

# Severe ME



**Now is the time...**

To say what Clinics say you want

**“The discrimination and inequality in the current system is unacceptable and a breach of our rights.**

**We call for an end to this discrimination, and our right to be involved in the planning of our health care services to be honoured and the patient voice heard loud and clear.”**

# ***Liberating the NHS: Greater choice and control.***

## ***Consultation on proposals : A Severe ME Response***

The Government's White Paper, Equity and Excellence: liberating the NHS sets out proposals which envisage a presumption of greater choice and control over care and treatment, choice of treatment and healthcare provider becoming the reality in the vast majority of NHS-funded services by no later than 2013/14.

### *Overview*

1. The White Paper, Equity and Excellence: Liberating the NHS, sets out the Government's vision of an NHS that puts patients and the public first - where patients, service users, carers and families have far more influence and choice in the system, and the NHS is more responsive to their needs and wishes.

. The proposals envisage a presumption of greater choice and control over care and treatment, choice of any willing healthcare provider, wherever relevant and choice of treatment and healthcare provider becoming the reality in the vast majority of NHS-funded services by no later than 2013/14.

We are seeking the views of patients, the wider public, healthcare professionals and the NHS about how we take forward these proposals. We want to know what sorts of choices you want to make, when you want to make them, what information and support you need to make the right choices for you, and how we make this happen.

This consultation document covers many different issues and therefore asks a large number of questions. The questions may not be relevant to everyone but you are invited to answer any question that you have a view on. You can respond here or download a copy from at <http://www.dh.gov.uk/liberatingthenhs> by email to [choiceconsultation@dh.gsi.gov.uk](mailto:choiceconsultation@dh.gsi.gov.uk) or by post to Choice Team, 11th floor, New King's Beam House, 22 Upper Ground, London SE1 9BW, making sure that your response reaches us by **14 January 2011**. After the consultation

## **Introduction :**

The NHS are asking us what choices we want in our healthcare service we have a chance to have our voice heard and included in the response.

### **NOW IS THE TIME to say what choices you want.**

The more replies they get the more our voice will be heard and documented  
it is our right to be involved in the planning of our health care services let the patient voice be heard loud and clear in this protest to the NHS choices team.

This reply to the white paper has been written by patients for patients, and is suitable for all levels of severity we hope we have stated the views concerns and bio medical needs and choices we want not only in diagnosis but also in treatment, and social care.

**The discrimination and inequality in the current system is unacceptable and a breach of our rights. We call for an end to this discrimination, and our right to be involved in the planning of our health care services to be honoured and the patient voice heard loud and clear.**

We as patients feel that the LP, CBT and GET are no choice at all. We want equal access to appropriate specialists such as neurologists cardiologists immunologists and a fair diagnosis using the Canadian Guidelines, with correct testing and treatment.

This is the choice we want, not harmful CBT and GET which our shown by patient surveys to worsen condition. We condemn the Wessely school and their vested interests, and dominance in the NICE guidelines as an unfair representation of the facts which leads to discrimination which is why they have been declared unfit for purpose.

The needs of the severely ill are neglected, with no home service available often the most in need get the least service. because their disability does not allow them to access services.

We call for equal access for the 25% of patients who are severely ill bed and house bound who have no access to choice for ME treatment or any other healthcare needs. Correct services need to be provide via home visits from all specialists involved in care. Otherwise the severely affected will continue to suffer discrimination in accessing appropriate bio medical treatments.

**Let your voice be heard loud and clear the more who reply the stronger the message is.**

## HOW to take part

Download the response document via <http://www.dh.gov.uk/liberatingthenhs> or email [choiceconsultation@dh.gsi.gov.uk](mailto:choiceconsultation@dh.gsi.gov.uk)

for a copy; subject **Severe ME choices response**

### By post to :

**Choice Team, 11th floor, New King's Beam House, 22 Upper Ground, London SE1 9BW.**

Below is a sample for your email or letter let them know if you have made additions, use bold so they can find them easily,

Dear Sir/Madam

I submit the following document for inclusion in the white paper consultation,

I have submitted research links in the document which support this submission and ask you not to reach any decision regarding provision of choice for ME patients without fully exploring this evidence.

## GREATER CHOICE AND CONTROL

### Q2. Which healthcare services should be our priorities for introducing choice of any willing provider?

Those healthcare services whose users have a right to elective care but who are currently denied this right. I believe that the current NHS exclusions from elective care are mental health, emergency and maternity services and that all other elective care services should have a right to choice.

However, this is not the current reality. Some patients are told that they are restricted to locally commissioned services and cannot access services in other parts of the country nor any local services other than the one deemed appropriate by the local commissioners leaving them with no choice. In most cases there are no local services at all for ME patients.

ME is listed in WHO as ICD10 G93.3 as a physical neurological illness. The introduction of choice for ME patients would make a huge difference to outcome in this disease that has 250 thousand patients within the UK (more than HIV and MS put together), that can reduce life expectancy by 25 years and is potentially fatal (Jason et al shows the three leading causes of death as heart failure cancer (of all types) and suicide). [http://www.theoneclickgroup.co.uk/documents/ME-CFS\\_docs/Causes%20of%20Death%20-%20CFS%20Patients.pdf](http://www.theoneclickgroup.co.uk/documents/ME-CFS_docs/Causes%20of%20Death%20-%20CFS%20Patients.pdf)

Introduction of choice would make a huge difference to outcome and quality of life for sufferers who are often more functionally impaired than those suffering from type 2 diabetes, congestive heart failure, multiple sclerosis, and end stage renal disease. (Anderson & Ferrans,

Priority healthcare services for ME patients (should be providing ME patients with the choice of a local biomedical clinic/service able to choose a local clinic led by a knowledgeable, biomedical Consultant with a specialism in Myalgic Encephalomyelitis, for example an immunologist and/or neurologist with access to cardiologists and other specialists as appropriate for this multisystem neuroimmune disease. ME patients, if referred at all, are currently referred to clinics or services led by psychologists or psychiatrists, which promote an inappropriate bio psychosocial approach, incorporating psychiatric techniques which potentially endanger the lives of people with ME.

These services should not discriminate against ME patients and should pay due regard to providing ME patients with equality in provision of service that patients of other neurological diseases and seriously disabling conditions receive, providing equal access to trained, qualified and experienced staff, who can provide a safe, quality and responsible bio medically centred service which honours and aims to treat the serious physical disease and multi-system dysfunction. It is unreasonable to deny ME patients access to these services. ME patients must be allowed to opt out of the psychological treatment of ME, and the freedom to choose a proper biomedical service which would treat them with dignity and respect.

Treating ME as a psychosomatic illness ignoring the who neurological listing of ME is a degrading way to treat ME patients when there is robust evidence to show that ME is bio medical.

The introduction of Choices for ME and correct appropriate bio medical testing treatment ,symptom control and the associated improvement in services and prognosis/outcome that this would bring would also be of significant financial benefit to the state, with fewer patients dependent on benefits and able to take a more active role in the Big Society.

Under the present system, diagnosis can take years and all studies on outcome in ME have shown the earlier diagnosis is made and proper treatment is administered the better the prognosis/outcome is.

Unless the underlying focus of the clinics is changed and appropriate biomedical criteria are introduced , such as the Canadian Criteria, specific for ME, as opposed to Fatigue conditions, including psychiatric illnesses, there will not be proper choice enabled or accurate diagnosis

Carruthers and van de Sand : An Overview of the Canadian Consensus Document  
[http://www.mefmaction.net/Portals/0/docs//Canadian\\_ME\\_Overview\\_A4.pdf](http://www.mefmaction.net/Portals/0/docs//Canadian_ME_Overview_A4.pdf)

#### **Q4. What would help more people to have more choice over where they are referred?**

1) Patients of all illnesses including ME are made aware that they should be entitled to an informed Choice in order to give valid consent and that if they feel they are being denied that right, there is a well defined and easy complaints system which if appropriate changes are not made and resolution cannot be reached via these channels can ultimately be settled in a legal setting.

To actually have a free choice, other options, apart from the inappropriate and dangerous bio-psychosocial approach, must be made available on the NHS, It is not good enough that the only choice available for appropriate treatment is to opt out of the NHS provision because it is inadequate and inappropriate.

2) Unbiased discussion of choice should be built into each and every consultation even if some services would necessarily have more choice options than others. This should be honest and open. If consultation is just paying lip-service to a principle, then it is a waste of people's time and

So, for example, if a patient is referred for suspected ME, then the GP should explain that the choices are limited, because service provision within the NHS is based on the NICE guidelines which do not offer a fair representation of the robust bio medical evidence consisting of over 4000 research papers and the NICE guidelines have been declared unfit for purpose by almost all charities and expert patient groups alike.

That the Canadian guidelines are an accurate and appropriate resource for diagnosis treatment and symptom management, along with the ESME guidance for most up to date treatment and research. Patients should also be directed as a matter of course, to websites, support organisations, and expert patient groups (e.g 25% ME group for the most seriously ill patients) where they can view patient surveys information of what patients have tried and tested and found to work.

Currently, if an ME patient is referred at all, it is often with no explanation and it is to the nearest ME clinic, or to CBT/GET physiological service, the majority of which treat ME as a psychological illness, which often leaves the patient distressed and takes away any control over their treatment. This is despite the fact that the Department of Health accepts it as being neurological in accordance with the World Health Organisation. . There needs to be the choice of proper biomedical tests and new biomedical treatments provided by the NHS. This would be real choice.

In some illnesses, to have any choice at all, a subgroup of the most severe patients would have to have the option of home treatment as the level of their disability would prevent them from travelling and accessing services and cause a worsening of their condition. In the case of ME, 25% of patients are severely ill, housebound and unable to travel to service providers or doctors for treatment of their ME and/or other healthcare conditions, and this remains an unmet need for diagnosis and treatment. .

Doctors should not be able to choose not to visit people with Severe ME at home whose disability prevents them from travelling, and should not be judging patients, without the use of proper diagnostic criteria to determine their disease and without adequate testing being provided.

**Q7. When people are referred for healthcare, there are a number of stages when they might be offered a choice of where they want to go to have their diagnostic tests, measurements or samples taken. At the following stages, and provided it is clinically appropriate, should people be given a choice about where to go to have their tests or their measurements and samples taken:**

- **At their initial appointment - for example, with a GP, dentist, optometrist or practice nurse?**
- **Following an outpatient appointment with a hospital consultant?**
- **Whilst in hospital receiving treatment?**
- **After being discharged from hospital but whilst still under the care of a hospital consultant?**

I believe that the patient should have the choice at all stages. This can only lead to improvement in services. The first choice in the line, at diagnosis stage, is particularly important in illnesses such as ME.

As an ME patient, if I could elect to have quick accurate biomedical diagnostic tests (markers such as immune system abnormalities, antiviral enzyme dysfunction (RNase L), decreased NK

cell number and function, increase in activated T cells and increases in inflammatory cytokines/chemokines) PECT and SPECT scans which will enable a diagnosis according to Canadian Consensus Criteria then my prognosis/outcome would be better and my treatment more appropriate compared to what happens currently with no choice involved i.e. diagnosis based on patient-referred symptoms fitting into the loose Oxford criteria and based on the prior exclusion of other illnesses which slows down the process of diagnosis and leads to a lack of appropriate treatment not just for ME patients but other illnesses that get misdiagnosed using the Oxford criteria.

If this choice at diagnosis were possible, then patients with ME could elect to be seen at clinics which correctly treat their illness as organic (e.g. testing for and treating of comorbid infections, new and reactivated viral infections, gastro intestinal and cardiac symptoms) such as the proposed National Centre of Excellence for ME at University of East Anglia / University Hospital Norwich which in turn can lead to improved prognosis and a return to the Big Society for ME patients.

The wasteful current treatments often offered to ME patients by psychology led services would soon become redundant as so few people would elect to go there in the knowledge that their treatment is totally inappropriate and based on belief not evidence in most cases.

**Q9. Would you like the opportunity to choose your healthcare provider and named consultant-led team after you have been diagnosed with an illness or other condition?**

Yes, as long as all providers agree to adhere to the patient rights and responsibilities in the constitution of the NHS in order that all service providers offer a safe quality and responsible service, and all service providers pay due regard to providing equal access for severe patients, and those house and bedbound.

**Q10. What information and/or support would help you to make your choice in this situation and are there any barriers or obstacles that would need to be overcome to make this happen?**

There needs to be full information available on all services. This should not be restricted to information only on quality. Other aspects should also be disclosed. In the case of ME, for example, the information should include the resume of the lead clinician, whether their main area of expertise is ME, whether they support a biosocial or a biomedical approach for ME are they trained in the systems affected by ME, such as neurological, immune, endocrine, musculoskeletal as with any neurological disease, which conferences they have attended for updates on research, whether they offer diagnosis only (as is often the case), and whether they offer treatment, and if so, what type

If they do offer treatment, what type of treatment, patient drop out rate, patient take up rate (i.e. how many patients who are within the local area, choose to go somewhere else or in the case of ME, opt out of the system rather than be forced to go to the only service available but unsuitable or harmful) and are there any patient testimonials available.

The pros and cons of this type of treatment should be clearly presented and unbiased taking into account the points of view of the clinician, patient support group surveys, international scientists, have concluded that CBT/GET cannot be considered to be curative therapies. If there is a risk, that any treatment may cause harm as is the case with treatment offered for ME, then this should be highlighted.

However this will only happen if the NHS uses the correct criteria to identify patients with neurologi-

The use of the Oxford Criteria means the patient group is muddled and neuro-immune illness is mixed with a depressed cohort, and allows for inclusion of other serious illnesses that present with fatigue, including cancer. In fairness to ME patients the Canadian guidelines allow for correct diagnosis of the neuro-immune illness Myalgic, to provide a safe and quality responsible service these guidelines must be used.

The main obstacle that needs to be overcome before I make my choice of healthcare provider/named consultant led team is that choice needs to be introduced into ME treatment as there is currently none. Other barriers include the current total exclusion of any other input into the information process other than the Wessely School of Psychiatry who, paying no regard to available bio medical expertise, make up far too large a majority on the Guideline Development Group advising NICE and who go unchallenged except by patients who currently have no control over the situation.

This situation has led to the creation of two other barriers: Many professionals who should be in a situation to support me in making my choice, cannot do so as they have been discouraged from embracing bio medical research by the stranglehold of the psychiatric school of ME and their influence on the NICE guidelines, which has directly led to and caused a destruction of ME patients rights. While doctors are allowed to prescribe outside the NICE guidelines, they incur thereby greater responsibility and many do not have the knowledge to and are just not prepared or able to take on that risk.

Providers should also provide a statement clearly identifying how they interpret ME, what they consider ME to be and who they are offering treatment for.

#### **Q12. What else needs to happen so that personalised care planning can best help people living with long term conditions have more choice and control over their healthcare?**

The NHS needs to reconsider the definition of long term conditions so that ALL people with long term conditions automatically have the option of a personalised care plan. Most ME patients are currently denied this option. Accurate truthful information is needed to allow patients to make an informed choice on creating a long term health plan. A health plan will be misguided if there is not a biomedical option, in bio-medical illness, and information provided to give free informed choice and valid consent.

The body responsible for the writing of the guidelines of what is needed in a long term plan should be non biased and there should be provisions for patient advocacy groups named by the patients to have an influence in the drawing up of the guidelines. If an advisory body such as the European Society for ME exists at a different level, then their advice should also be taken into consideration along with groups such as the 25% ME group and Invest In ME. Indeed, this would increase affordability as resources and research would be shared.

Social care to assist with self management are important to be a part of any care plan. And if not met increase symptoms and can cause a worsening of symptoms (which can lead to fatality) and condition directly related and linked to these unmet needs. Patients can pace and feel empowered to self manage with these payments for social care and would be able to pace themselves which is known to be a very important part of stabilising condition and avoiding relapse.

The mitochondrial functioning test is an affordable option for measuring the level of a patient's disability and functional pace level via blood tests.

Not making social care a part of any care plan can also have a direct effect on mental health and wellbeing as a direct result of and directly relating to lack of social care and appropriate support.

Some patients have chosen to commit suicide rather than live with the loss of quality of life related to disability ill health and pain thresholds, this is especially so in the case of severe unable to live an independent life direct payments for example would help to overcome this problem regarding care needs.

**Q16. What sort of choices would you like to see about the NHS treatment that you have? Treatment could mean therapy, support for self management, medication or a procedure like surgery.**

I would like choice of bio medical treatments for which there is robust evidence which take into account current peer reviewed research It cannot be considered unnecessary and must be considered unreasonable not to offer choice of bio medical testing and treatment with appropriate specialists as detailed in questions above. Choice of treatments that local commissioners think are appropriate are dangerous and lead to increased disability with poor outcomes as patient surveys clearly show.

I would not expect to be refused any help or support if I declined treatments which not only do not fit the above criteria, but which I deem dangerous to my health and not in my best interests or those in my care. It is within my rights to decline treatment which is not in my best interest.

I would also like the choice of support for self management advice and instruction by Expert Patient Groups, who in the case of ME , are currently best placed to give this support eg "A Care Pathway for Patients with Severe ME" by the 25% group: <http://www.me25group.org>

**Q18. How do we make sure that everyone can have a say in their healthcare?**

By examining in more depth the meaning of "*No decision about me without me*". i.e. not only should we ensure that individual patients are well informed about their illness and treatment options, but also that advocacy groups and patient surveys play a part in the gathering of that information so extending the patients rights as an individual to his rights as an individual within a patient group.

A patient can not be said to have a say in their healthcare if they make a decision based on incomplete or wrong information. This is the only way to prevent an individual or group within the medical profession for whatever reasons, feeding incorrect information into the system denying the patient any real say in their healthcare.

A well defined formal shared decision-making protocol should be drawn up and adhered to. Patients should have the right to request or be automatically offered a review of this protocol in relation to their case and the outcome should be recorded and acted on if appropriate. This procedure It would also have highlighted the breakdown of Choice for ME sufferers.

The protocol should cover things like:

1) Records to be kept re training of all health professionals which is a compulsory starting point in making sure that everyone has their say in their healthcare. During any consultation at any level the professional should always have at the back of their mind not only "what choice am I offering this patient and am I making it clear that they have a choice?" but also " how am I involving this patient/carer, is this patient engaging in the decision and if not, what can I do to engage them more?"

2) Clear independent Department of Health guidelines which have allowed patients their right to be involved in the planning of their healthcare services, the development and consideration of proposals for changes in the way those services are provided and in decisions to be made effecting the operation of those services and what choices are needed.

These guidelines should not be static and should allow for frequent reviews of current UK and international bio medical research. Again it must be considered unreasonable not to have procedures that take into account the bio medical research as this would not be a fair representation of facts and is leading to discrimination and unequal access for ME patients compared to access other neurological and seriously disabling illnesses have.

In the case of ME, these reviews could be facilitated by the European Society for ME whose mission is to “create a Think Tank where top scientists from relevant fields can discuss current ME knowledge in order to determine the most crucial direction of future research, and to provide a reliable source of cutting-edge ME information that ESME will incorporate in the education of medical professionals” This would have prevented in excess of 4,000 medical papers proving the organic nature of ME being ignored. Mechanism for patient input which should be formally recorded as per their rights to be involved. All healthcare professionals would be bound to consulting these changing guidelines regularly updated with latest bio medical research on a regular basis. Unless these guidelines are more dynamic than they currently are, then the patient is excluded from any say in their healthcare as they would not have the true picture which must necessarily form the basis on which they form their opinion

3). There should be a democratic process for electing members of the committee drawing up these guidelines with a public veto by people with the illness and their carers, to avoid members being elected or remaining on the committee when it has been proved they have a vested interest in any outcomes.

The onus should be on the committee members to provide sufficient evidence to satisfy the public that there is transparency in their recommendations, and declare whether they follow a psychosomatic or bio medical school of thought. Demonstrate that they represent the views of the patients they represent, and patient input has been sought.

When a case for judicial review of the NICE guidelines was recently brought by ME sufferers, over 20 internationally renowned ME experts provided damning statements in support of the claimants case. No transparent explanation of why these statements were ignored was offered,

These measures would prevent a repeat of unacceptable situations such as the historic lack of choice for ME/CFS patients. The current set up, with no safety mechanisms, has allowed a weighted presence on the GDG of experts in psychiatry and psychology (who feed recommendations to NICE on this organic illness) to the exclusion of any members with appropriate bio medical expertise in clinical definition, analysis and research of neurological ME and has lead to the situation where most ME patients feel that ME/CFS has been hijacked and there is nothing they can do about it. They can not have their say in their healthcare sometimes with disastrous or even fatal consequences such as in the case of Sofia Mirza, who died from M E aged 32, having been previously committed against her will to a psychiatric unit, because her bio medical neurological illness was treated incorrectly as mental health. This incorrect treatment lead to a deterioration in her health from which she could not recover.

<http://www.sophiaandme.org.uk>

Ean Proctor was also sectioned against the wishes of his family, and while in the mental hospital, to compel him to move, the staff placed Ean face down in a swimming pool without water wings. Too weak to doggy-paddle, he sank underwater and had to be rescued. see link-  
<http://www.cfscentral.com/2010/06/hard-cell.html>

### **Q23. Should healthcare professionals support the choices their patients make, even if they disagree with them?**

Yes, especially in cases of illnesses where there is a lot of discrepancy between what patients ask for and what choice is offered. ME patients know the pace they can work at without causing relapse or worsening of symptoms and more progress would be made towards recovery if healthcare professionals listened.

A good example of this is a survey of over 4,000 ME patients carried out earlier this year by the ME Association which indicated that 3% of ME patients improved greatly with Graded Exercise Therapy and 55% regressed. 75% of patients trying CBT, and 60% trying the Lightning Process, found it made no difference or made them worse.

In a survey carried out by the 25% group (most severely affected), these figures were even more conclusive (arriving at 85% adversely affected and 10% no difference) and many severe patients were not severe before having graded exercise therapy.

This finding was backed up by 4 previous similar surveys and is what patients have been telling their doctors for years and yet the care givers are not listening and continue to offer harmful and wasteful therapies. In some cases this can lead to an outcome of disability for life or even prove fatal.

### **MAKING IT HAPPEN**

### **Q41. Do you agree with proposed approach to establishing a provider's fitness to provide NHS services? What other criteria would you suggest?**

No, it is not comprehensive enough. The public need to have veto on who sits on the Care Quality Commission to ensure that there are no vested interests and quality of care is first priority. Private companies or service providers are by very nature run to make profit, severely ill patients may prove less profitable and attract less service providers and therefore choice. Without any democratic input into this process, the field is wide open to abuse and manipulation

When they are considering whether a provider is safe there should be a well defined process including consideration of the following points:

1) what criteria the provider base their initial diagnosis on. This is particularly important in the case of ME as a diagnosis based on the loose Oxford criteria (which have not been adopted anywhere other than the UK) is not helpful to the patient nor to research. For example, the PACE trial (results due out soon) included patients (mis)diagnosed according to the Oxford criteria, thereby invalidating the results for patients who can also be diagnosed with the more stringent Canadian Consensus Criteria.

In a recent study of ME CFS services in Newcastle, it was found that 40% of patients had been misdiagnosed in this way and therefore 40% of funds destined for treating ME patients are being spent on treating other illnesses incorrectly. In fairness to those misdiagnosed patients who do not have ME they need correct treatment for their illnesses

[http://www.rcpe.ac.uk/journal/issue/journal\\_40\\_4/newton.pdf](http://www.rcpe.ac.uk/journal/issue/journal_40_4/newton.pdf)

This has very serious implications for the suitability of any subsequent treatment. Any provider who is prepared to waste government money in this way and to harm patients, can not be considered safe or fit to provide NHS services .

2) what precise evidence their preferred treatment(s) is/are based on. Any provider should not be permitted to overstate the evidence for any one treatment. In cases where they have done so and evidence actually shows that they are ineffective or harmful, then those providers should be deemed not fit. In the case of ME, this process would rule out providers who claim that CBT/GET and the Lightning Process are curative.

The LP is based on an unproven scientific theory and is subject to a ruling by the Advertising Standards Authority against the miss selling of the process as having the ability to aid recovery in people with ME. The current trial of LP on children is also widely held to be unethical with both the ME Association and Tymes Trust making joint statement condemning the trials of the lightening process in children as unethical.[http://www.meassociation.org.uk/?page\\_id=1341](http://www.meassociation.org.uk/?page_id=1341)

3) If the provider is offering treatment for ME patients then the Care Quality Commission

- a) should be looking for transparency so that the patient has a real choice. For example if there were transparency, an ME patient would then be able to make an informed choice between a clinic that offers bio medical testing /treatment with counselling for ME patients to help cope with the devastating effects of ME or a clinic that offers Cognitive Behaviour Therapy and Graded Exercise Therapy as they believe that ME is a psychosomatic illness. A clinic that disguises its motives is not fit to provide NHS services and allow ME patients to be treated with dignity and respect. Anything less than full transparency is degrading to patients, and does not allow for an informed choice and valid consent.
- b) Should request documentation on what tests the providers carry out to make sure that alternative treatments offered are suitable for particular patients. For example, if an ME patient has not been tested and treated for new and reactivating viruses/infections and symptom management, any provider who offers them a therapy (such as GET) which makes them worse, should be deemed not fit and irresponsible.

4) Is there proof that they are keeping abreast with international research? If not, they can not be

**Q43. Do you agree that an “any willing provider” directory should be established to make it easier for commissioners to identify providers that are licensed and have agreed to the NHS standard contract terms and conditions?**

There needs to be tight control over the licensing of the providers (see above), and all providers agree to abide by the constitution of the NHS in order that a safe, quality and responsible service is provided by all service providers.

**Q45. How can we make sure that any limits on choice are fair, and do not have an unequal effect on some groups or communities?**

A process needs to be set up whereby any limits on choice need to be explored, documented and explained throughout the process starting with diagnosis of ME. In fairness to ME patients limits on choice of correct bio medical diagnosis and treatment must be considered unreasonable, and harmful to outcome. NHS must even in times of economic difficulty pay due regard to equality and patients right to treatment for a potentially fatal illness. A limit on bio medical choice at diagnostic

level for ME would have an unfair effect on subsequent provision of correct treatment and therefore lead to discrimination in provision of and access to appropriate bio medical service and social care provision. In particular the needs of the 25% severely ill ME patients needs must be taken into account.

If the limit on choice at diagnostic level was lifted and patients had the choice between diagnosis according to loose Oxford Criteria or the more acceptable Canadian Consensus Criteria, then much of the discrimination against the ME community would automatically disappear with the more accurate diagnosis, it would be easier to introduce choice for effective treatment.

Any limits on choice also need to take into account the manifestation of a particular disease. For example, if there were a blanket limit on home visits, then that would have an unequal effect on the ME community compared to other illnesses due to 25% of ME patients being severely ill for whom travel can lead to a serious worsening of symptoms and deterioration of their health. For those patients house and bedbound travel would be impossible.

## SAFE AND SUSTAINABLE CHOICES

### Q48. How far should we extend entitlements to choice in legislation and hold organisations to account against these?

Patients have a right to be involved in discussions about their healthcare, and to be given information to enable them to do this. Be this being involved directly or through representatives in the planning of healthcare services, the development and consideration of proposals for changes and in the way those services are provided and in decisions to be made affecting the operation of those service.

It is unfortunate that process is being considered before there has been a proper opportunity for discussion about strategy and evidence involving patients, before the proposed changes in choice are put into legislation. If this is not allowed for there could be a fundamental problem because of bias within the system, and ME patients could do nothing about their lack of choice which has arisen because of the bias introduced by the dominance of the theories as expounded by the Wessely School of somatoform ME/CFS.

This would lead to an **unsafe** assumption that those in control of the NICE guidelines in ME/CFS are able to understand the biology underlying the symptoms and has led to widespread ignorance in the medical profession, blocking the voices of those medics actually qualified to comment on the biology of ME.

Without legislation in choice and in the case of ME, the consequent enforced overhaul of the NICE guidelines and taking on board of points made here and by Invest in ME in the document linked below, sick people will continue to be vulnerable to exploitation and abuse. In the case of ME, organisations should be held to account by legislation and made liable for harm inflicted by unsuitable treatment which they have offered without proper consideration of evidence.

### Q52. Are the responsibilities of organisations as outlined enough to:

- ensure that choices are offered to all patients and service users where choices are safe, appropriate and affordable?
- ensure that no-one is disadvantaged by the way choice is offered or by the choices they make ?

No, the responsibilities as outlined without the changes that I have proposed, would not put an end to the unacceptable discrimination and destruction of rights of ME patients who are denied choice and hence due regard would not be paid to providing equality with other neurological and seriously disabling diseases. Along with equal access to services for severe and house and bed bound patients who are currently disadvantaged in provision of and access to healthcare.

The DoH should not be satisfied that the responsibilities of organisations to provide a safe quality and responsible service are enough until the documents below have been read and the decision is reached that you have broadened organisations' responsibilities to such an extent that all the issues contained in these documents could be rectified by reminding organisations of their responsibilities

[http://www.investinme.org/Documents/NICE/liME%20Submission%20to%20NICE%20Review%20of%20Clinical%20Guideline%20\(CG53\).pdf](http://www.investinme.org/Documents/NICE/liME%20Submission%20to%20NICE%20Review%20of%20Clinical%20Guideline%20(CG53).pdf) ( Invest in ME's submission regarding Review of Nice Guidelines

<http://www.sophiaandme.org.uk/> (How lack of choice and control lead to Sophia Mirza's death as her ME was treated as a mental health issue denying her proper treatment for a neurological disease)

[www.meactionuk.org.uk/magical-medicine.pdf](http://www.meactionuk.org.uk/magical-medicine.pdf) An in-depth account of the history of supporting bio medical and dangers of inappropriate psychological treatment.

**Q53. If you do not get a choice that you are entitled to, what should you be able to do about it?**

I would like to be able to have a voice in the discussion on why the mechanism for enabling choice has not worked and why patients right to be involvement has not been allowed for.

I would also like to register my lack of choice on a national database using Link groups to register complaints on a local and national basis. This database would then be able to highlight geographical areas where there is a lack of choice and also specific to ME patients areas where there are no choices, paving the way for improvement in those areas.