Des Turner MP (Chair): Good afternoon Ladies and Gentlemen and welcome to the all-party group on ME. Sir Peter Spencer has distributed a document to you, which is the interim report of the inquiry. We will discuss that in a short while but you have a chance to have a look at it before that.

I am glad to see so many people here this afternoon. The inquiry is the main topic of this meeting. Blood was sweated over this, but the piles of evidence were such that given the limited time and resources available to the group, we were not able to bring together a report with which we were totally satisfied—we nearly managed it, but not quite. Therefore, we decided to produce an interim report that contains the findings. Those findings are not going to change. The conclusions and recommendations of the report stand as they are in the interim report. The rest of the report has been reduced to a very brief introduction. We hope to produce the full report in due course, but it will contain the same recommendations and conclusions. They are as clear as daylight as far as the group is concerned, and are taken from the evidence. We thought it prudent to get something out as soon as possible, so that we could produce some effect with the recommendations. That is why the document is somewhat truncated. However, as I have said, the recommendations stand.

Paul Davies: A report has been handed out by Sir Peter Spencer. What was the consultation on that interim report?

Chair: This is the report. Let me make it clear that an all-party group is a group of parliamentarians. That group of parliamentarians has produced this report.
Paul Davies: But did you consult with Action for ME and the ME Association?

Chair: Yes, we did.

Paul Davies: Why did you consult only with those organisations?

Chair: Because they are the only groups who gave us any assistance. They are the only people who assist with the business of running this group. If you would offer to help with the secretariat you might get consulted, but you don’t.

Paul Davies: Yes, but the point is that this shows bias towards those organisations.

Chair: I am sorry. This does not show bias to anyone.

Paul Davies: It does because those organisations—

Chair: That is your opinion. This report is our assessment of the evidence. It is not biased for or against anyone.

Paul Davies: It is biased because you only consulted with Action for ME and the ME Association. Those groups support the clinics that we believe the large majority of ME patients do not want.

Sir Peter Spencer: May I make a quick point? The Minister will not have much time. Perhaps we could talk about this matter properly afterwards and have a proper discussion. Otherwise, the Minister will leave before we have had time to make use of his presence. We should get on with the main business.

Chair: I quite agree. Those comments bear no relation to the report. Can we get on with the report?

Paul Davies: They bear relation to those patients who do not want these clinics.

Chair: We will have that discussion afterwards. I know you feel that you represent millions of patients, but I do not think that you do. We will have that discussion afterwards. We
are here to discuss the report.

The report is before you and the recommendations speak for themselves.

**Ciaran Farrell:** I was going to ask for some reading time. Perhaps we could go briefly through the report and the recommendations, so that we can understand what the Minister has to say.

**Chair:** You don’t know what I am about to say. To be honest, I am beginning to lose patience with you two. You would stretch the patience of any Chairman.

**Countess of Mar:** May I propose that these two people be evicted from the meeting so that we can carry on our business?

**Chair:** That would be the sensible thing to do. You two people spend most of your time trying to disrupt the work of this group.

**Nicky Zussman:** I don’t agree. I think that they bring important points.

**Chair:** I have yet to hear one.

**Countess of Mar:** In that case, I am going to leave. I am not prepared to waste my time listening to you when I have other things to do. I am sorry. I will not stay in a group with people who cannot behave themselves in a meeting and listen to the Chair.

[Countess of Mar leaves]

**Chair:** If you are not prepared to be quiet or leave, I will terminate this meeting. What will you do?

**John Sayer:** I am sorry Mr. Chairman. Why are you looking at me? It is the first time I’ve been here. I am a bit surprised at how things have gone so far.

**Chair:** So am I—surprised and exceedingly disappointed.

**Nicky Zussman:** We are the ill people. It is us who are being described. It is 11 years
since a serious working group was convened, and we are still being told what to do like very young children. I think that Paul has a point.

Chair: The Countess of Mar has put a lot of work into this. She works very hard to support ME sufferers, but she has just left in disgust. I feel very inclined to do so myself. If you wish to terminate the work of this group, continue with this utterly pointless discussion.

Nicky Zussman: We are not at school.

Chair: You are not at school, and you are on your own.

Janet Taylor: Please do not leave, Dr. Turner. I have come all the way from Yorkshire. I want to hear the Health Minister. I have important things to say.

Chair: I am sure you do. I am sorry, but we seem to have an element that is determined to be disruptive and does not want to listen to anything. Some people only want to rake over the coals of arguments that they have been making for years which lead absolutely nowhere. They are greatly to the detriment of the ME community.

Mary-Jane Willows: May I speak? On behalf of those patients who value and respect the work that you have tried to do for many years, I understand where you are coming from. I ask you to try and finish what you were saying. If you are interrupted again, I totally respect your decision to leave. I beg you to try once more and speak, without interruption.

Janice Kent: I second that.

Chair: Alright, but one more interruption, and I will call the police to remove you.

Janice Kent: Can I just say that this is the best chance we have got? We fought for years and have got nowhere, but now Des is helping, so is Sir Peter Spencer.

Janet Taylor: Can I just say that because of the APPG in Yorkshire, in Kirklees we are working in partnership with neurology and with the clinics to provide a full service? We are
going to manage and train GPs in that area. That is because you do this group. Thank you, Dr. Turner.

**Nicky Zussman:** The thing is, we don’t have that in Sussex.

**Chair:** Do you mind? Let us proceed. Since no one has had time to see the document before the meeting, I will quickly go through it. It is very straightforward. The first problem is the fact that we do not know exactly how many people actually have ME. The first recommendation is to ask the Department of Health to undertake research to accurately establish the numbers of patients with ME/CFS. We need that information.

The second recommendation refers to the fact that we think there should be a national service framework so that all trusts can be expected to provide a minimum level of service. It would help to establish that if we knew the numbers of patients involved. It is obviously not entirely reasonable to ask the Department of Health to produce a national service framework for every disease. However, for diseases that affect large numbers of people, there is a case for it. We suggest that if that research is done, it will produce a number that will justify a national service framework.

The third recommendation refers to the CMO’s report, which has been on the table gathering dust for many years. We feel that if those recommendations had been carried out, many of the problems that we are talking about might have been addressed. We ask the Department of Health to go back to the CMO’s report, and ensure that those recommendations are addressed.

The fourth recommendation concerns the postcode lottery. The variation in the level to which PCTs take seriously the provision of services for ME/CFS sufferers is completely unacceptable. Of those PCTs that took the trouble to respond to our questionnaire, only a third
provided a choice of services that was acceptable, while others were unacceptable. However, the majority of PCTs did not take the trouble to respond at all, and we will draw our own conclusions about those. The fourth recommendation is to ask the Department of Health to take steps to remedy the variation, and ensure that each PCT offers a full range of services promptly. That process should involve meaningful consultation with local patients and patient support groups.

We come to recommendation No. 5. Adult sufferers of ME/CFS have enough problems, but children have even more and the availability of services to children is extremely poor. We therefore call on the PCTs, the strategic health authorities and the Department of Health to undertake a detailed review of the current services for children and adolescents, and to ensure that all receive adequate care and that all decisions are made in conjunction with personal carers, education authorities and social services where appropriate. Children with ME have been extremely badly served.

Recommendation No. 6 concerns medical education and training. It is clear that far too many doctors and other health professionals are not necessarily even aware of the difficulties of ME. Some GPs still do not treat it as a real condition. Our first recommendation says that although ME/CFS does not have the same obvious impact as cardiovascular disease or cancer, for example, it is still necessary for medical students to receive adequate training in ME/CFS. The relevant Royal Colleges should ensure that students receive training in this disease.

Recommendation No. 7 concerns primary care givers such as GPs. It recommends that GPs should receive ME/CFS awareness training as part of their continuing professional development, to ensure that they are able to adequately recognise the symptoms of ME/CFS and deliver a correct diagnosis. They should also be aware of various management pathways. It is
clear from the evidence—particularly patient evidence—that this is not universally true of GPs at present.

Recommendation No. 8 concerns treatment. Through patient surveys, concerns have been expressed about the acceptability, efficacy and safety of several treatments, in particular CBT and GET. It is clear from the evidence that many of those concerns and the difficulties that patients encounter with these therapies might relate to the fact that they are not being delivered by properly trained health care workers. Just as it is important to ensure that doctors are properly trained in ME/CFS, all other health care professionals who deal with ME/CFS patients also need to be properly trained. It is clear that treatments such as CBT or GET are more likely to help patients if they are delivered by properly trained professionals. We also think that NICE should carry out a detailed review of its management guidance on ME/CFS. In particular, there is mounting evidence that we need to broaden the range of appropriate therapies beyond CBT and GET, and specify that all such therapies are delivered by specifically trained professionals.

Recommendation No. 9 concerns research. This report has not been taking evidence on research as that was done by the Gibson report a few years ago. However, it is quite clear that although there have been many publications on ME/CFS, they have not represented much substantive progress. There are a number of recent finding which give glimmers of hope—the most obvious one is the publication of the findings with XMRV. It is too soon to raise hopes unnecessarily, but this may well be a way into biomedical research on ME/CFS that has previously been lacking. The recommendation states: “The group is sure that it is vital that further biomedical research is undertaken to help discover a cause, and more effective forms of management for this disease”.

The other problem, which I am sure is all too familiar to everybody in this room, is that
the evidence makes it clear that patients are still encountering a lot of problems with the DWP when it comes to benefits, whether that is incapacity benefit or disability benefit. I personally can speak anecdotally as I have helped a lot of my constituents with the benefits issues. It is clear that decision-making staff in the DWP are not sufficiently aware of the specific problems of ME sufferers, and neither, sadly, are the doctors who work for Atos Healthcare and carry out patient examinations. The recommendation is that the DWP should review its guidance to decision makers to increase the awareness of the specific difficulties faced by ME/CFS sufferers. Furthermore, the group recommends that Atos Healthcare staff also receive increased training to ensure that they are fully aware of ME/CFS and the limitations that it places on patients.

It is sad that we still have this situation. Having taken cases such as this to tribunal, I know full well that disability benefit regulations take account of the difficulties of ME/CFS sufferers. None the less, the fact that it is there in the regulations—it does not say ME/CFS, but it covers it—gets ignored completely. After all this time, that area really needs to be sorted because it causes a lot of stress to people who have got enough problems already.

The group was aware that many patients affected by the disease receive either inadequate care or no NHS care at all, which is not consistent with the NICE guidelines. The final recommendation is that specialist referral services must ensure that high priority is given to the needs of the severely affected, especially in relation to domiciliary services, and in-patient facilities for assessment and management.

Those were our findings and recommendations. I hope that they are helpful. I will now ask Mike if he will give us his response.

Mike O’Brien (Minister of State, Department of Health): It is good to see you all here. I apologise that I have a limited amount of time and must get to another meeting—I will be
here until about 4 pm. I shall respond for about five minutes, and then take about 10 minutes of questions. The 2002 report by the Chief Medical Officer was a major turning point for people with CFS/ME. For the first time, we had a senior person in the medical profession who said not only that the condition exists, but that it causes major disabilities to people and needs to be addressed by the NHS and other Government Departments and organisations.

As anyone who has been involved with ME will know, one of the points made in the report is that although the CMO’s report set out a good outline proposal for how the system should respond to ME, the system has not responded adequately to that. Therefore, we need to ensure that we have a clearer care pathway in relation to people who have ME. The difficulty is that ME is a complex and diverse set of conditions. Some people are substantially debilitated and end up in bed for prolonged periods of time and have their whole life is blighted by it, while others have periodic difficulties where they are unable to function at an optimal level for periods of time, but they then recover and later relapse.

The condition also has a path, whereby people develop it, it becomes severe and then they move out of it. The length of that path tends to vary substantially between individuals. As a result, ensuring that responses are tailored to individual conditions is something that the system has not been good at doing. The system likes simple things and responds easily to them. One thing we can all say about CFS/ME is that it is not simple or straightforward. You know what is happening to you if you are suffering from it or if a member of your family has it, but that does not mean that another person’s family down the road has exactly the same situation. They might also have ME, but they might have a different approach to dealing with it.

There are also different views about how treatment best deals with the condition. Some people feel that things such as the lightning process, CBT or GET are the right response, while
others feel that those are not the right approach at all. Talking to people who have ME, it is striking how many of them have clear views about what has worked for them, which does not always work for other people with ME.

In a sense, the report from the CMO was a breakthrough, but only a bit of a breakthrough. It has not developed sufficiently in terms of a response from the national organisations to ensure that people with ME are in a position where they know that the system will deal with them—it patently does not. Therefore, there is a need to improve the way in which the whole system responds. How do we do that? I think that this interim report from the all-party group is another milestone. Some may not feel that way, but when you look back on the development of recognition of this condition, you will see that some of the recommendations are blatantly obvious and fairly sound. They cannot all be done by the Department of Health, but the Department can deal with some of them and refer others to the appropriate organisations.

Going through some of the recommendations, the problem is clearly mostly at a local level where primary care trusts are not always delivering consistently to ME sufferers in individual areas. Some are very good, some are mediocre, and some barely respond at all. That means that there is no effective national response. The research issue is difficult because only some of the statistics are collected—some organisations easily recognise ME while some are more cautious about recognising it. Therefore, at the moment the statistics do not tend to be terribly reliable, and there is a national effort to collect them. The extent of the problem is acknowledged, but the measuring bit is not in place at the moment. The idea that research should be done on this is a good one, but we need to look at how that will be undertaken. It is not as easy as people might assume.

As far as the national service framework is concerned, there are a limited number of those
and they apply to the major diseases. There is certainly an argument for that, but a number of other frameworks will probably be developed before we get to this one. Certainly, a greater evidence base needs to be developed for ME in order to create the basis for a national service framework.

The real issue lies with the PCTs and in ensuring that they have a stronger push from the Department of Health to ensure a clear policy for dealing with ME. That should have come out of the report by the CMO, and it was expected that PCTs would respond to it in a positive manner—some have, but others less so. Because a lot of power is devolved in the NHS, it is not the case that Ministers can just command from Whitehall. Those days have just gone and we now have a lot of diversified power. We can make recommendations, but when it comes to medical treatment we are reliant on the way that the medical profession decides the clinical pathway should develop.

There were number of other recommendations about medical students being better trained and GPs being more aware. Some of them are aware, but others—especially some of the older ones—are still sceptical about this condition. You still get dire stories about the way that some GPs deal with ME, despite the CMO’s report in 2002. There is also the fact that when discussing possible treatment, some people respond to those with ME in a way that leaves a lot to be desired. CBT and GET are recognised in regard to the development of treatment, but others take different views about how treatment should be developed.

We have not yet got a clear consensus about what should be available, and what the options should be. Part of that, with respect, is due to some of the ME organisations which still spend a lot of time arguing between themselves, rather than getting together and ensuring a clear, consistent view about how they will develop a strategy. The groups should also develop
alliances, because that is important, particularly in the area of health. We need to ensure that the CFS/ME groups are involved with the Neurological Alliance and engaged in the discussions that take place with the clinical network co-ordinating centres and the clinical champions for the NHS, so as to ensure that we get a clear view of how treatment for CFS/ME should be developed in the future.

The Medical Research Council is in charge of the funding for research. I would be very happy to write to it and say that these proposals have been brought forward, and that there is a strong argument for more work to be done to identify the causes of CFS/ME. Initial research over the last few weeks has suggested some possible indications about CFS/ME, but it is early days for that research, and it is clear that a lot more needs to be done.

I was a Minister in the DWP, and you are right, Des—it deals with simple things fairly well, but the difficulty is when it becomes complicated and people have an intermittent condition that causes a serious problem, then they are ok, and then they have another serious problem. The system does not deal with that particularly well. It is not only CFS/ME, this is a problem across the board.

When people look back on the development of this—these are early days for CFS/ME—we will see that not only was there a milestone in 2002 but, because this report is so fundamentally obvious and sound, it will be seen as another milestone for CFS/ME. That will require CFS/ME groups to get behind the report and give it a good strong push.

Chair: Thank you very much, Mike.

Janet Taylor: Regarding the national service framework, one for neurological conditions has existed since 2005. Both CFS and ME come under the umbrella of the Neurological Alliance—it is listed as such. I am pleased that we are looking at treating it as a neurological
condition because we have the clinical lead and the neurological commissioner on our side. Therefore, I am not sure why there is a need for another NSF, because the one for neurological conditions does not operate successfully at the moment. It is supposed to be finalised by 2015. One of the major quality requirements in that—which covers all QRs—is quality requirement No. 1, which states that high-quality information is the core requirement that underpins all the other quality requirements in the national service framework for neurological conditions. That is not happening.

The White Paper that the Government issued in 2006, “Our health, our care, our say”, published the commitment that by 2008 everyone with a long-term condition and/or long-term need for support and their carers could expect to continually be offered information about the condition. We are talking information, information, information. Earlier this year, Ann Keen said that neurology as a whole has been ignored. It is an area that has been ignored. The footfalls through the door have never been measured. How can you provide a service in neurology where you don’t know what the needs of the people are? This is no more strongly stated here, where the biomedical, physiological aspect of this illness is not there. It needs to provide the quality requirement in the NFS 2005, which is good information. If people have good-quality information, they are in control of their condition. The good information is not out there; it is all the psychiatric model. The 2006 White Paper asks for good-quality information to be given to patients. That empowers us. It links into so much, but the research is not happening. It is a neurological illness, and the research has not taken place.

Only recently on the ME Association site, a response to a question about the research for ME/CFS was, “Yes, we are aware of the panel that is being held by Stephen Holgate”—that is a monumental move, which I commend and I commend the report. However, the answer on that
side from MRC is, “OK, this is going ahead, but ME/CFS must stand in the queue like everybody else.” I have lost years of my life. I am developing other conditions, and I am sure that everybody else around the table who has had ME/CFS are going on to develop other conditions as a consequence of not getting the right treatment at the right time in the right place with the right information. What are you going to do about it?

Mike O’Brien: Right, I think the question at the end is all in relation to information. I will be very clear with you. The information costs a lot of money, so does research.

Janet Taylor: Yes, I accept that, but billions is being lost by the people with ME/CFS not working. You are losing revenue. It is one pot into another pot.

Mike O’Brien: I listened to you for five minutes, so let me respond to that. The problem for people with ME at the moment is the quality of the service that they don’t get. What they get is fine and good in some cases, but in other cases it is pretty poor. There is such variability across the country, that if I were you, my first focus would be on the quality of that care. I can tell you that nearly every group or organisation for a condition, disease or illness will come to me and say, “Can you get more information on that, can you get research done?” The answer is that if we put the entire budget into that, yes, we could do loads of things and look into other issues as well. However, statistics and research are expensive things. What is my priority? It is to get a clear quality and level of service that is available throughout the country so that every single PCT knows that if there is a person with ME, that person will be offered the basic things that the CMO’s report said they should be offered. That is my number one priority.

We must still get to that point, but if we want to develop beyond that we must have a clear view about what clinical pathways should be available to people with ME. That requires a consensus among the medical profession. Therefore, we must get the medical profession to agree
on what a GP, a consultant or a hospital should offer to each patient. That must be agreed nationally and that is my second priority.

The third priority would be that in order to deliver a higher level of service than just the basic service required by the CMO, you need the research and statistics. You must have all those things in place in order to raise the quality of care that people with CFS/ME require in the long term. It is variable, and we are trying to move towards a higher degree of personalised care so that people—not only those with CFS/ME, but across the board—are responded to for the condition that they have. The NHS is moving in that direction, but we are at the beginning of a process.

I know that a lot of people have seen the system fail them for too many years. Frank Dobson described the NHS as being like a supertanker, and getting a system like that and turning it around is not quick. Directing a whole lot of the budget at something means taking budgets from elsewhere, and you know as well as I do that NHS budgets are going to be under pressure. I have identified some priorities, and I have told you mine. I am sure that each person will have a different view, but I would say that research and statistics are important, but there are other things that should be a priority because we have not even got the basics done properly yet.

**Janice Kent:** Thank you, Des. I have two quick points. You mentioned the lightning process. The Sussex service has been giving out cards so that patients can go to a lightning process practitioner. It costs £560. Dr. Mike Broughton, the clinical lead of the Sussex service, held a “Meet the doctor” session at the Chalky Road surgery a couple of weeks ago. He was questioned about the lightning process and—surprise, surprise—it seems only to work for those patients who are not ill.

My other point is about the insufficient services. We have a Gypsy in our area, and a very
nice chap he is too. There is guidance that patients should be returned to their GPs, and should not be over-investigated as it builds up illness beliefs and so on. I have a very dear friend—Des, you can verify this if you want to visit her when you come—who for a long time has been reporting anaemia, abdominal pain and not feeling very well. She became acutely ill, and her husband telephoned to say that she had abdominal pain and fever. The response was, “Oh, it is swine flu. You have ME, better rest in bed for the week and see how you do.” In desperation, her 75-year-old husband bundled her into the family car and took her to the surgery. She has a huge abdominal mess. There is an abscess on it that has perforated. She went straight from surgery to MASU and into theatre in less than 24 hours.

We need doctors who will check and check again on their patients. We want proper, consultant-led services from doctors that know what they are doing. The Chief Executive of mid-Sussex PCT, who commissioned the service, agreed with me that Gypsies are not the right model for this illness, but the only way we could get our bid in was to conform to what the Department of Health said. It was the only way that we could get money for those services. Please, let us move on and give everyone the dignity of consultants who know what they are doing. I expect that there are many patients who say that they could do with coping strategies. Quite a lot would admit that they could do with emotional support and some gradual rehabilitation. Let us listen to the patients. I know that you don’t like patients in the Department of Health. I used to be welcomed into the Department when my husband worked there, but once I became a patient, I was told that I could stand outside in the rain. I rest my case.

Mike O’Brien: Well, you rest it badly, sadly, because I am a patient of the NHS at the moment as it happens, and so is another Minister. There are a number of Ministers who happen to be patients too. If you look at every Minister in the Department of Health, they will at some
stage have been a patient of the NHS. We spend a lot of time consulting with people who are currently patients and have to deal with a lot of different conditions.

I am aware that there is a lot of controversy around the lightning process. Some people feel that it is absolutely useless, and others think it is wonderful and a process that can help them to recover.

**Janice Kent:** If they’re not ill.

**Mike O’Brien:** Well, that is your view.

**Janice Kent:** That is Dr. Mike Broughton’s view.

**Mike O’Brien:** Well, I don’t happen to share it. It is a matter of controversy among people with ME. Clearly, it is not working for some, but it does appear to help others. Because it is basically about the way that people deal with a long-term condition, it might assist them in dealing with that condition. However, it is probably not a cure in itself—no one is arguing that.

**Janice Kent:** That is how it is presented.

**Mike O’Brien:** I don’t want to get into a detailed argument about the lightning process, which I do know a fair amount about. I would say that it seems to be a way in which CBT can be used to help people deal with a long-term condition that would otherwise be more debilitating than it is. Is it a cure? That depends on the extent to which you regard ME as a physical rather than a psychological condition. If people are ill for a long period with a physical condition, they’re also psychologically affected. My basic view about CBT and the lightning process in particular is that it can help people who have long-term illnesses, but that does not necessarily mean that it is the cure for anything. If the illness is caused by physical issues, a psychological response might help the individual to deal with it, but not cure them.

**Dr. Charles Shepherd:** Can I take you back to the problem with the PCTs, and the fact
that we had a dismal response from the PCTs—very few actually produced meaningful results to the questionnaires? A lot of PCTs are not interested and will not provide services for people at a local level. Local groups bang their heads together and go and meet the PCTs, but they will not budge. That is clearly wrong and not in line with the CMO report or even the NICE report. What can people do if they are in that situation and the PCT will not budge?

**Mike O’Brien:** Every group needs to basically organise and unite and ensure that its voice is clearly heard. That is what needs to be done at the local level. From the point of view of the Department of Health, it is clear that every PCT ought to have a clear view about how it responds to ME.

**Dr. Charles Shepherd:** But what people want is for you to say to the PCTs, “You can’t just ignore this”.

**Mike O’Brien:** I know. That is my point. PCTs have devolved budgets. They are responsible for creating the local services that best deliver to a local community. Ministers in Whitehall have long since gone past the situation where they can issue a diktat and get it done. That does not happen in the NHS.

**Dr. Charles Shepherd:** But if they were not providing services for people with cancer, hell would be let loose wouldn’t it?

**Mike O’Brien:** Yes, it would be. You’re absolutely right. Those who have cancer are extremely well organised and make their point of view heard at a local level. People with ME need to ensure that they work with us. You’ve got a completely open door. I am well aware of the damage that ME does to individuals. It is a serious problem that can blight lives, particularly if people are young. One of the key things in this report that I thought could have been brought out more effectively, was about young people in particular and the conjunction with the local
education authority in ensuring that there is educational provision for young people with ME. That is one area where I would have developed the argument a little more strongly. For young people in particular, the level of service is poor.

I have already gone five minutes past my time. I will take one quick question, and give one more quick answer.

**Sir Peter Spencer:** I thought that your three priorities were very helpful. Thank you for taking such an interest in all those recommendations. If you look at priority 2 and priority 3, priority 2 was to get the medical profession to agree, but they will not do that until there is more evidence. I think the problem about getting enough resources to do scientific research is very bad. We have been here for too long. The MRC is revisiting this, but it will not happen unless something is done by the Government or by a Minister.

**Mike O’Brien:** I am happy to say to the MRC that I have been lobbied by the all-party group, and that it is concerned that the lack of services is linked to a lack of research and background information, and that I wish to draw that to its attention. It is time that we improved the medical consensus—I hesitate to use that word, but in a sense that is what you must end up getting—for CFS/ME.

**Dan Ward:** Can I tell you what happened with a consultant this year?

**Mike O’Brien:** I would love to stay but I’m afraid—

**Dan Ward:** It was a 15-year-old girl. A consultant asked her to prove her fatigue. That happened this year.

**Nicky Zussman:** Minister, I do not know that we want hypnosis in the NHS—NLP cowboys.

[Minister leaves]
Nicky Zussman: It is an NLP con. I never thought I’d see the NHS taking it seriously.

Chair: I don’t think that the NHS is.

Nicky Zussman: Well who is taking it seriously? The Minister? It was the first thing the Minister said—what about treatment, so lightning process. We will have an invasion of NLP cowboys. What they are best at is selling.

Michelle Goldberg: Can I make a quick comment for clarification. The issue of finances came up again regarding the Medical Research Council and the cost of funding research. A documentary has been made called, “The marketing of madness”. It is a story of a high-income partnership between psychiatry and drug companies that has created an $80 billion psychotropic drug profit centre. It exposes psychiatrists’ fraudulent diagnoses to further sell their drugs to normal people. The profitable market makes $150,000 every single minute. You are welcome to have a copy; it is just a flyer about the documentary. Is there a link with the Medical Research Council?

Chair: I don’t think there is a link between the Medical Research Council and that lot.

Michelle Goldberg: I think that there might be. Money is being made out of people’s illnesses.

Chair: Yes, but that has nothing to do with the MRC. Minutes of the last meeting have been circulated. Are there any comments?

Paul Davies: They turned up on my computer yesterday afternoon about 3 o’clock, sent by Action for ME. Does Action for ME think that ME patients will be able to read tens of pages of information the day before a meeting? Patients who attend these meetings are resting up the day before the meeting. I haven’t read them, so I can’t comment. I would like to put that question to Sir Peter Spencer, is that reasonable?
Chair: Do you want to comment, Peter?

Sir Peter Spencer: Can I put this into context? People have previously asked for full verbatim reports of this meeting, which we have produced and funded jointly with the MEA. It takes time for us to receive that. We are aware of people’s concern about accuracy, so until we receive that verbatim report, we cannot produce the minutes. There is quite a long time between the meeting and producing the minutes. On this occasionally, exceptionally, the meeting took place only six weeks after the last one, so there was no time to do any better. We could have either not produced the minutes for the Chairman to approve and send out for comment, or we could send them out for those who are able to read it. That is for the Chair to decide, but in my view, if people need more time before they approve them, that would be perfectly understandable. I know what the problems are, and I agree with them. On this occasion, it was difficult to know which way to go. We tried to do the best we could under the circumstances and not put anybody under pressure to agree to something if they were not in a position to do so.

Paul Davies: Could I propose that the minutes of the last meeting are held over so that ME patients will at least have the opportunity to read and digest them?

Chair: They’re only the minutes of the meeting. Is it that important? It is not the biggest issue in the world.

Andrew Stunell MP: I want to make the point that this is a record of the meeting, which I understand the gentleman said he wasn’t able to attend at the time. I understand that, but this is a record of the meeting. There will be opportunities for people to return to them at a subsequent meeting and say that there were issues that they wanted to be considered further. This, as I understand, is simply to approve a record of a meeting which is, quite unusually for all-party groups, absolutely verbatim. It is about 16 pages longer than I would have expected. That is
because there were requests from members—actually, if I may be accurate, it was not members of the all-party group, but people who attend the group who asked for a very full record. I do not want to provoke controversy, but it is a little bit perverse that having been provided with exactly what they wanted, those who attend the meetings should feel that the minutes should not be approved. As an actual member of the all-party group, I propose that the minutes be adopted.

**Chair:** Thank you, Andrew. The minutes in the past were virtually a verbatim record of the meeting. They were too long, and that is not the conventional way to record meetings. Usually you record decisions taken and so on. We have produced business minutes of the meeting and a separate transcript, which has been circulated. I don’t think anyone can really complain about not being informed. I am happy to accept Andrew’s move to adopt the minutes. If anyone wants to revisit items in the minutes, they can raise it as a matter arising in the next meeting. Are people reasonably happy with the accuracy of the minutes? That is what I was going to ask. I will take silence as assent in a moment. Yes. Okay.

We have three matters already on the agenda. The first is the question of the legacy paper, which is intended for the APPG if it reforms itself after the general election—it is a bit like having a time capsule. Many people will not be here. I shall not be here. There will be at least 200 new Members of Parliament who may or may not reform this group. They may or may not be able to find someone who cannot move fast enough to avoid being Chairman. This is a suggested programme of work which the group in its next incarnation can consider in the future. It is not binding on the group in any way, but it represents things that have, at one time or another, been concerns of this group.

**Ciaran Farrel:** I have one small point, not about the great issues of the legacy paper, but about point 5: the Mental Health Act and the Mental Capacity Bill. The Mental Capacity Bill is
now an Act and has come into force.

**Chair:** Thank you for that correction.

**Paul Davies:** Again, this was circulated yesterday. A lot of people will not have had the time to read and digest what is in the report.

**Sir Peter Spencer:** I will put that into context. This is the version which has now been drafted in response to an earlier version to which a large number of helpful comments were made. We circulated the initial version; a lot of people wrote in and this is the amalgam of what we received. Inevitably, as part of a consultation you cannot write everything that everybody sends in because some of it is mutually inconsistent. In terms of the balance of what came in—this is already rather longer than the members of the group would ideally like. We were asked to aim at two pages and it is hard to do that without appearing to censor some strongly held views. Those people who have been doing this—which includes a lot of people in this room—have had a good chance to look at this and this is the version as it stands now.

**Chair:** It is a revised version.

**Paul Davies:** Yes, but was it not published yesterday?

**Chair:** It was circulated yesterday.

**Paul Davies:** I am just saying that ME patients who have problems with cognition and so on might not have the time to read and digest this information the day before a meeting.

**Chair:** Well, possibly not, but they are not necessarily going to come either. I am afraid that this is not a professional organisation. It does its best within the limits of its resources.

**Sir Peter Spencer:** Paul, nobody is asking anybody to agree this today. We are saying that the proposal was made: should we do a legacy paper? There was strong agreement that we should. We then said that rather than a blank sheet of paper, here is the earlier version, which we
circulated. Four or five weeks later, this is what has come back. As part of matters arising, it is being presented back to the group to say, “Here is where it stands now.”

Paul Davies: So if we want to we can—

Chair: If you want to submit comments you can.

Dr. Charles Shepherd: We have given people two opportunities to submit comments. The last submission went up to November 18—November 20—there was quite a lot of time for people to submit them, and a shorter period of time to get to the next stage.

Paul Davies: Yes, but if people submitted comments by November 20, will they have had time to read the whole document and see whether those comments have been incorporated?

Chair: They can submit comments at any time. Let us not get bogged down in process, again. I suggest that we put this item in the agenda for the next meeting. Obviously, the meeting will be asked to approve it. If anyone has comments on this revised version, they are welcome to submit them and they might or might not be incorporated. Bear in mind that whatever we leave behind for the successor group is not binding on it in any way. It is just a guideline.

Right. The outstanding bit of new research is XMRV.

Dr. Charles Shepherd: Des, I have some notes on what is happening with XMRV at the moment, if that would help. This is probably the most important bit of research to emerge this year with the results from America. Talking to people in this area, the first step is the urgent need to see whether other groups in other countries can replicate these findings that have come from the WPI. If they can be replicated, we can then move on to look at the pathogenicity of the virus—is it a disease-causing virus? We could even look at ways in which it might be treated, if that seems appropriate.

XMRV was discussed in some detail at the two-day MRC expert group workshop on
November 19 and 20. We were lucky to have four researchers present in that area who are all actively involved in XMRV research. We had Dr. Jonathan Stoye from the National Institute of Medical Research at Mill Hill, Dr. Kate Bishop who works with him, Dr. Jonathan Kerr and Dr. Suzanne Hagan who works with Professor John Gow in Glasgow. To the best of my knowledge, there are other UK virologists and retrovirologists who are interested in this new retrovirus. A few weeks ago, I met for most of the afternoon with Professor Greg Towers, who is probably one of the other great experts in this area and works at University College London.

Those of us who attended the MRC meeting and are following this in respect of research charities are fairly well informed about what is going on. It is good to know that there are some replication studies taking place, or about to take place, in the UK. The replication studies are going to involve stored blood samples. There are two strands to this. People are keen that the patient criteria used in the WPI research—the use of Fukuda patients—would also meet the Canadian criteria. If people want to try to get off first in the race with stored blood samples, the immediate problem is that very few people in the UK—and probably around the world—have stored blood samples from patients that meet both of those diagnostic criteria. Inevitably, we will find that the early replication results from different groups that come in over the next few months, will probably be from Fukuda CDC criteria patients. You can move on with fresh patients, new cohorts of patients who meet both clinical criteria, and obviously that would be a good thing to do.

ME Research UK plus the Irish ME trust are funding a replication study in Sweden. The Ramsay research fund, which is the research arm of the ME Association, has made it clear—as have I to all the people in the UK who are doing this—that the money is there if they want to come to us. However, our feeling at the moment as far as UK studies are concerned, together
with people such as Jonanthan Stoye, is that money is not a particular problem at the moment. They are getting on with what they want to do and funding is not a problem. The initial implications of all this, and the off-the-record feedback suggests that we may well get some early results from the replication studies fairly soon, possibly around the end of the year.

The other important issue is that of blood donation and the ME Association has been in correspondence with Sir Liam Donaldson about this. He has repeated the guidance that people with ME/CFS should not donate blood until they have recovered. That is previous guidance that has been around for some time. He has referred those concerns to various expert groups that look at new emerging infections to consider the implication of XMRV being present in the healthy population. There is some suggestion from America that that might be around 4%, so what implication does that have for the safety of human blood? That is being looked at by the CMO, and he will clearly take note of what his experts tell him, which will include the sort of people that I have referred to who are doing work on XMRV. That is a brief summary of where we are with XMRV in the UK.

Chair: That is helpful. I knew that some virologists were working on it, and I believe that the results are looking quite promising and that the original findings will be confirmed—that is probably a bit premature. If they are confirmed, it offers an avenue for finding and evidence-based approach for treating ME/CFS, which has not been there before in any shape or form. Watch this space, but don’t get too excited yet. Even if it turns out to be true, it will be several years before you could expect a clinical treatment to emerge.

We were going to address the accessibility of APPG meeting venues. Is there a problem? Believe it or not, these rooms are accessible. There is wheelchair access to the Palace.

Paul Davies: At the first meeting which was opened up to the public in April 2006,
chaired by Mr. Stunell, was at Portcullis House. ME patients found the access considerably easier than they do to the Committee Rooms in the Palace of Westminster.

**Chair:** Point taken, but there is access to both.

**Paul Davies:** I have raised this point on a number of occasions, but I have not been given a reason why—

**Chair:** There are two factors. First, Portcullis House has a number of fairly large rooms which are heavily booked, and a number of rooms which are too small for our purposes. If we want a room that is about the right size, we tend to come here. It is a simple practical reason.

**Paul Davies:** In the meeting in April 2006 there seemed to be plenty of room.

**Chair:** Well, there isn’t now, I can assure you. Who is going to speak about the welfare update? Has anyone been doing any work on it?

**Sir Peter Spencer:** A short summary has been circulated which we have put together with Lady Mar. I think it would be an appropriate moment to put on record the thanks of this group for the huge amount of work that Lady Mar has put into this Bill at various stages as it went through the House of Lords. A number of Members of Parliament also spoke to the House of Commons. I am not sure that we’re very happy with the outcome. A lot of it will depend on monitoring and implementation, and there is further work outside the legislation for us to monitor in communication and to take up with the DWP, particularly regarding the experiences that people with ME have of the welfare support system.

All patient groups are getting growing numbers of stories that are distressing and extremely worrying. As the pressures mount on the public purse, your sense tells you that it is likely to get worse. We will have to work very hard on behalf of all people with ME to ensure that they don’t just get trodden underfoot by the merciless adherence to a set of processes which,
as the Health Minister said, don’t really cope with a complex and difficult illness. The evidence is that fewer people are actually getting support, so the problem is getting worse because the process and the rules have changed in a manner that has a highly adverse impact on people with ME.

**Chair:** I think this is an unintended consequence that we must watch for. We need to have evidence to follow this up. If people know about someone who has had specific difficulties, it would be useful to let the charities know and let me know.

**Ciaran Farrel:** I have a number of points because with the changeover to employment and support allowance come a number of different assessments—a work-related assessment, work-focused interview and a health-related assessment. Every time you see a personal adviser, you might get referred to the various establishments, usually third-sector establishments. I have a series of leaflets that I have been sent, and there are various workshops and things that people would be expected to do to improve their health and make people more work-ready. This is causing difficulties because it is not only the fluctuating nature of ME that is the problem, it is the perception of that fluctuating nature.

Mr. O’Brien made the same point—thinking that with ME you are okay for a certain amount of days and then you are not okay. However, the actual problem is that you are never okay, but it is a question of sometimes being better than other times—that does not mean to say that you are ever “okay” at all. That needs to be understood not only by the DWP decision makers, but by the Jobcentre Plus advisers and various other people, and those in the third-sector who are contracted to provide these workshops. That is where a lot of the problems are coming from.

I have friends who have other conditions, and instead of attempting to understand the
conditions that they suffer from—in two cases, cancer—my friends have been pushed through the system. One ended up collapsing in one of the offices of these organisations. That is clearly not acceptable. The feedback that I have had indicates that ME claimants are suffering, as you would imagine, in a much greater way proportionally because ME is not understood. I am not quite sure what to do here, but one of the things that should be looked into is the range of health-type seminars and courses. They seem to overlap with some of the treatments, in terms of sleep and routine, exercise, mental health, coping strategies and so on. If somebody is in a certain situation, what would happen in terms of their relationship with the DWP over courses such as these?

**Chair:** Good question. I don’t know the answer, but clearly there is a potential problem. With more evidence we can lobby the DWP to improve the operation of the system. A system is only as good as the people operating it. It is always the people who operate a system who create the problems.

**John Sayer:** Can I suggest that the system causes the problem in the first place? Clearly, these people are not going to be in business unless they are siphoning-off people into work-focused interviews and trying to get them back to work. It seems to be a self-perpetuating problem. I have had a letter from the Shaw Trust—I think that was the latest one—saying, “Let us help you overcome your obstacle to work”. I never did write back because I wanted to say, “My obstacle to work is the fact that I have fairly severe ME. Unless you can cure me, what the hell are you doing writing to me?”

**Chair:** Give us examples of these problems and we will follow them up. That is the only thing I can suggest at the moment.

**Dan Ward:** I have been a carer since 1988, and I have never received one document or
any advice. I would like to receive some good advice. I have been a member of the ME Association and used to talk to Action for ME. I am a member of ME Support in Norfolk, and this week I know of three people who have lost blue badges for cars. Two of them are what I would consider bedridden. I have had a lady phone up about her child who was told by a consultant to prove her fatigue by walking up and down the corridor in a major hospital. That was this week.

Chair: That sounds like a version of some sort of exercise therapy…

Dan Ward: Oh no it isn’t. All I would like to say is that I have never received any information in that time—since 1988.

Jan Taylor: There are two things I would like to say. It is something that I picked up from the minutes of the last meeting. I don’t know whether we are unique in Kirklees, but are there not welfare benefit adviser officers in other metropolitan boroughs, who work on behalf of the person with a condition and fight for their right to keep their benefits? That is what we are being told by our benefit advisers who work in Kirklees. They are fighting on our behalf to keep our benefits. In Kirklees there has been an onslaught of people asking for advice, and all the charity associations have all said, “Even though you have filled in the forms before on your own and got your claim, do not fill them in without some kind of advice. Take advice from somebody.” I know that if someone is on benefits there are some firms of solicitors that operate on a free basis.

Dan Ward: I am sorry—it is still failing.

Jan Taylor: Yes, but you then take it further. There is a group called the Links, which works on behalf of the patient. There can be formal complaints; it is all a partnership that is linked. You can also go to your local MP, but if that fails there should be a neurological group
near to you that you can make an alliance with to get better information. That is what we are doing at the nerve centre—we are a platform for people with neurological conditions. We give information and training for people looking for benefits advice on neurological conditions.

There are lots of neurological conditions that are very little understood, such as ataxia, dystonia and many others. People suffering from those conditions have much the same problems that we do and they are not understood by the benefits system. I know somebody who went for years with ataxia and had never claimed benefits in her life. She was knocked back until an expert in ataxia came over from Manchester and helped her to fill in the form, and she got what she required.

I went to a summit of the regional neurological alliance in Tyne and Wear. The regional neurological alliance for Tyne and Wear has commissioned research from the university into living with a long-term condition. One of the problems is that there is very little research out there on people who are living with a long-term condition. There is a Sue Ryder foundation document from 2007 called “Filling the void; how real life health information builds better services.” There is very little information out there for people.

Chair: You are very lucky in Kirklees to have local benefit advisers. Not many councils do that now. It clear that there are some problems with the employment and support allowance, and we will have to follow that through.

Nicky Zussman: There is a problem regarding where people have gone through several appeals to get their DLA, and even to a commissioner’s appeal. That might have taken years, and they were then awarded backdated DLA. However, five years later, the DWP pursues them and tries to prove that they have been taken over a savings allowance. It literally hauls them in like criminals and treats it as an overpayment.
**Chair:** Yes. I am aware of those problems.

**Nicky Zussman:** It is predatory. The young men who do those jobs were predatory. Their attitudes and behaviours were predatory. It is very disturbing.

**Chair:** Yes. It is almost an entry qualification for the DWP I sometimes think. Okay, any other business? We will issue a press release to go with the report, and issue copies of the report to the press. Any other points?

**Ciaran Farrel:** Quickly, on the lightning process. If you look at Phil Parker’s website, you will find that he describes the lightning process in terms of NLP—neuro-linguistic programming, and autogenic training. Involved in that, there are elements of hypnosis. It is a hypnotic technique. That can be seen in documents such as this. I and others were rather concerned some time ago when a witness was called before the inquiry, because we felt that we were hearing what might be just one side of the story. I do not want to take up everybody’s time delving into the lightning process, but one of the things that you need to do with lightning process is fill in a very detailed form. It is not about simply making an appointment and paying £560. You have to sign up to a process called “Are you ready for the training?” You must commit yourself to being helped by lightning process and being cured by it, even though lightning process is not itself a cure. It is a training, and it is not registered as a treatment.

**Chair:** Nobody is endorsing the lightning process.

**Ciaran Farrel:** I am not suggesting that the lightning process is being endorsed, but I raised it as a matter of explanation and a point of information.

**Chair:** It has all the hallmarks of high-pressure salesmanship.

**Jill Cooper:** I want to do this quickly. It is because I heard Mike O’Brien talk about the lightning process, although this is not actually about that. I will read this; it is quite important. I
would like to make a brief comment about the current situation regarding the CCRNC, which Mike O’Brien was talking about—the clinical research network collaborative. By chance, it has been discovered that this is now metamorphosing into the British Association of CFS/ME—BACME. Apparently, this was decided quite a few months ago, and after the comments made at the last APPG meeting of 21 October, we are concerned that too many people do not seem to comprehend the role of this collaborative/organisation. Contrary to the Countess’s assurance that this is for research and is not part of the Department of Health, it is clear that this group is determined to influence Government policy and train NHS staff. The fact that this organisation refuses to operate openly and transparently, should be of great concern to those of us who believe in democracy.

Chair: Thank you.

Michelle Goldberg: Can I make a quick point about the legacy paper? Item No. 4 deals with child protection issues, but there is nothing about adult protection issues. Exactly the same applies—I have had to go to the safeguarding adult protection unit in Hackney where I live.

Chair: Can you give us a note to remind us of that, and we will incorporate it?

Dan Ward: Will this be available on the internet to download? Can it be reproduced?

Chair: It is not at the moment, but we will put it on the website.

Dan Ward: In the meantime, could the recommendations be reproduced? I am speaking as the editor of a newspaper.

Chair: Yes.

Mary-Jane Willows: Before we go, I would like to thank you, Chair. I don’t know whether we will meet again before the election, but if we don’t, or if I am not present, can I thank you for the work you have done on behalf of children and young people in your area and
nationally? Thank you very much indeed.

Chair: Thank you for that. We have to decide whether we will have a further meeting before the general election, and if so, when. If we are going to have another meeting, I suspect that it would be pointless to have it after the middle of March. Do people want another meeting? Perhaps we should aim for a meeting in February. I will not set a date now, but we will circulate a date later. Thank you. The meeting is closed.