APPG on ME

21 October 2009 1.30 pm

Des Turner MP (Chair): Ladies and Gentlemen. Thank you for coming to the meeting of the APPG on ME. Our star performer today is Yvette Cooper. She is not here yet, but she is definitely coming. I suggest that while we wait for Yvette, we slightly rearrange the agenda to avoid wasting time and deal with minutes and matters arising. Have the minutes been circulated?

Heather Walker: Yes. There was just one amendment.

Chair: Are people happy with the accuracy of the minutes?

Heather Walker: I have one apology to make because Doris Jones was not present at the last meeting, as she was preparing the APPG inquiry meeting for the day. That was my mistake.

Chair: Any other comments on the minutes?

Sir Peter Spencer: Mary Jane Willow has asked me to offer her apologies for today's meeting. She is not well.

Chair: Okay. Before anyone changes their mind, let us adopt the minutes as a true record and proceed to matters arising. We already have a list of matters that we intend to deal with. The first is this group's inquiry into NHS services. That is proceeding; we have the evidence and the drafting is in progress. We are approaching a first working draft, which will be circulated among Members—the parliamentarian group—for finalisation and comment. I will also submit it to Charles and Peter for their comments. Hopefully, by December, we will have the final report. I suggest that we make the report the subject of the group's next meeting, and that we ask a Health Minister to attend to respond to the report. I am not going to tell you what the report contains yet, but it does say some critical things about health service delivery at present.

For me to be present, it would have to be in the first week of December. Is that acceptable to people? That is our target. It gives us a target; it will have to be ready and published. It will not be a glossy report because it will have to be published as cheaply as possible, but it will be there in the first week of December. I nominate the Wednesday of that week. December 2—we have a commitment there. Are people happy with that?

Sir Peter Spencer: On a point of detail, if people are going to come and discuss the paper, we should bear in mind that for some it is more of a challenge to get through a large document than for others. We probably need to agree a date by which the paper will be distributed, so that people have got time to read it, consider it and talk to members of their groups about it.

Chair: We could do that. It depends how quickly we can get the report printed. We could perhaps circulate a summary and the recommendations of the report to everybody.

Sir Peter Spencer: I am just concerned that occasionally, we have inadvertently but incorrectly put people under too much pressure to be able to take an intelligent view of a report that they will feel quite strongly about.

Chair: Yes. The other thing to consider is that it would be good for the report to have the impact of a Select Committee report. You do not get that if you let it dribble out. You have to put it out at once. There are two sides to that. If we circulate it, I strongly suggest that Members regard it as being embargoed until the publication date at that meeting, and be fairly strict about that. We want it to make the maximum impact. Are there any other comments?

Michelle Goldberg: The CFS/ME working group report was quite substantial, and was also given to the Department for Work and Pensions. It had significant responses to the lack of service provision. Is that going to go in as supplementary? Will that be referred to?

Chair: Are you talking about the original CMO's working group report? That was back in 2002. Clearly, in our report, there is reference to that report and to what has happened since. The answer is yes.

Paul Davis: I am Paul Davis from RiME. I want to say that we are setting up a bank of evidence. RiME has received well over 50 copies of evidence submitted to the inquiry. Having read the large majority of them I can report that, with one exception, they are wholly negative. ME patients are not writing in with concerns saying, "It's a good start but it needs to be improved". Rather, they are saying that the basis on which they were set up—the CMO report—was bogus, and we don't want it.

Chair: We obviously have that evidence, but I don't want to prejudge the report before it is published. There are obviously a lot of negative comments, and they will be reflected.

Paul Davis: Yes, but can I say one more thing? ME patients are not interested in matters such as structure, finance or the postcode lottery.

Chair: They are if they are on the wrong end of it.

Paul Davis: They are saying that if the nature of the services is no good, those other matters become irrelevant.

Chair: We are virtually starting to discuss the contents of the report without the report, and I don't think we should do that. Hold that for the next meeting when there will be a full discussion.

Paul Davis: Sure, okay.

Ciaran Farrell: I would like to pick up on the point that Peter made in relation to some specifics. Not everyone here attended the second evidence-taking session. As I am sure you will know, Chair, the Minister Mike O'Brien said some extremely interesting things about the way that the postcode lottery, for example, should be addressed by local action that would be taken by national ME charities, local patient groups and a consortium of local patients and carers.

I do not want to prejudge what may be in the report, but I can see that there is a difficulty regarding the consultation over what would happen. This is an issue where I really feel that all the local groups, as well as the national charities, need to have a very clear input. It seems to me that the inquiry report will only have the impact it seeks, if those sorts of factors can be dealt with effectively through some sort of consultative process.

This is not only about the services involved. There was also the suggestion—I don't know to what extent the panel will take it up, and I don't want to prejudge matters—made by Lady Mar about some kind of ME or fatigue nurses in GP clinics. That would also involve fundraising by this local consortium, according to Mr. O'Brien. Consultation on that issue, as well as on a number of other issues, is absolutely key. It is simply about how we think of a mechanism whereby people's views can be fed in so that they can have a say. The report will be stronger for that.

Chair: Again, we will have to wait until we have the report before we have that discussion. Is there anything else, bearing in mind that the report is not ready yet and has not been published? We will save discussion on the report for when we have it.

Paul Davis: During the oral presentations, ME patients believe that matters outside the terms of reference were allowed by the Chair.

Chair: I was being flexible.

Paul Davis: It was specifically on the issue of lightning process.

Chair: The report will consider that.

Paul Davis: Yes, but ME patients are saying—are you aware that the lightning process is being practised in clinics set up following the CMO report?

Chair: I am aware that it is being practised.

Paul Davis: The terms of reference say that it is about the clinics set up following the CMO report.

Chair: Sorry, I do not see the problem.

Paul Davis: If there are terms of reference, should they not be stuck to?

Chair: The terms of reference do not specify any particular therapy.

Paul Davis: No, but I say to you, is the lightning process being practised in any of the clinics that have been set up?

Chair: It would be pre-empting the report to discuss that. I do not recall any of our evidence suggesting that that is so.

Paul Davis: But you are reported as commenting positively on the lightning process.

Chair: I cannot remember what I have said. It was probably along the lines of, "It sounds as if it is worth looking at."

Paul Davis: Well, ME patients would say no.

Chair: Let us wait and see.

Ciaran Farrell: On the same point, that has caused a lot of consternation, because there was a certain amount of reporting of a witness to the inquiry speaking at length about the lightning process, and obviously undergoing considerable questioning from panel members about it. I hear what you say about being flexible, but a lot of people in the ME community, including myself, would welcome some kind of statement as to the flexibility that you are using. People cannot see how the lightning process fits into the terms of reference.

Chair: It is just one other attempt at therapy on a list of many.

Christine Harrison: I would like to try and bring a positive note to that. I do not know how to beg or implore that you will get the right answer to this. As people are aware, we had the best service, but for three years we have struggled against everything and we are left with nothing. We have gone through every due process—we have done everything that has been asked of us. We have gone through every procedure, and we are left with nothing. We hope that this will have some impact, because how else do we get people to listen? We have been told that money is not the problem.

Chair: Exactly. It should not be the problem.

Christine Harrison: We have been told that money is not the problem. Obviously, it is an attitude to the illness. We have everybody waiting to take over the service, and we just can't get it. I hope that you can create some impact for us.

Chair: I devoutly hope so too, Christine.

Shall we move on? The next topic is about the future of the group which, after the general election, is in the melting pot. I shall not be here, and I expect that several other Members will not be here, whether voluntarily or not. We just don't know.

Dr. Charles Shepherd: Will you still join us if you get elevated to the House of Lords?

Chair: Charles, I think that is about as likely as a squadron of flying pigs.

Janice Kent: I think that we should have some optimism. Let's look on the positive side.

Chair: I am definitely not counting on that one. We have to identify a prospective victim, if we can—I use the term advisedly. I don’t think that we can do that now, but I hope people will bear it in mind as it is clearly a problem. All-party groups have to be reformed from scratch at the beginning of a new Parliament. However, we can—and shall—leave views about the sort of work that we think the group should be doing, and a draft legacy paper has been tabled. Has everybody got it? It sets out the scope and programme that the next incarnation of the group might wish to follow. Of course, the group will not be bound by it in any shape or form, but this is a fairly comprehensive list of activities. Does anyone have any comments?

Ciaran Farrell: Because this paper has been sent round today, could it be put on the APPG website so that a consultation process can happen? That is simply because it is difficult for us here today to read through and make comments.

Chair: That is fine.

Sir Peter Spencer: That was always the intention.

Chair: We can do that. I know how attached you are to consultation. We can certainly satisfy you.

Ciaran Farrell: Thank you.

Chair: Does anyone have any initial comments?

Joy Birdsey: In the meantime, what is happening? Even though we have a helpline, I have not got any positive help to give people who are really struggling. By the time you get the report out, I was hoping that I would have some positive things to say to the people on the end of my phone. At the moment, I feel like I am banging my head against a brick wall. I have people saying, “I have been rejected for the mobility allowance. I have been rejected again and again. I keep appealing.” I have people saying, “But I was on there, Joy, and now I am not. I am being treated by everybody at the DWP as a psychiatric patient.” From the point of view of my helpline, I think I need more positive feedback from you to give to the media and to help with education. These people should not be treated like this. We have parents and adults—one adult has been told that if he doesn’t get his act together, he will be on £12 a week.

Chair: This is an issue that you should be taking up with Yvette when she arrives. I know that it is a very serious matter—I have dealt with a number of cases in my own casework. I know how difficult it is, despite the fact that the regulations for the disability living allowance actually make provision for the circumstances of ME.

Joy Birdsey: It does, yes.

Chair: But decision makers don’t take any notice.

Joy Birdsey: That’s right.

Chair: I have been able to go along to tribunals with constituents, and successfully get tribunals to recognise this and award it.

Joy Birdsey: We must do something about the tribunals. Several of the people who phone me up after going in front of the appeal courts feel that they have been treated worse than a prisoner. This is serious.

Chair: It is so dependent on the make-up of an individual tribunal panel. If you get a good one, it is marvellous. You can get absolutely inhumane ones at times.

Joy Birdsey: Yes. That has been the experience of quite a few of my group. It is going on and on, and I have nothing to offer.

Chair: This is an issue to take up with the Secretary of State.

Joy Birdsey: Will we have time?

Chair: It is a central issue, so I think that the answer is yes, we will have time for that.

Christine Harrison: Can I just extend that? I am challenging one of the issues in the Green Paper—I was speaking of the document at a meeting. They said that they are not at that stage yet…but if you are going to have a national assessment, you have to have an appeal system alongside it, especially if you have a fluctuating condition. That was one of the things that I thought we should keep an eye on.

Michelle Goldberg: On the same subject, there are a number of things that I have identified in various areas of current law that, to me, are part of the profile of how people are being treated. They are in the Human Rights Act under domestic violence, hate crime and vulnerable adults. Perhaps I can read it to you, because these are the kinds of things that people are coming up against, and they are illegal.

The Human Rights Act, article 3, prohibition of torture, states that no one should be tortured, punished or treated in a way that is degrading or inhuman. It is very serious to breach article 3. It goes into more detail, and makes reference to cases of social services. Article 8 is about having respect for everyone's family life, home and correspondence, and the right of people to get on with their lives without interference and to control their body. Article 14 is the prohibition of discrimination. That includes many types of discrimination on a number of grounds, which are listed. The courts are likely to accept that the article covers discrimination against someone because they are disabled.

Regarding domestic violence and hate crime, the report has identified physical abuse and also psychological and emotional abuse. It says that domestic violence can include sexual, emotional or financial control. Under psychological or emotional abuse, it lists isolation, threats, manipulation, ridicule, humiliation, aggressiveness, jealousy and criticism. I am sure everybody who has had to deal with the services and the DLA, or a tribunal, would recognise some of those responses.

Then, there is financial abuse, which includes the controlling or withholding money, asking someone to account for every penny and so on. The Government define domestic violence. I would call this institutionalised domestic violence, which is any incident of threatening behaviour, violence or abuse—psychological, financial or emotional—between adults. There is a clear cross-over there.

The definition of a vulnerable adult in the 1997 consultation paper "Who decides?" is a person who is, or may be in need of, community care services, by reason of mental or other disability, age or illness, or being unable to take care of him or herself and unable to protect themselves against significant harm and exploitation. As far as I am concerned, that is exactly what the system is doing. I hope that that was clear in response to the failure of the NHS to provide services, and the problems that people are having with the DLA tribunals. People who are ill don't need to deal with such things, they just need to be supported and be able to get on with their lives and have the support that they need socially and financially.

Chair: I entirely sympathise. If it is any consolation, I know that ME/CFS sufferers have particular problems with the benefits services and particularly disability benefits. However, other groups do as well. People with straightforward physical disabilities also have terrible difficulties.

Joy Birdsey: And social services. People have problems there as well.

Chair: It is not so much institutional—

Michelle Goldberg: Abuses.

Chair: Well, it is to a degree abuse. There is an institutional attitude.

Countess of Mar: I got somebody discharged from hospital on the basis of article 3 of the Human Rights Act. I have quoted it to the doctors. I have used it.

Chair: Very good. I have never actually used it. I have only ever tried it on with the Home Office, and it never works with them.

Countess of Mar: But it would really take a court case, and nobody in the ME community has the money to go to court.

Michelle Goldberg: Or the strength, or the energy.

Janice Kent: Perhaps I can just endorse item 7 in the programme of work. As you know, I worked with AIDS patients in Brighton before I became unwell. They campaigned and got a consultant of their own, with only 84 active AIDS cases in Brighton. If you look at the areas and at the number of ME patients…we need more consultants and more help. And also, on the parity with multiple sclerosis, I had a friend who was diagnosed with ME and the diagnosis changed to multiple sclerosis. The abuse she received was appalling. She was admitted to her local A and E, with what was actually an exacerbation of MS, but they did not see it. One young doctor took her family to one side and told them that she was suffering from Munchausen syndrome. The effect of that on the family's attitude and the doctor's attitude was appalling. She said, "I like having multiple sclerosis, because I am treated with respect. Within a couple of weeks of the diagnosis I had a speech therapist, a special physio, a continence nurse and so on. I have the help I need."

Jill Cooper: I'd like to say that I like having Chromes disease. As soon as they diagnosed me, they could say that I was ill.

Chair: The important thing is that there was actually a clear physical diagnosis, which until now there never has been with ME/CFS.

Jill Cooper: But you have to look for it.

Chair: However, the latest findings with the XMRV virus might—just might—provide the key to that actual, measurable diagnosis which could make all the difference to attitudes.

Janice Kent: So might Jonathan Kerr at St. George’s as well. He is tracking that.

Dr Charles Shepherd: That is a very good point, but we must also accept that we have at least 500 consultant neurologists in this country, all of whom have been trained in MS, fully accept that it is part of their specialty and like dealing with it. There are another 500 or more senior registrars, or whatever, waiting to become consultant neurologists. Again, they are all trained in MS, they all know about it and want to get involved in a subject like that. We do not have that structure anywhere within any “ology”, as far as ME is concerned and that is a major stumbling block. It is not only finance that prevents services from being set up; it is the availability of suitable, qualified medical manpower able to deal with the assessment and management of this illness. This is not an MRC matter; it is the Royal Colleges, the medical schools, the postgraduate deans. Perhaps we should have someone like that along to one of our meetings.

Janice Kent: I think so. As I said, there were only 84 AIDS patients who were active, and they got a consultant. He has made such a difference to lives in that area.

Chair: There are rather more than 84 patients now I think.

Janice Kent: Yes, there are. There were many who had not made the flip. That was when there were 84 people actually with AIDS, who had been HIV diagnosed.

Sir Peter Spencer: It is clear that people have a lot of useful stuff to feed into this paper. To be boringly procedural for a moment, if we are to meet again on 2

December, accepting Ciaran's suggestion that this draft should be posted on the APPG website tomorrow, it is beginning to look as if we should seek responses by 19 November, which is in four weeks. That would give a realistic amount of time for those responses to be looked at, analysed, fed back into a revised paper, which can then be sent out in advance of the next meeting. Would that be a way of ticking off this item?

I am not trying to curtail the debate about the content, but there is a danger that we end up not having something in place which will take it forward. This was always meant to be about what other people felt, not something that was tabled to be tacked off. In the light of the example that has been set by the cross-party group in Scotland, there was a feeling that that model worked quite well there. It was a way in which we could lay something out and say, "This is the sort of thing that we have in mind. This has worked well elsewhere; this is the sort of granularity that is appropriate." If it is too long, it will not get read. If we want people—especially the parliamentarians—to feel that this is the basis for something that will be practical and useful, we need to get the content right and get the right balance from the patient group.

Countess of Mar: Could I put on the record our appreciation of the work that has gone into producing this paper? I think it is important.

Chair: Thank you for that.

Ciaran Farrell: I agree with what Peter has just said. He sort of beat me to it, as I would have suggested something along those lines. There is one other quick point, which is to return to the issue of the mobility allowance for ME sufferers. There is a specific problem, because although the medical guidance, which was produced through consultation with the ME charities and the DWP several years ago, addressed the medical guidelines, it did not address the decision maker's guide. Within the decision maker's guide, there are articles that advise decision makers not to award the mobility allowance if, in their opinion, the person's mobility is limited by what is described as the "psychological component" of ME, as opposed to the physical component. That to my mind sets up the assessment in an entirely wrong-headed way. The disability in its entirety ought to be looked at, not separated out into physical and psychological components.

Chair: But what should count is what it actually says in the regulations. The regulations are quite specific in making provision for people with a variable condition which means that if they undertake exercise, they are left much worse over the following days—someone may walk a couple of miles and do the shopping, and the next two days they cannot get out of bed. That fits in with the regulations, and that is what the reference should be.

Ciaran Farrell: I agree. I am trying to point out that there is a contradiction with the medical guidelines for CFS/ME that actually states that section 73 does apply in terms of ME. However, there are things within the decision maker's guide that detract from that when they should not.

Chair: That is a DWP matter.

Paul Davis: I would like to thank you very much for mentioning the research and breaking news that is coming from America. ME patients desperately hope that the British Government will begin to put some money into researching the underlying physical causes and disease process of ME.

Chair: That goes without saying. The research is extremely helpful and exciting. It is the first time we have ever had any sort of evidence of a cause for ME. If the association between the virus and ME is right, it opens up the avenues for evidence-based treatment, which has been completely lacking up until now. It will take some years for that funding to be translated into therapies.

Paul Davis: We totally agree with that. We must be cautious in terms of the findings. The point is that, to my knowledge, the British Government have not funded biomedical research.

Chair: Well…it is a chicken and egg situation. There have not been many proposals coming forward, and you can quite see why there has been a lack of good research proposals. Where do people start? Researchers look over their shoulders from their career point of view—or they have in the past—at what is called the research assessment exercise, and they are reluctant to go into fields where they have no idea whether they will come up with anything publishable. That has been the situation in ME and has bedevilled it. Now that these papers have emerged, we will see quite a rapid change.

Doris Jones: I understand that the details for testing for this particular virus are available from the Nevada Institute and can be obtained. I think they are already available in this country to some people. That being the case, cannot one or more clinic in the UK be charged with applying those tests?

Chair: It is entirely possible.

Colin Barton: I think that a number of clinics are doing that now. A couple of centres—they are doing it at Barts at the moment. They are even getting a group together at the moment to try and replicate what has happened in the United States. You must remember that this has not been replicated…we had the same thing in 2001, with the retrovirus research that was published in a good journal in America before. Unfortunately, that turned out to be a false dawn.

Chair: It is early days.

Nicky Zussman: There was a new statement this morning from Jean Michowitz, which was much more definite. It probably has not been seen by most people here.

Colin Barton: Part of it is about whether this virus is a cause or a consequence of ME. That is an important issue that has to be looked into. It is very exciting, but that is part of the work that has to be done.

Chair: There is an awful lot of work to be done.

Annette Barclay: But why do they want Barts to look at it?

Colin Barton: Barts is an excellent centre.

Annette Barclay: Barts has wasted our money recently. Does anyone else think that Barts has squandered our money? It has taken our money and spent it.

Chair: Okay, we are going to suspend that conversation for the moment. Yvette has arrived.

Welcome, Secretary of State. Yvette, you are the third or fourth Secretary of State from the Department for Work and Pensions to sit next to me at these meetings in front of the group, and we keep discussing the same problems. You will probably have a good grasp of them yourself. Do you want to say a few words before we open up the questions?

Yvette Cooper: I am happy to say a few things first. It is a pleasure for me to be here. Tony Wright MP and I first discussed setting up the all-party group on ME back in 1998. I obviously have a strong personal interest in it, having been an ME sufferer back in 1993. I was off work for about a year. I had to work part time for a year or two after that, and then it was another couple of years before I stopped getting any relapses.

I obviously have a personal interest in this, and although it is true that I am the third Secretary of State to come before the group, I think I am probably the only Secretary of State from the Department for Work and Pensions who has actually claimed sickness benefits. As well as having statutory sick pay for six months, I also claimed what was then invalidity benefit for six months, before going back to work. I was lucky to have a supportive employer who allowed me to work part time—I worked alternate days, as that was the best way for me to do it when I started back at work—and who was very considerate when I had bad days. I am very conscious of the difficulties and challenges that people can face. That includes both those who have the condition and can work, although they can only work certain times and need it to be flexible—that was the position I was in for some time—and those people who cannot work at all.

I am happy to listen to the concerns that the group wishes to raise. I have also been through the new work capability assessment, from the point of view of how I felt and the condition that I had at the time. I know that I was not able to work; I was desperate to get back to work, but would I have passed the work capability assessment in terms of getting the ESA? I have been through all those sorts of questions because I have a personal interest in it, but I am interested in hearing your views too.

We have done a lot of work to try to ensure that the whole approach to the employment support allowance takes account of fluctuating conditions and fatigue, not only inability to do things. It should look at those conditions where someone is able to do something, but it wipes them out for the rest of the day. It is not that someone cannot do a particular thing because they are incapable of doing it, but it wipes them out. That must be taken into account in the assessment process. A lot of work has been done to try and do that, and to build that in to the assessment process. I obviously have personal experience of how that is going, but we are keen to keep trying to do that, and ensure that we respond to what I know is a difficult condition. Des, I am in your hands.

Chair: That is a good start Yvette. I have a series of questions that have been submitted. Generally, it boils down to the issue of how people with a fluctuating condition such as ME get treated by benefit decision makers. This is an ongoing problem that has been recognised for years. Sadly, it is still current, despite the fact that, for instance, the regulations for the disability living allowance mobility component actually make provision for it. Although the provision is there, decision makers do not use it. People have to go through the tortuous appeals procedure, and may or may not be treated justly at the end of it.

I have two specific questions that I will put together. People with ME have told Action for ME that the new work capability assessments do not give them adequate opportunity to convey the fluctuating nature of the condition, that the descriptors used in assessing capability for work are not appropriate for people with ME, and that the venues are not accessible to those who cannot walk more than a few metres. People would like a response to that and to hear what plans you might have to address it. With specific regard to the DLA, how can a tribunal panel be trained to understand that post-exertional reactions to exercise make the mobility of a person with ME seriously impaired? That is the nub of the question.

Yvette Cooper: The whole purpose of this is to try and ensure that people have the opportunity to set out details of both fluctuating conditions and fatigue. There is a specific thing that clearly flags up what the fatigue issue is. If there are problems about venues not being accessible, that is clearly a significant problem. I would be keen to have details of any particular venues that are not accessible. It is clearly a problem if that happens, and we should look into it. The second question was—

Chair: The training of tribunal panels to recognise and understand that post-exertional reactions make the mobility of a person with ME seriously impaired.

Yvette Cooper: That is an interesting point. I think it comes back to the point that you made at the beginning, Des. Are such problems due to the framework and the people operating it, or is it about having the right sort of training and so on? The more we have examples that we can look into—the medics and medical advisers in the Department have been doing a lot of work to take that issue extremely seriously. That does not mean that everybody who applies for a particular benefit will get it, but it does mean that the assessment process should be fair and appropriate and should take people's personal circumstances into account.

Chair: It is both. It is lack of awareness and thought by decision makers—there is certainly a lack of imagination. It is not just about the decision makers, but also doctors who carry out examinations on behalf of the benefits agency. I will give you an example of a case I recently went to a tribunal with. It was a girl aged about 15 or 16. After she went out, she was laid up for two days. The disability living allowance had been applied for. I went along, fairly confident of getting her a low-rate mobility allowance, despite the fact that a doctor had written a report saying, "With cognitive behaviour therapy and so on, she should progress and get better." Of course, it isn't like that. That was clearly yet another doctor who was not very ME-aware. I was fortunate in that there was a tribunal with a doctor who did understand ME, and they insisted on awarding her a high-rate mobility allowance. The range of variations from no award to the highest award was rather excessive. It is not down to the regulations because they make provision. It is the way in which those regulations are being applied by DWP staff.

Yvette Cooper: James, I don't know if you wanted to come in? We have been trying to do a lot of work with medical advisers and assessors, in order to ensure that people are aware. Is there anything that you could add?

Dr James Bolton: My name is James Bolton, I am the deputy chief medical adviser. We have training programmes where we have worked with the decision makers in a department, to try and make them aware of these kinds of issues. I have responsibility for Atos Healthcare, which does a lot of the medical advice for decision makers. We work with it; we have regular ongoing training each year and we have had ME/CFS as one of the modules within that to promote awareness and ensure that practitioners are aware of those kinds of issues. We do quality monitoring as well—we keep an eye on them and like to see what is going on. We listen when people complain about individual practitioners, and we will look into that. We have all those things to try to deal with those issues.

Countess of Mar: My postbag this summer has been full of letters from people complaining about Atos and how the doctors sit at their computers, hardly look up at the patient, do no physical examination and do not appear to read the GP's notes or the consultant's note. They produce these things—there was one where everything was zero, right the way though, and the woman was declared fit for work, but she clearly was not. For a start, she is bowel incontinent—

Yvette Cooper: But there are specific questions on that.

Countess of Mar: Yes, but they had misinterpreted it, and said that she was bladder incontinent. I do not know whether that is because they do not have time to assess problems and do the reading properly. There was a letter sent to me from the press. Is it correct that they get £25 for each rejection?

Dr James Bolton: That is not true at all. They are not given any kind of target to turn people down. They are given an amount of time to do an independent medical assessment. We make no ask at all in terms of what that advice would be.

Countess of Mar: Because repeatedly I have descriptions of "examinations" that seems to be just checking a computer list. That is totally unsatisfactory. I wonder what the cost is each time someone goes to a tribunal.

Yvette Cooper: There is an appeals system, and there will always be cases that need to go to appeal in any system where someone is effectively doing a medical assessment on somebody's condition. We have the new work capability assessment in place, and that is still settling down—we are still monitoring the numbers of cases that are going to appeal on that. Also, we will be conducting a full review of the work capability assessment. The purpose of that is to focus more on what people can do, rather than on what they cannot do, and that is a good thing.

For our implementation process, it is obviously helpful to have feedback from the cases where things are not happening and where things are going wrong. However, because of the way that the test focuses on things that people can do, there will be cases where people will be found able to work, even when their GP might have come to a different conclusion. Their GP might have been thinking about the person's previous job, as opposed to thinking about whether they could do a different kind of job and so on. There will be differences between the GP's assessment and the work capability assessment. However, it is hugely important to ensure that assessment is done by people who understand this particular condition, and understand that it is different to a lot of other conditions.

Countess of Mar: I understand the argument about what people can do, but it is not just about that 20-minute slot when someone is in front of a guy with a computer. It is about what someone can do in the long term. People need to listen as well as look.

Joy Birdsey: I agree with you completely.

Chair: Okay. Charles, then Tony, then the lady in the corner.

Dr Charles Shepherd: I am Charles Shepherd, medical adviser for the ME Association. I would like to ask about the audit and monitoring of the introduction of this new ESA. The charities have been doing their own monitoring. Our feedback from people over 6 to 9 months is fairly limited—I cannot give you the exact number of people who have come to us following an ESA application—but the success rate is absolutely appalling. It is virtually something approaching zero per cent. of those people who have come to us. Some of the stories are really harrowing. These are people in real despair. They are people who, as you would recognise, are in the early stages of their illness and cannot get ESA. Presumably you are also doing some sort of audit, but I wonder whether you are doing it in relation to specific illnesses, and what the success rate—the turn down rate—is in individual illnesses. I hope that that is so, and if not, I would like to know why not. If it is so, what is the success and failure rate of people with ME?

Yvette Cooper: We do not have figures like that at this stage. As you say, we have got only the initial six to nine months of it. The results over the whole process include the cases that go through appeal—James, I don't know if you know the details of what further information we will have as we go through?

Dr Charles Shepherd: Are you saying that you are not monitoring specifically?

Yvette Cooper: I am going to ask James to fill in some of the detail on that. We are doing two reviews of the work capability assessment. We are doing our own internal review, which is ongoing, and we are also commissioning an external review of the work capability assessment. There will be an independent assessment.

Dr Charles Shepherd: This is terribly important. The other area, as you know, is mental health—there are terrific concerns about people with mental health problems getting turned down.

Dr James Bolton: You mentioned that you had some information. I would genuinely be interested to see that. I am sure you understand that the difficulty of starting to look at things by condition, when you have comorbidity and multiple medical problems, is in identifying which is the main disabling condition. There might not be a single disabling condition; there could be multiple medical conditions. Do you use the information on the sick note, which may or may not be accurate? The actual assessment itself is not about diagnosis, it is about function. You do not necessarily have nice, clear, diagnostic information on every single person that can be used to easily categorise them.

Dr Charles Shepherd: You could go quite a way towards getting that.

Dr James Bolton: You could. The first thing we have done is look at the whole assessment as it is supposed to be in functional terms. That is what the internal review has done. We have published some statistics over the last couple of weeks about broadly what is happening on ESA. The next step is to do exactly what you say and try to break things down and come up with something more sensible. Because of the difficulties I have mentioned—comorbidity and so on—it will take us a bit longer to come up with something meaningful.

Dr Charles Shepherd: We are obviously pushed for time here and a lot of people have questions. Would you be prepared to meet a small group of charities involved in this to discuss our concerns in more detail?

Dr James Bolton: Absolutely.

Tony Wright MP: I found that it was not so much about writing instructions about how the medical profession should assess people with ME, but rather the fact that a lot of the medical profession did not accept that ME existed. There was that particular bias in the very early days, leading up to the Chief Medical Officer recognising ME as a real entity, but we have moved on from that.

I made representation to the then Secretary of State on the issue of benefits, as we found that the vast majority of people who went to appeal after being refused—the largest group of people with success on appeal—were those with ME. That proved that they should have been assessed correctly in the first case before going to appeal. I am glad that the situation on appeal is being monitored. Is that going to be true of assessment as well, in terms of categorising people with particular illnesses who go through the first process and fail, but succeed in the second process? To me, that was quite significant. To put people with ME through the first process is bad enough, but to expect them to go through appeal and find out that they were correct in the first place is a worrying statistic. I am going back seven or eight years. I don’t know whether things have changed since then, but I would guess probably not.

Yvette Cooper: Through the appeals process, we are trying to look at whether we are seeing particular things that have not been picked up, which are then picked up on appeal. Is there a common pattern? I will ask the specific question that you raised about whether there is a particular issue with ME compared with previous situations. There is a set of questions about this that I asked when I arrived in the Department.

They are similar to the questions that I asked Social Security Ministers between 1997 and 1999. The difference that I found since then is the extent to which this has been an active process of training people in ME, and recognising that fatigue is a different kind of condition. That needs to be consciously highlighted as part of the assessment.

I remember talking to Stephen Timms about this when he was first Social Security Minister dealing with some of this in the late ‘90s. Clearly, that had not been done exactly because, as you say, a large section of the medical profession did not recognise it at all. There has been a huge amount of progress in terms of the institutional attitudes towards this, and the awareness that it is a different kind of condition and that it will therefore not meet the same tests as a traditional physical disability, although it will be at least as debilitating in terms of its impact on people’s lives and ability to work. However, it needs to be picked up on in a different way.

Having raised that awareness, and having built that into the training programmes and so on, the next challenge for us is about how far we implement that in practice and how far that is filtering down to each local area and local level. It is something that we are keen to monitor.

Annette Barclay: My name is Annette Barclay and I have ME. I asked the second question—thank you to the Chair for including it. With all due respect, my question has not been answered.

Yvette Cooper: Sorry, which was your question?

Chair: It was about the training of tribunal panels.

Annette Barclay: I have been through two DLA tribunals, and in both cases the people at the tribunal were unwilling to accept post-exertional problems. I do not have fatigue, I have a viral disorder and swollen glands—I will get very ill just from being at this meeting—but they refused to accept it. They also refused to accept the report that I had done by a respected NHS consultant—not some fly-by-night person—which clearly laid out my level of disability and the problems that I have. The first tribunal was set aside, and I had to wait for nearly a year for the second tribunal. The second tribunal was exactly the same. I had six people and two tribunals, both of which did exactly the same thing. The report from the consultant was totally ignored.

Yvette Cooper: When was the second tribunal?

Annette Barclay: About 18 months ago. It is exactly the same thing. This is obviously failing. There must be some way of giving these people at the tribunals some direct training. There must be something else we can do. I was told by my adviser that, once again, they have done exactly the same thing. They have ignored the report from the consultant that lays out quite specifically what my problems are. They have refused to address that, and have refused to accept that there is such a thing as a post-exertional problem. For me, it is likely to make me really sick. They have done that both times. I was told that my only choice was to have this tribunal set aside once again and have yet another tribunal. As I have already been through two, I had to give up at that point. Physically, my health was damaged by going through the two tribunals. I could not go to any more. That was it; there was nothing more I could do at that point.

Chair: I know that people want to come in with more supplementary questions. Can you answer that one? Then let us move on to a different angle.

Yvette Cooper: Okay, I am going to ask James if he could say something about the way that the people who sit on tribunal panels have to undergo training.

Dr James Bolton: Yes, well, the tribunals are obviously independent from us, so they are part of the Ministry of Justice. I think that the most helpful way to take this forward…they have a medical member in charge of the appeals service, who I know. Perhaps it is something that I could raise with her if that would be useful. Perhaps you could give me some details afterwards.

Annette Barclay: There must be some way of finding these people who are not fit for purpose. These people at the tribunal are not fit for purpose. It is about challenging them, and taking them out of these jobs.

Joy Birdsey: Absolutely. Some of them are barbaric.

Annette Barclay: We need to get these people out of their cushy jobs, with the money that they are being paid, and find something better for their talents. We should put in people who can do the job. There are plenty of people who could do their work.

Dr James Bolton: Sure. As I say, I will take that point away and raise it with the tribunal service department.

Chair: The whole appeals system is certainly dependent on the quality of people who make up the tribunals. Sadly, they do vary quite considerably. I am happy to say that some of them are extremely good, but not all of them. Can we move on slightly? You were lucky enough to have a consultant report, and it still did not help you that much.

Annette Barclay: I had to pay for it, to add insult to injury.

Chair: Other people do not even have that.

Annette Barclay: They would do if they paid for it.

Chair: As the fairest, most efficient and cost-effective processing of all benefits is dependent on claimants being able to provide up-to-date, independent, objective and qualified clinical evidence of a patient's condition (functional ability prognosis, illness impact and provisional needs), how can patients with ME/CFS support their claims, when they have demonstrated the total lack of appropriate services and therefore appropriate clinical evidence from both primary and secondary care? That is another very real problem. Some people take years to achieve a diagnosis of any sort, so they are not able to produce a consultant report, proper GP reports and so on. That places an extra burden on the quality of Atos.

Yvette Cooper: The assessments are now designed not to depend on having a diagnosis, a GP's report, a consultant's report and so on, but rather to depend on the assessment—are there things that you can do? Perhaps you cannot do something because it makes you ill if you do it, or perhaps you could do it once, but then that wrecks you for the rest of the week. The guidance is clear: if doing something creates great fatigue, you should be treated as if you cannot do it in terms of the assessment. Therefore, the assessment itself ought to pick up people who cannot work due to ME, rather than relying on whether there is a consultant's report.

Obviously, the nature and level of support from primary and secondary care is a matter for the Department of Health and the Chief Medical Officer. My personal experience was back in 1993, so I am a little bit out-of-date in terms of the scale of support. It is important not to design the whole approach to the benefit system where people may need support, to be dependent on particular bits of the NHS, but actually to be able to do the work capability assessment under its own terms.

Chair: But that places a heavy onus on the DWP assessors.

Yvette Cooper: Yes. Certainly, for the work capability assessment, the idea is to put an onus on getting that questionnaire right, and the assessment process, and being sensitive towards and understanding the condition. That is why we have tried to build in specific training about ME/CFS, in order to do that.

I am conscious of the time. Perhaps I can take a few questions, and I will try to respond to as many as possible.

Chair: Okay.

Janice Kent: This does not always happen with ME patients, but I think that the initial assessments and the initial questionnaires are wrong. They hinge on someone's ability to know how to answer them. I will quote a friend who was the head occupational therapist in her area. She was appalled that some of her elderly, confused patients were not getting help. There was a question, "Can this patient dress themselves?" and the relatives would put, "Yes." However, if the question had been, "Can the patient find their clothes, and when they take them off do they know where to put them for washing?" the answer would have been, "No." We would save a whole process if we asked more sensible questions to start with.

Yvette Cooper: Have you been through the work capability assessment and the questionnaire?

Janice Kent: It was years ago when I claimed it. I never had a problem with the benefits people. I found the two doctors courteous and most helpful, but I seem to have been an exception for some reason. I must admit, my husband also looked at the forms, and he used to work at the Department of Health. He said, "If I had to fill this in…it is a nightmare." We must ask, "Can you walk down the road?" and some people will say "Yes, but then I cannot because I am fatigued." Perhaps it would generate a lot of pain. Unless someone has been coached, they do not know what to say. We must go right back and start again. We could save bags of money and bags of heartache to patients.

Yvette Cooper: It might be worth having a look at the new questionnaire for the work capability assessment. I have been through it—it was introduced before I was appointed, but we have been going through and reviewing it. It includes a series of questions that are designed to capture the idea of people who are confused and who might not be able to find their way to places and so on. It also includes an assessment process for people. The purpose is to do that, and there are a series of questions about walking down the street or how far someone can walk. They are supposed to take account not only of whether someone can move their limbs physically, but also what the impact of doing that is. Will they need to stop? Do they get tired? The purpose is to do that, and obviously the assessments have changed over the years.

Janice Kent: But we are still not picking the issues up as there are still problems. I ended up in France one summer in a chateau with the chairman of one of these appeal tribunals. She said, “They don’t give us the right answers. We have to work on the answers we get.” Perhaps we should be looking at the tribunal searching, instead of waiting for the response. It is geared like that to keep it ambiguous. Perhaps they think it is simplified, but it is not. The process goes on and on and wastes more time and money. I will have a look at the recent questionnaire.

Chair: Shall I throw you a few more questions? The first is very personal. Given that, according to the *Independent* of 9 October 2009, you are reputed to have made a full recovery from CFS, do you believe that being ill with CFS or ME is a temporary state? To what extent as Secretary of State for the Department for Work and Pensions does your experience and attitude influence the way that CFS and/or ME sufferers are viewed and dealt with by the DWP? Can you confirm that the DLA will not be included in the Government’s proposed changes to benefit reform in relation to those moneys being paid to social services? The DLA and the attendance allowance should be available to recipients to enable them to pay for their daily needs. I will leave you with those for the moment.

Yvette Cooper: It is always unwise to generalise from your own personal experience. For me, the whole experience of ME lasted in a serious, debilitating way for about two years, with another couple of years of being up and down and not quite right. Since then—touch wood—I have not had any further problems despite working slightly ridiculous hours, as we all do with the late night votes, and having three kids. I have been very lucky, and have not had any recurrence. My father had a similar condition, and for him it lasted two or three years and then there was no recurrence at all.

However, it is not for me to judge other people's experiences. For some people it has been different. I had a consultant who was very good and sympathetic. He reckoned that 90 to 95% of the cases he saw made a full recovery eventually, but it varied as to how long it took. That was back in the early `90s, and I don't know what case mix he saw.

I cannot say that my personal experience affects the work that the DWP has done. The DWP did a lot of work before I arrived, and it did a lot to try and build in the training. I have tried to review where it has got to, and to take another look in the light of my personal experiences. The question about the DLA and the attendance allowance is important. We are doing a wide-ranging consultation on social care at the moment. This is all about elderly care and how we need to change in response to an aging society. It is not our intention for working-age DLA to be part of that and part of the national care system. It is a completely different range of support and circumstances.

We should look at the attendance allowance and the wider social care that is currently provided alongside it, because we know that a lot of people are not getting the support that they need in old age. At the moment, support is provided through different routes, and we should look at all that together and ask what support people should have in the future.

The important thing about attendance allowance is that it is a personal budget. It is money that you have control over. Any new system that we move towards must have that same sense of control for people who need care and support. You cannot move away from that when that is one of its strengths. We should be going more down the route of individual budgets. We are still at an early stage in that consultation process and there is a lot more work to do. However, people recognise that there is a big problem with long-term care, because a lot of people are not getting the long-term care that they need, or they are ending up having to sell their home and losing their money in order to pay for it as it is such a lottery. We have to do something about it in a way that builds on the strengths of the disability benefits system and gives people flexibility, rather than forgetting that approach and going in a different direction altogether. Choice is critically important.

Michelle Goldberg: If that money goes to local authorities, I can guarantee that it will never see the light of day. We will never see that money. It will be taken and used for a whole range of other things, and we will not get any benefit from it.

Chair: That has probably been overtaken by the future possibility of a national care service and free personal social care, which could transform the whole situation.

Michelle Goldberg: The whole system is about exploiting vulnerable people. The most vulnerable people who need the most care and who are the most vulnerable, are those who are the most affected and the most exploited. Why do it to the most vulnerable people?

There is something else I wanted to say. It has been calculated that for a disabled person, the cost of living is 44% more—just the cost of living. With the DLA, probably all someone gets is their basic cost of living. I don't know if you know this man, but I want to refer to him as I studied with him. I did disability training, and he is one of the top people in the country. He is really very good. His name is Richard Reiser do you know him? I can give you his phone number. He would be a good person to consult with.

Chair: The point you are making?

Michelle Goldberg: That is where I got the information. It has been calculated that the cost of living for a disabled person is increased by 44%. I would like to throw something out about the DLA. I am in the stage where the GP's report was not strong enough, so I have had to go out and pay to see a specialist. I had to borrow the money to do that. These are the questions that came up in the approved disability analyst's report, which indicates where their thinking is. The first, which I do not necessarily need to explain, was, "She has no care plan." That is certainly not my fault, and it is not for the trying. Those are the questions that have come up in my DLA appeal. They focused on the relapses and the seizures, and said, "She is not on potent medication and she is not on epilepsy drugs." I go to the Royal London Homeopathic Hospital, and I am treated with homeopathic, herbal and other therapies. Can you see where their thinking is?

I know people have brain lapses. "Debilitative fatigue, triggered by minimal activity." No, it is debilitating fatigue all the time, and minimal activity—it is difficult, they don't understand. There was another question about the history of epilepsy.

Chair: I think you have made the point.

Michelle Goldberg: Details of frequency of seizures—they still don’t understand.

Dr Charles Shepherd: Can we get back to the DLA, as this is terribly worrying for people with ME at the moment? You seem to be very clear on this. There is no intention of putting this into the review. However, Lord Ashley of Stoke apparently asked a question in the House of Lords, and got a reply from Lord McKenzie of Luton: “My Lords, as I said in the answer to my first question, no particular benefit is ruled out of consideration in relation to this review.” We seem to be getting mixed messages from people in your Department.

Yvette Cooper: We want to clarify the position, as it has been causing too much concern. It has never been our intention to look at the working age DLA. This is a different group of people and a different kind of support. Andy Burnham will be talking about this tomorrow. He is doing a speech and an event tomorrow, and he will also clarify it so that we have clear information to reassure people on this. We are looking at benefits for older people, which are supposed to also provide care. The disability living allowance for people of working age is not about providing care, it is about the disability living allowance.

Dr Charles Shepherd: A lot of people would be very pleased if you could make a clear statement on that.

Yvette Cooper: As I said, Andy is going to do so tomorrow as part of a speech on long-term care. He will try and make that clear so as to reassure people.

Chair: We have Yvette for five minutes more. Can I ask you if you have any concluding remarks you would like to make? Perhaps you could say something about the Welfare Reform Bill.

Yvette Cooper: We are trying to ensure that those people who can work, get the support that they need to get into work. Although we have talked a lot about the benefits system—I will return to that in a second—it is also important to think about people who have long-term ME conditions but who could perhaps work part time or work from home, if they had a sufficiently supportive employer or help to do so. Certainly, after I had spent a year at home, the idea of being able to get back and do some intermittent work and so on, was hugely important. However, there were an awful lot of jobs that I could not have done at all, as there would not have been an employer sympathetic enough to support that.

We should look more at employment and how we can provide people with support to work part time and so on if they can. That is particularly important, as is having an employer who is sympathetic to the fact that someone has a fluctuating condition and might be able to work for a while and then have a relapse and a more difficult period. That is also important as part of the welfare reform work that we are doing.

Going back to the benefits, I have tried to make the position about social care clear, but we are continuing to review this more widely. We are working very hard, and having seen it from my own personal experience I think that a lot of changes have been made over the past 10 years and certainly more recently to try and increase the training and the awareness and understanding. I am sure that there is always more that we can do, and I would be keen to keep in touch with you and work with you on how we do that, and how we ensure that the things set up in the framework actually happen in practice at local level.

Michelle Goldberg: Can I just say mention the contributions that people like me and the majority of people in this room make in society and our lives every day? It is called the third sector and it is a free service for the country. That is not given any value. I am sure that there is not one person in this room who does not help another person or make a significant contribution, day-to-day, in their community. It is not valued and not quantified. We are expected to do this. It is like being a mother; you just do it, and you do it for free. I might be disabled, but I am not stupid. There are a lot of things I can do. I make a significant contribution. I cannot work for a whole range of reasons, but the contribution that I make is not valued and in fact, it is often discriminated against by people who are working and who are not making a positive contribution. Everybody else ends up running around having to clean up the mess that people who are being paid to work are making.

Chair: Peter, this will have to be the last word.

Sir Peter Spencer: One thing that you said about getting back into employment is good news. Perhaps you could also take a look at the permitted work levels. One of the difficulties that people have is that there is an economic disincentive. Many people are prepared to accept that, because they put a value on getting back into work—as we found with our own volunteers. They feel strong enough to do a small amount of paid work but it is difficult for them financially. I am sure that there is scope for a more intelligent view, which will play straight into your own experiences of gradually getting back into work and encouraging employers to help people who want to do that.

Christine Harrison: On the 104-week rule—I thought that from the very start of welfare reform you took the Australian model. I asked James Purnell, and I hope you will look into it. The 104-week rule is brilliant. Can that be reviewed, especially for people with long-term or fluctuating conditions? Someone might have cancer and they get better, but then they get it again. The 104-week rule should be reviewed, and then another 104 weeks should be given for people with fluctuating conditions. They can go back on to benefits or fast-tracked on to them. Like you said, you were ill for two years, and then another two years. 104 weeks is great if you have a specific illness. However, if you have fluctuating or long-term conditions, people can keep trying to go back to work or gradually build up part time.

I was going to add earlier that I worked with Terry Moran and Pauline Thompson years ago. They will tell you that there was a definite black hole with ME that they were trying to address. When is the revision of the next guidelines, and can we be invited back?

Dr James Bolton: We have not set a firm date for the revision of the guidance yet. As with all our guidance, it will be done as we get more evidence. You are welcome to be involved.

Chair: We have run out of time with Yvette. Can I thank you, Yvette, for coming and fielding questions from what is not the easiest audience in the world? I am sure that we all appreciated Yvette’s contribution this afternoon. Thank you very much.

Okay. We have a few minutes left and we come to a statement from the West Midlands ME group.

Jill Cooper: I will be quick, because I know that everyone is tired. I have prepared a pink booklet and I am quickly going to go through what is on the front. The blue section is the CFS/ME Clinical and Research Network and Collaborative Constitution (CCRNC), which we are criticising nicely and politely. Then there is a yellow sheet that supports and explains our criticism of certain aspects. Then, just to remind everyone what we are talking about and where this stems from, there is a green sheet, which is the West Midlands ME Group Consortium. On the back sheet you will see how many people endorse what is in this document. I thought you would all like to read it on the train, to make sure that we all understand what Jennifer has written.

“Thank you for agreeing to look at the WMMEG statement again and the issues raised about patient representation, transparency and the suitability of the education and training programme provided by the CCRNC.

To open up the discussion further, I would like to tell you that WMMEG have pursued these issues with Dr. Crawley and have recently received from her a copy of the CCRNC Constitution and this document clearly excludes anyone who does NOT “explicitly” support NICE Guidelines. Therefore, a large body of patients and patient charities cannot be part of the process of the CCRNC which at present shapes and defines the NHS service for CFS/ME.

This cannot be acceptable to those who support the definition of patient representation as described by the Department of Health—briefly that the purpose of patient representation is to “provide a free exchange of ideas, questions, comments or criticisms…”

While we appreciate the chief executive of Action for ME, (Sir Peter Spencer)’s assertion at the July APPG that AfME is “a critical partner” on the CCRNC Executive and we are sure it does a good job in many ways, AfME does not always represent our views—in that it supports the NICE guidelines “explicitly” and we do not.

WMMEG and all those who co-signed the WMMEG statement hold the view that the NICE Guidelines are unacceptable to those patients with ME and would like the opportunity for those patients to be able to clearly and politely express their views at the CCRNC or to have a charity which supports their views to represent them on the Executive of the CCRNC.

Jennifer Griffen wrote that. I have put my name on it as I will be the person recorded as saying it. It is supported by many groups.

Chair: I have just speed-read this, and I do not see how it excludes anyone—it does not say anything about having to support the NICE guidelines.

Jill Cooper: It does. If you look at the yellow sheet—

Chair: You were referring to the blue constitution. I could not find anything there.

Jill Cooper: If you go to the yellow sheet and look at the second box on the left—that is to help, as it is quite a complex document. They have dug those points out. I will read them quickly.

From the constitution of the CFS/ME CCRNC, December 2008.

Objectives: 2.2.1 “To champion evidence-based approaches to the treatment of CFS/ME, such as those provided in the NICE guidelines.”

Chair: But that is not exclusive to the NICE guidelines.

Dr Charles Shepherd: Can I point out that we had Dr. Crawley and another lady from the organisation along to our Forward ME group? This is a point that I raised with them. Although we did not get what could be described as a crystal clear reply to the question that was basically about whether charities that do not support the NICE guidelines could become eligible for membership, the clear implication from the answers that we received was “No.”

Chair: That is not what it says in the paper.

Sir Peter Spencer: On a point of clarification, the way this is written suggests that Action for ME is a critical partner on the CCRNC executive. That is factually incorrect. Action for ME is not part of the consortium, it has not signed up to the constitution, and it is not part of the executive. We fulfil a role of being a critical partner, and I would also add that while Action for ME supported the NICE guidelines, it did so with some considerable reservations, which have been frequently stated and are available on the website. I am perfectly content to accept that different charities and different patients have different views—that is for them to state. However, I would maintain the right for our position to be put accurately on the record.

….

Chair: Does the West Midlands group want to be on the CCRNC executive?

Countess of Mar: May I point out that the CCRNC has nothing to do with the Department of Health? I established that in questions in the House of Lords. It is a group of researchers who have got together for their own purposes, for training and things. If you do not like what it does, then keep out. It is up to those people. I am neither supporting or not supporting it, I am pointing out that it has huge numbers of research projects. It has 600 medic researchers on its books as members of the CCRNC. It thought that it would be nice to get other people in, and that it would assist it to have the voice of certain charities. If you do not like it, or do not like what it promotes—under its objectives there is a bit that says specifically that it should stick with the NICE guidelines.

Chair: It says to, “Champion evidence-based approaches—”

Countess of Mar: Quite, but I don’t know why this has become such a storm in a teacup.

Jill Cooper: Please bear in mind what I have said—do not shoot the messenger. However, even for me, and I am fairly thick, this first point, 2.1, “The

CFS/ME Clinical and Research Network and Collaborative (CCRNC) is a multidisciplinary organisation which exists to promote and support the delivery of evidenced-based treatment for children, young people and adults with CFS/ME throughout the UK."

Countess of Mar: That is the same as any charity. If you want to be a member of a charity, you can be.

Jill Cooper: I think at this stage, Des, this has been handed out, and I would appreciate it if everybody really had a look. If there is a problem, or if it needs to be raised again—I have done my bit, and I would like it if people read it.

Chair: I have read it.

Ciaran Farrell: There is a simple point here, which in a sense Michelle alluded to—the training given by Richard Reiser. He is a disability trainer, and within the disability movement there is a simple battle cry, "Don't talk about us, without us." What is being spoken of here is that there is an organisation where the voice of ME sufferers and carers is not being heard because it is not adequately represented. Of course, different bodies are set up and constituted in different ways. That is part of the technicalities of the way that bodies are constituted. However, in the ME community, there is a great deal of concern about the NICE guidelines. Those who were able to attend the second evidence-taking session would have heard Dr. Crawley state, quite categorically, that she considered the NICE guidelines to be a commission, that is a way of obtaining services, clinical input and so on, for patients. The problem that the ME community has, is whether it necessarily wants a service that is based on that model. There is the classic dilemma of either signing up to the whole loaf, or having none at all. That returns to the issue of the post-code lottery and the clinics.

Chair: The network is essentially established by service providers. Clearly, if the product of the network is going to satisfy ME sufferers, they need to listen to ME sufferers. You need to talk to them further.

Colin Barton: I think actually they have a number of patient representatives on that executive. They met the other day.

Annette Barclay: Then they are doing a very bad job.

Colin Barton: Well, seeing as they are in a team with over 30 people…it can't be that bad.

Chair: There seems to be a certain disagreement here.

Colin Barton: I am having trouble keeping quiet.

Chair: I don't think we can resolve it here this afternoon.

Colin Barton: There are people out there doing their best for people with ME. All the services in the country have seen over 33,000 people through their doors. If there was something drastically wrong, I'm sure we would have heard about it.

Annette Barclay: We are hearing about it.

Chair: Alright, alright.

Colin Barton: I am going to speak up, because I have not been here very much, and I really think that the services deserve a lot of support. The ME services are doing a good job. If they have had 33,000 people through their doors, it can't be that bad. They are not perfect, they can't deal with everybody with different degrees of ME and different variations. They can't do everything. This is an illness that there is no cure for, so you have to deal with it by managing the symptoms and managing people so that they can improve their lives and live with it. You cannot sit back and say, "Let's wait for a cure".

Chair: You have stirred up a hornets nest.

Colin Barton: Well, I'm quite enjoying it. Neurological people are dealt with in the same way…nobody is doing anybody any harm.

Annette Barclay: They are doing a poor job.

Chair: I think we are in danger of getting bogged down in semantics here and into non-arguments. We have run out of time. It is good to see you, Colin.

Colin Barton: If some of what I said could be minuted, that would be useful. I don't come here very often.

Chair: Colin Barton has spoken up in robust support of the network…That conversation can be carried on after the meeting. We need to wind the meeting up. Is there any other business? The date of the next meeting is 2 December.

The meeting is closed.