relies entirely on the falsely optimistic reports of its own practitioners to justify its continued existence.</i></p> <p><i>Example of the type of language used by the physiotherapist: "People who do what I say get better, people who don't, [dramatic pause] well, [sneer]."</i></p>
<b>1020</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	Be adapted to provide different services	<p><i>I know more than they do &amp; they are fixated on exercise/activity levels increasing which is just incorrect.</i></p>
<b>1021</b>	Liverpool CFS/ME Management Services	Be closed and a new service rebuilt with patient input	<p><i>There's no services for severe patients. I had to beg them to let me do the workshops and one to ones even though they said there's nothing they can do for me. I was discharged after missing an appt because of my m.e</i></p>
<b>1022</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<p><i>It couldn't cater much for my personal circumstances although the advice to rest was what I needed. I still needed more support to be able to attend other treatments they had.</i></p>
<b>1023</b>	Fareham - South Coast Fatigue	Be adapted to provide different services	<p><i>I feel it was more based upon managing the illness rather than recovery. Pacing information was useful but it didn't deal with the root cause of my illness.</i></p>
<b>1024</b>	Norfolk and Suffolk ME/CFS Service	Be adapted to provide different services	<p><i>I would like it Consultant led by a medical professional experienced in ME so that appropriate tests, treatments and medication could be prescribed for relapses, flares and also ongoing as it's a life long condition. In my experience with severe ME diagnosed 17 years ago, GPs are either unaware and/or unwilling to prescribe anything to ease symptoms ie to increase blood volume, prednisolone to reduce severe inflammation evident from blood tests. Only being able to talk about one thing at GP appointments is not helpful for such a complex multi system illness.</i></p>

<b>1025</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	Be adapted to provide different services	<i>I don't think get is good for cigs/ me</i>
<b>1026</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>I was recommended exercise therapy and counselling which is completely inappropriate for ME sufferers</i>
<b>1027</b>	Nottinghamshire PICS CFS/ME Service for Adults	Continue to provide current services	<i>The service was good providing a good basic grounding so that you could go out and research further. It was also very helpful having a group of people with the same symptoms problems and understanding</i>
<b>1028</b>	Leeds and West Yorkshire CFS/ME Service	Continue to provide current services	<i>Excellent service which enabled me to adapt and modify strategies to manage energy levels.</i>
<b>1029</b>	Bolton - Bury and Bolton CFS/ME Clinic	Be adapted to provide different services	<i>the clinic has probably, hopefully changed since 2012. I already had Fibro and M.E. I'd had it for 8 years at this time. I just wanted the M.E bit confirmed but I wasn't offered any hope, or advice other than OT sessions to manage the illness.</i>
<b>1030</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Continue to provide current services	<i>They have been very supportive</i>
<b>1031</b>	Norfolk and Suffolk ME/CFS Service	Continue to provide current services	<i>It gave me some general helpful advice. But I should have been advised to drop my level of work instead of staying as busy as I was able.</i>
<b>1032</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Consultant I saw was terse to the the point of rudeness really not interested in me just my condition.</i>
<b>1033</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be adapted to provide different services	<i>They are trying but they are trying to find other reasons for symptoms, like arthritis or exhaustion instead of thinking of ways to help the patient understand what ME is and how best to cope.</i>
<b>1034</b>	Bath Centre for Fatigue Services	Be adapted to provide different services	<i>Intentions good, but severe lack of up to date biomedical research findings.</i>

1035	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Continue to provide current services	<i>They just need to be more up to date with advice.</i>
1036	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>either answer 2 or 3 as long as the service is appropriate</i>
1037	Newcastle - North of Tyne CFS/ME Service	Be closed and a new service rebuilt with patient input	<p><i>The service is run by 2 psychologists and a physiotherapist. I asked to see the physiotherapist because I have had no benefit to my ME from past psychological intervention. His whole approach at this time (when I was most vulnerable and was looking for professional, fact based advice as to ANYTHING I could do to improve my ME), left me feeling he believed it was all 'in my head'.</i></p> <p><i>This left me feeling weak, to blame for my own situation and further lowered my self-esteem to the point I started with suicidal thoughts. This was due to the hopelessness that I could not regain health.</i></p> <p><i>He advised that I needed to use GET to increase my activity levels. Unfortunately I followed his advice re GET and this caused me harm as my ME worsened when I increased my activity levels.</i></p> <p><i>He told me the only treatment he knew of that improves ME/CFS is the Lightning Process, and that the unit was trying to become trained up to be able to deliver the Lightning Process themselves (2015).</i></p> <p><i>He knew nothing about orthostatic intolerance which was one of my most debilitating symptoms.</i></p> <p><i>I feel strongly that until more is known biomedically, that these units should be closed down to stop more harm being done. Very importantly, the money allocated to them should be ring fenced and invested into ME biomedical research and not just spent by NHS elsewhere.</i></p> <p><i>I would also like to add that I was regularly posted questionnaires to complete and return to say how much the ME/CFS unit had helped me to improve my health for many months after I was discharged. I felt under pressure to say I had improved when I had actually got worse, as the questionnaires were to be sent back to the unit where the staff members worked (who I have no doubt gave me well intentioned advice), but had no scientific basis and only made me worse. I did not want to hurt their feelings by 'telling the truth', that their advice and 'knowledge gaps' were making me worse.</i></p> <p><i>I also doubt whether some of the other referrals did actually have ME as so many people are inaccurately diagnosed, eg many seem to have fatigue caused by long term depression (which causes them pain and needs psychological support to help) but is not helping depressed patients nor ME patients to</i></p>

			<i>try and use 1 size first all - very different illnesses which should be dealt with by seprate specialist units.</i>
<b>1038</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The current service is geared towards people with mild ME, and serves them relatively well. However, it is completely unsuitable for people with Moderate/severe ME. Also the consultant is openly hostile to people with ME and does not seem to believe that it is a real condition.</i>
<b>1039</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>Once you've been diagnosed and attended a symptom management course your discharged so no longer receive support, ie so many more symptoms arose that aren't addressed or acknowledged as they're not on the nice guidelines, i.e air hunger finding it hard to breathe as my muscles feel too relaxed. As your incredibly ill it's a lot to take in, most of my more scientific understanding I had to find through my own on-line research. Not sufficient treatment offered, ie I can literally feel my brain is swollen and swells further the iller I get, why no immune system support? Accupuncture makes a noticeable difference in reducing the swelling of my brain &amp; strengthens the immune system. Although firstly I had suffered for years with ME &amp; my doctor gave me no guidance nor referred me to a specialist clinic. As I was mostly bed bound it could be 8 mths before I can leave the house to get a docs appt. about 7 yrs after being very ill I was only referred to a specialist clinic when a friend told me that I needed a proper diagnosis &amp; that I should be referred to one. Why hadn't the doctor organised this for me. We're so ill and basically paralysed in bed we can't think of solutions or get the help we need. It's like we have to be our own doctors. It's wrong. I literally had to be carried to the classes and had to lie one a bed and not talk to anyone and put ear plus in my ears most of the time, there needs to be a better service for people who can't leave the house or if by attending like myself put me in a severe relapse. Graded exercise Therapy is pure abuse, you would make a person run on a broken leg with no plaster on!!! Every task we do we are already pushing ourselves, Just doing menial tasks like brushing our teeth feels like weight lifting which I can't do every day, and immediately starts a relapse</i>

<b>1040</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be adapted to provide different services	<i>M.E/CFS is a complex health condition which also includes issues with Mental Health. I was diagnosed with Agoraphobia, Social Anxiety and Panic Disorder due to become more housebound over the years. My M.E/CFS deteriorated but due to my Mental Health deteriorating I was dismissed from the service despite trying to arrange an appointment via the telephone. I believe that the ME/CFS services across the UK should take into account the impact of having such a illness can have on someone Mental Health, learning more about how this illness can leave many feeling isolated and alone. I would suggest learning more about how Mental Health can be brought on by M.E/CFS and be more accommodating to people with Mental Health problems on top.</i>
<b>1041</b>	Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service	Be adapted to provide different services	<i>Good service but really just for newly ill patients - I have had no ongoing support or review and feel abandoned because my GPs are ignorant about the illness</i>
<b>1042</b>	Manchester CFS/ME Service for Children and Young People	Continue to provide current services	<i>Paediatrician was helpful. Therapy was not as the service and travelling every week was too much for my daughter to manage</i>
<b>1043</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>They really did not understand anything about my condition and were the opposite of helpful</i>
<b>1044</b>	Not listed	Be adapted to provide different services	<i>Gartnavel - Topics such as nutrition were covered which were important but were generalised and not evidence based. A doctor who led the group had recovered from ME and I expected the same. I found CBT had some good coping techniques but these things should be delivered one to one. I was offered homeopathic treatment for anxiety which was wholly inappropriate. I was told to maintain some movement and was given exercises for muscle wastage. I believe there was good intention but I've always been told by doctors that I will recover rather than given any real treatment.</i>
<b>1045</b>	Oxfordshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>CBT and GET were inappropriate forms of treatment for my neurological illness. I knew more about the physical aspect of ME than the people treating me, probably through no fault of their own. People with the illness, alongside medical professionals who are up to date with biomedical research and real life case studies of the thousands of ill people, who are interested in the illness could create a much better system of support and help. It could change the lives of thousands rather than leaving them alone at home, ostracised and humiliated by the lack of worth they are given.</i>

<b>1046</b>	Oxfordshire CFS/ME Service	Be adapted to provide different services	<i>they are limited and can't provide on-going general support as things change</i>
<b>1047</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Even though I found a few aspect of the service helpful on the whole they showed little understand 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. When I asked about studied I can come across they refused to comment, or look at any new evidence. Lastly is based in the psychology department, which is the not the right area for ME.</i>
<b>1048</b>	Manchester CFS/ME Service for Children and Young People	Continue to provide current services	<i>Not sure, really. Basically, we go to make sure we get the letters to back up what we want with our daughter's education. The Therapist has pretty much said that my daughter gets what pacing is and should continue as she is. She does have some small positive ideas on what my daughter can to take help. We only have telephone appointments now, as the 5 hour round trip to get to Manchester was making my daughter more ill, although we still have to go for a 20 minute appointment with the Consultant every six months. These feel like a waste of time, they can't do it by telephone or Skype apparently, but we have to go to get the medical evidence we need for school and get referred to other services (CAMHS) When was asked about PoTS testing, they didn't have a clue, unfortunately.</i>
<b>1049</b>	Private clinic	Continue to provide current services	<i>LCON is a private clinic looking at pathological causes of diseases like ME. Therefore it can't be ruled out that its services which are very good won't work for some people - although I am skeptical they work at all. Nutritional advise however does make a massive difference to an ME patient, so again the clinic should continue to advise ME patients on this basis.</i>
<b>1050</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>The advice given is 'blanket' coverage and doesn't apply to everyone in the same way. It was frustrating to hear a lot of emphasis on pacing, when I was not then, nor am I now, in a position where pacing works for me.</i>

<b>1051</b>	Maidstone - Kent & Medway CFS/ME Service	Be adapted to provide different services	<i>I think the people there meant well. It was actually my referral to a follow up of the pace trial that was the problem and it was the treatment I received from them that caused the severity of my illness to increase to the extent I was unable to work for over a year and still have not regained the level of health I had before that time. The Maidstone services people I believe were just trying to help me when they recommended me for the trial. But they were just therapists and otherwise just offered CBT. They were not medical professionals as such. And CBT, whilst useful in helping me cope emotionally, in a very small measure, with the stress and trauma of living, with a chronic illness, was useless in doing anything to help me with my symptoms or the illness itself.</i>
<b>1052</b>	Bishop Auckland - Durham & Darlington CFS/ME Service	Be adapted to provide different services	<i>All management options were given as large A4 handouts which I was too ill to read or process</i>
<b>1053</b>	Bristol CFS/ME Service for Adults	Continue to provide current services	<i>very good service , helpful, but more patient input is needed to help staff understand are experiences of having ME, the difficulties of having this illness on everyday tasks , more liaison with healthcare professionals like GPs , as it is hit and miss as to whether your GP understands ME /cfs , and will refer you to the right place. I felt I was passed around different areas of NHS , and no one was talking to each other , liaising with each other properly , GP surgeries need more information on ME , then patients would get the proper help , support, diagnosis much quicker , not years later .</i>
<b>1054</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>When I first attended the clinic (2015) I was prescribed Graduated Exercise Therapy. This made my health even worse. Any attempts I made to discuss other treatments were rejected. In 2018 I returned to the clinic for a course in Mindfulness meditation therapy, which has been beneficial in helping me cope with the disease (though not, obviously, addressing the cause of the disease). The clinic's attitude seems to have improved; being honest that there is currently no cure but offering help in ways to improve quality of life.</i>
<b>1055</b>	Sunderland - South of Tyne Paediatric CFS Service	Continue to provide current services	<i>Excellent client centred approach</i>
<b>1056</b>	Bristol CFS/ME Service for Adults	Be adapted to provide different services	<i>Needs to provide support over a longer period</i>

<b>1057</b>	Bath Specialist Paediatric CFS/ME Treatment Service	Be adapted to provide different services	<i>needs to link to the biological treatments</i>
<b>1058</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Patient input would help as it's a poorly understood condition</i>
<b>1059</b>	York - Yorkshire Fatigue Clinic	Be closed and a new service rebuilt with patient input	<i>It just offered C B T and exercise, M E is not a psychological condition.</i>
<b>1060</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Based on psychology (CBT / Mindfulness approaches) and service design not good</i>
<b>1061</b>	Liverpool CFS/ME Management Services	Be adapted to provide different services	<i>It was absolutely useless and out of date</i>
<b>1062</b>	Leeds and West Yorkshire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>Because I think it was closed and became more Psychology-based, which isn't helpful.</i>
<b>1063</b>	Oxfordshire CFS/ME Service	Be adapted to provide different services	<i>The psyiotherapist was good who I saw first but it was following advice from a psychologist that meant I ended up in wheelchair and unable to care for myself and they still haven't acknowledged this.</i>
<b>1064</b>	London - University College Hospitals Children and young people's specialist adolescent services	Be closed and a new service rebuilt with patient input	<i>Appalling advice. We spoke for 50 minutes as they wanted info. At the end we were advised to find occupational health and offered physio! No understanding or explanation whatsoever. These leopards can't change their spots/beliefs. Complete new team and new approach needed!</i>
<b>1065</b>	Middlesborough - South Tees CFS/ME Service	Be adapted to provide different services	<i>The Service personnel were nice but needed far better training in the illness by experts who actually know the illness [like redacted or redacted]; the service and system is not really helpful to patients: e.g.:attending a clinic when too ill to travel, or seeing a physio to increase activity is daft!</i>

<b>1066</b>	York - Yorkshire Fatigue Clinic	Continue to provide current services	<i>YFC understands the illness and deals individually with patients.</i>
<b>1067</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>Services for me/CFS patients are poor. There needs to be more understanding on what is and isn't helpful and patient input is important, as we have had to be our own doctors and have probably done much more further reading.</i>
<b>1068</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>It makes ME sufferers worse - not just me, I know of lots of others made worse by them.</i>
<b>1069</b>	Salford CFS/ME Service	Be adapted to provide different services	<i>I felt like the initial appointments I had with consultants were helpful but this did not continue when I met with a physiotherapist and began graded exercise therapy.</i>
<b>1070</b>	Torquay - Torbay and South Devon CFS/ME	Continue to provide current services	<i>I was satisfied with service</i>
<b>1071</b>	Oxfordshire CFS/ME Service	Continue to provide current services	<i>There was good understanding that approach needed to adapted to fit the phase of illness.</i>
<b>1072</b>	Liverpool CFS/ME Management Services	Continue to provide current services	<i>Because it is good enough and I have nothing else to compare it with.</i>
<b>1073</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Continue to provide current services	<i>They have helped me.</i>
<b>1074</b>	Edinburgh - Lothian CFS/ME Service	Be adapted to provide different services	<i>The clinic is based in Psychology dept. I feel there should also have been some medical input seeing as it is a physical disease.</i>
<b>1075</b>	Liverpool Children's CFS/ME service	Continue to provide current services	<i>The only things wrong with this clinic were that it couldn't get the funding for me to have an in-patient stay, and that there wasn't anything to replace it once I aged out of the service.</i>

<b>1076</b>	Not listed	Be adapted to provide different services	<i>They were simply offering physio - graded exercise with no option or explanation</i>
<b>1077</b>	Bristol CFS/ME Service for Adults	Be closed and a new service rebuilt with patient input	<i>Too much emphasis on exercising yourself out of illness. Too little acknowledgement of the expertise developed by those who have been ill for many years. Person running the centre had v good understanding of this when i met him many years ago. More recently, the practitioner had nothing to offer at all and has not grasp of the impact (physical, emotional and life chances) of 35 years of illness.</i>
<b>1078</b>	Plymouth Sentinel CFS/ME Service	Be adapted to provide different services	<i>The team were knowledgeable and nice but aspects if the advice given I didn't feel were appropriate, particularly surrounding GET</i>
<b>1079</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	Be adapted to provide different services	<i>Limited options for treatment which weren't tailored</i>
<b>1080</b>	Gillingham - Kent CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I specifically requested info on pacing, which was provided very well at home. The clinic routinely offers CBT and GET which I have found inappropriate. The clinic does not offer ongoing support, no longer caters for the housebound, and lacks a consultant clinician.</i>
<b>1081</b>	Leicester CFS Service	Be closed and a new service rebuilt with patient input	<i>Despite having made good progress through self management (pacing, diet etc) &amp; with help of PoTS consultant, she didn't understand that some of my 'unhelpful behaviours' such as sleeping in the day weren't a choice. Also gave literature that was 20 years out of date &amp; still pushed GET (although called it another name to make it seem more acceptable) I felt the progress I made could have been at risk if I followed their plan &amp; was concerned for other patients who weren't aware of this.</i>
<b>1082</b>	Preston - Lancashire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The current services and staff are inappropriate , not fit for purpose and need to be scrapped and replaced . A fresh start.</i>
<b>1083</b>	Plymouth Sentinel CFS/ME Service	Be adapted to provide different services	<i>couldn't offer me the help I needed, only offered pacing, discharged as a 'non attender' when an appointment letter took so long to be sent out I didn't get it in time to attend the appointment</i>

<b>1084</b>	Preston - Lancashire CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>The appointment was less than five minutes, he rushed through the paperwork and didn't offer me any support.</i>
<b>1085</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	Be adapted to provide different services	<i>They use to have an M.E specialist Doctor but he retired years ago and they never replaced him. They need a Doctor that has some understanding of this illness and is up date on the current research. They also need a physiotherapist who understands this illness and won't pressure patients into GET.</i>
<b>1086</b>	Newcastle - North of Tyne CFS/ME Service	Be adapted to provide different services	<i>The staff were (naturally) following NICE guidelines. The exercise programme was well thought out and each patient encouraged to do as much as they felt appropriate, but the tendency was to keep up with the others; the exercise - on top of the energy needed to get to and from the clinic - made me feel much worse.</i>
<b>1087</b>	Edinburgh - Lothian CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>no help /treatment /or support for ME suffers</i>
<b>1088</b>	London - Royal London Hospital for Integrated Medicine CFS Service	Be adapted to provide different services	<i>I also have Brain Damage so GET was adapted to me. There is proof GET is not a good therapy. I was only able to attend every other week</i>
<b>1089</b>	Not listed	Be closed and a new service rebuilt with patient input	<i>It expected me to travel a long distance each week to the clinic for 2 hours of discussion, both physically and mentally exhausting and unachievable.</i>
<b>1090</b>	Oxfordshire CFS/ME Service	Continue to provide current services	<i>Visited 12 years ago so unable to accurately answer this question</i>
<b>1091</b>	Grantham - Lincolnshire CFS/ME Service	Be adapted to provide different services	<i>It was based on GET, QI kong and CBT. Which might work for some, but not others. It was treated as if ME/CFS was mental not a physical disease. To my mind it is physical. But the lady was very understanding and professional.</i>

<b>1092</b>	Stockport CFS/ME Service	Be adapted to provide different services	<i>I had an amazing nurse who fully understood the limitations of treatments of my situation. However, she was under constant pressure by management to stop seeing severe patients who needed ongoing support rather than people who could be dealt with in 6 sessions. She quit because of this ultimately. There needs to be a long term support system in place and not just a limited session period after which the patient is dropped.</i>
<b>1093</b>	Romford - Queens Hospital National CFS Diagnostic and Specialist Rehabilitation Service	Be closed and a new service rebuilt with patient input	<i>clinic no longer exists. Also was not in my country</i>
<b>1094</b>	Wells - Somerset CFS/ME Service	Be adapted to provide different services	<i>Make it better</i>
<b>1095</b>	Dorchester - Dorset Children and Young People's Chronic Fatigue Service	Be adapted to provide different services	<i>More research, i decided not to continue with the clinic as what they could help with - school letters wtc They didn't do as I didn't want their treatment - so I couldn't have the letters of diagnosis if I didn't attend the clinic - even though it made me worse to get 1 hour away to attend. It was too much</i>
<b>1096</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	Be adapted to provide different services	<i>No nutrition advice, only gave out drugs which made me worse. Didn't listen to me when I said the drugs made me worse. No good emotional support.</i>
<b>1097</b>	Maidstone - Kent & Medway CFS/ME Service	Be closed and a new service rebuilt with patient input	<i>I was no well enough to attend. I had a phone counsellor. The entire service needs overhauling. I have laid in bed for 24 years. I am an RGN. I financed myself working for a year in slums in Asia. I travelled across China alone. I ran a health centre in Hackney in London for 7 years. I have been left all alone to suffer public shame due to the disbelief surrounding this illness, the classification that it is mental. I have a younger sister who has a BA and an MA in Biochemistry from London School of Economics. She has laid in bed for 22 years. I have an older sister who was the Chief Hospital Administrator of a major hospital for 15 years. She has now been in bed for 20 years. Essex, Surrey and Kent. NOT ONE OF US has had appropriate support in all these years. The neglect and disbelief is damaging.</i>

<b>1098</b>	Bristol CFS/ME Service for Adults	Continue to provide current services	<i>As I'm referring to my first attending of this clinic it was very helpful . The health care provider explained much I didn't understand at the time but could relate to regarding my symptoms. Her help and support plus the pacing method explained has been of great help. When this advice changed in subsequent years with other health professionals I Began to have problems which I will have to do a second survey about.</i>
<b>1099</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	Continue to provide current services	<i>I had a weekly face to face CBT hourly meeting for one year and then following up meetings every 3 months for another year and then I confirmed when I felt able to manage on my own/support with my GP. I also had the option to be re-referred if I felt I was not managing my CBP optives/coping methods</i>
<b>1100</b>	Exeter, East, Mid and North Devon CFS/ME Service	Be adapted to provide different services	<i>I do not feel it needs closing as then there will be nothing around till something new is built but I feel a lot of doctors advice doesn't fully work In the real world, like to just stop the activity your doing isn't always possible... but I feel unless the person has been in your position with the illness it will always be hard for them to understand how it truely effect you and how silly some of the advice is.</i>
<b>1101</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	Be closed and a new service rebuilt with patient input	<i>Service offered inappropriate &amp; potentially harmful for those impacted by ME as simply treated as fatigue caused by negative, depressive or inappropriate thoughts even mid blood tests showed abnormalities &amp; patient has co-morbidities such as Thyroid disease, low B12 &amp; Vit D. Model of care fits Psychological BPS model &amp; 'treatment' based on speculative subjective questionnaires. Plus 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.</i>
<b>1102</b>	Surrey - South West London and Surrey Chronic Fatigue Service	Be adapted to provide different services	<i>No need to start from scratch</i>
<b>1103</b>	Norfolk and Suffolk ME/CFS Service	Be closed and a new service rebuilt with patient input	<i>It's too focused on the mental and psychological side - not helpful. Not up to date with current research.</i>
<b>1104</b>	Blackburn - North West Fatigue Clinic	Continue to provide current services	<i>Although the advice was basic it was caring and did encourage me to pace myself</i>