

## **Verbatim record: APPG on ME**

*Transcript of the meeting of the All Party Parliamentary Group on ME, 1 April 2009, prepared by a Hansard transcriber on behalf of the Secretariat (ME Association and Action for M.E.) with the aid of a recording produced by Westminster Sound.*

1. Dr Desmond Turner (Chair): Welcome to this meeting of the APPG on ME. Congratulations to those of you who have managed to brave the demonstrations—or the fear of them. I have not personally noticed any difficulties, but perhaps I have been lucky.

You may have noticed that we have a television crew with us. It is from the BBC Politics Show, which is taking an interest in ME and one sufferer in particular. I suggest that it does no harm for this group to be featured, providing that we are all on our best behaviour.

Minutes have been something of an issue. The minutes have been very exhaustive recently and have grown, a bit like Topsy, to become almost verbatim transcripts. That makes it very hard work for the minutes secretary, and it is not the form of minutes that I am used to in Committee work, which essentially record the business decisions of a meeting. I therefore suggest that we keep the minutes per se as strictly for business. We have the services of a *Hansard* transcriber with us this afternoon, so a verbatim transcript of today's meeting will be produced and made available. The business minutes will be concise and record the decisions taken. I hope that that is acceptable to the meeting.

Let us proceed to the minutes, which have been circulated. I have been notified of a couple of queries about accuracy starting with one from Paul Davis. I cannot comment on what Lady Mar said.

**Paul Davis:** On the first issue, it was reported that “he, Paul Davis, also asked if the services inquiry would cover research.” I did not say that.

**Chair:** Fine, we are happy to delete that.

Nicky Zussman spoke to a paper, and wishes the appropriate reference to that paper to be included in the minutes. Is that acceptable? We will do that.

That is all I have been notified on. Are there any other points about the minutes? Is it the Group's wish that I approve the minutes? Good—we must ask the television crew to come again as it obviously has a calming influence on the group.

Are there any matters arising from the minutes that will not be covered by the agenda?

**Heather Walker:** I would like to note for the record that the Welfare Reform Bill is now proceeding through the House of Lords.

**Chair:** That is something that must be watched. When it comes to the House of Commons, any concerns that people have picked up regarding provisions in the Bill should be made known. People can direct them through me if they wish, and I will ensure that they are raised in the House.

Item 4 is our long-gestating inquiry, which we propose to set in train as of today. Everybody should have a copy. Before we discuss terms of reference, people should know that there is a group of parliamentarians who will take oral evidence at the inquiry in the manner of a Select Committee.

They will put their names to the final report because this is ultimately a report of parliamentarians. They include myself, Ian Gibson MP, Tony Wright MP, Andrew Stunell MP, the Countess of Mar and Baroness Finlay.

The next item is the terms of reference. Those have been open to consultation by members of the group, and the responses to that consultation have been carefully considered. These are the terms of reference with which it is now proposed to proceed. My parliamentary colleagues have agreed them, and we must finalise them today. We cannot go on discussing this matter indefinitely or we will never get there. Does anyone wish to say anything?

**Derek Pheby:** You asked for estimates regarding other people with ME living in the area, to whom the survey might be sent. Would it be worth also asking about the basis of those estimates, as they could be numbers plucked out of the air? You might get raw data and will not know what to do with it.

**Chair:** I think we will get estimates anyway. We ask other questions about the criteria for diagnosis. It is inevitable that those figures will be hedged with a certain amount of uncertainty.

**Derek Pheby:** Yes, but the criteria for diagnosis will be in respect of people who are being treated by the service. They will not be applied to the population as a whole.

**Chair:** You suggest that after a question about the number of people with ME, we include something about the basis for the selection?

**Derek Pheby:** Yes, a question at the end asking on what basis the estimates are made.

**Sir Peter Spencer:** I suggest that that could be covered by the way the question is worded, so that it becomes an implementation of the terms of reference.

**Chair:** Yes, we can do that. We would do that in the questionnaire anyway.

**Paul Davis:** Will people who are not at this meeting have a chance to reply to this?

**Chair:** No. There has been an extended period of consultation. If we are ever going to complete the inquiry this year, we must proceed today. Otherwise it will stretch into the distant future and we will never get anywhere.

**Paul Davis:** This is an amended document.

**Chair:** Yes.

**Paul Davis:** I am just a little concerned because, I repeat, there are many people who would like to be here today but cannot because of the illness. They will not have the chance to respond.

**Chair:** I am sympathetic to that point, but we cannot go on indefinitely. We have to draw a line at some point.

**Sue Waddle:** But people who are not here can give evidence?

**Chair:** Of course they can.

**Sue Waddle:** Can I return to what Derek was saying, as I did not quite catch it? Were you asking a question about the collection of data from the strategic health authorities?

**Derek Pheby:** I was asking about the third bullet point in the terms of reference, which is the estimate of the number of people concerned. I said that we should try and establish the basis on which the estimates are made. Sir Peter Spencer sensibly suggested that that could be reflected in the

wording of the questionnaire, and does not need an amendment to the terms of reference.

**Sue Waddle:** I have brought up a few times—I think it was noted last time—the fact that there is a question over the Read Codes that exist, even if they are not necessarily used by GPs. I have said for a long time that this is a simple way of collecting data on everybody, even those severely affected who do not normally come to the attention of anybody else. They do not come to secondary attention because they are lying in bed and are too ill to go out and visit the doctor. If read codes were applied at initial diagnosis, it would give a good estimate of how many people in this country are affected.

**Chair:** Again, that is something that we can cover in the questionnaire.

**Derek Pheby:** I do not want to delay the meeting too much, but I know a little about read codes as I was Chairman of the project assurance team for the development of the read code. Read Codes are not a bible in themselves; they are designed to reflect what GPs are doing—which in some cases we know can well fall short of what we think they ought to be doing. As part of the observatory project, we developed an algorithm to search Read Codes in order to identify people with ME. That seemed to work quite well. A variety of Read Codes are used. It is not as simple as going for a Read Code that says, “ME” as lots of other factors are relevant. There are ways of tackling this.

**Chair:** Are there any more points on the terms of reference?

The website is not yet up and running. The person who was going to do it has nipped off to Australia for a holiday. He will be back next week, and the website will be up and running then. It will carry the terms of reference and an invitation to submit evidence, which we will notify to the press.

Can I assume that the Group is content with the final version of the terms of reference? I have a letter here<sup>1</sup>; it does not seem to have any relevance to the terms of reference that we are considering at the moment. Are people happy with the terms of reference?

**Alan Gold:** As far as I am concerned, I do not suffer from chronic fatigue syndrome. I suffer from Myalgic Encephalomyelitis.

**Chair:** We do not wish the inquiry to be phased by arguments over terminology. Whether it is called ME or CFS, we will be looking at it. We do not wish to get sidetracked by a debate on terminology.

**Alan Gold:** It is at the heart of the issue.

**Chair:** That is a matter of debate. We are looking for services to be on offer to people classified as having either ME or CFS.

**Jane Colby:** Perhaps I might add to that point. The idea that ME can be separated from CFS is something that the Young ME Sufferers Trust is very keen on. It seems that until that is done, there will not be any real clarity. I can see that it is difficult for this inquiry to go down that route, but this is how we see the future going, as there is more and more evidence. I do not know whether anything within the questionnaire can take account of that aspect, or whether we should leave it alone for this inquiry.

**Chair:** It will certainly take account of that. We will be asking questions on diagnostic criteria and so on. Hopefully, that will emerge from the inquiry in any event.

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<sup>1</sup> Secretarial note: letter from Ciaran Farrell

**Paul Davis:** I would like to back up Jane's point to say that this needs to be about ME. Centres set up for the CMO report would not fit the G93.3 criteria. The APPG said in November 2006 that it recognises G93.3.

**Chair:** It does.

**Paul Davis:** We continue to get feedback from around England with people saying that these services are not strictly about G93.3.

**Chair:** That point will inevitably emerge, hopefully quite clearly, from the inquiry. That is the whole point of that paragraph being there as a preface to the terms of reference. We recognise that there is a problem with terminology, and we will ask the necessary questions. The NHS uses the term CFS. We will ask what it means by that. Whether the distinction is a real one is open to debate. We are looking to survey the services that are available to patients, whether they are classified as having CFS or ME.

**Paul Davis:** People with ME would say that they have an illness that is defined by G93.3 and the Canadian criteria. That is different to chronic fatigue and to conditions that could be included under a loose definition of CFS.

**Chair:** That does not nullify the intention of the inquiry.

**Alan Gold:** As long as we can get some clarification.

**Chair:** We will endeavour to do that. My point is that we do not want to be sidetracked into a debate on that. We are looking to find out about the consistency, or otherwise, of the nature of services on offer.

**Alan Gold:** People with Myalgic Encephalomyelitis can tell you about that.

**Chair:** No doubt they will.

**Doris Jones:** In the judicial review hearing that took place on the NICE guidelines, we received information from the World Health Organisation that the term used by NICE in its guidelines—CFS/ME—is not satisfactory and needs to be clarified. Here you refer to the NICE guidelines as being ME/CFS. We are still talking at cross purposes. Which takes precedence?

**Chair:** We were talking about NICE guidelines. That is how NICE describes their guidelines.

**Doris Jones:** But the terminology CFS/ME is not acceptable to the World Health Organisation.

**Chair:** These paragraphs are setting out the background as we see it. They do not intend to try and resolve the debate.

**Annette Barclay:** I have a question about page 2, point 6 on the way in which patient outcomes are measured. I want to double check that that will include adverse reactions to treatment.

**Chair:** We will ensure that that is covered. An adverse reaction is in itself a patient outcome. If someone is directed into an inappropriate treatment and there is an adverse reaction, we want to know about it.

**Joan Duvey:** We must be careful about people who drop out of treatments that they are offered. People often do that because they are not suitable and it takes a lot of energy for them to go. We need to be careful about treating them as the results could be deceptive.

**Chair:** That is by definition a patient outcome, or lack of outcome, which hopefully we will pick up.

**Kirsty Haywood:** I am from the Royal College of Nursing research institute at the University of Warwick. I want to follow on from the point about patient outcomes, and how patients measure those outcomes. Patients per se

do not really measure their outcomes—they report and comment on them. To capture current USFDA guidance on how we measure and understand patient outcomes, we should refer to the term “patient-reported outcome.”

**Chair:** That is a good point. That was certainly the intention.

**Joy Birdsey:** There are a lot of patients who will not be able to report on outcomes because they cannot get to the clinic. That concerns me. How do we report on people who are so ill that they cannot report on how they are getting on? There are a lot of parents who are in fear.

**Jane Colby:** We often find that the outcome reported is not the outcome that we are told is happening. People are afraid; they want to keep the paediatrician on side and are afraid of social services. We talked about that at a previous meeting. I see what Joy is getting at. It is hard to know whether what we get with vulnerable young people is true. The Royal College of Nursing did a study on patient outcomes, which nobody has seen. Will you tell us about that?

**Kirsty Haywood:** My apologies. I was on maternity leave, and that is why it was delayed. The report has been submitted to the journal of the Royal Society of Medicine.

I will summarise the results. We undertook significant programmes of work that in the first phase explored qualitative work with patients with extreme forms of ME/CFS, to try and get to grips with what they considered to be their important valued outcomes. We also conducted a structured review of outcomes used in all types of published research. The take-home message was that there are real inconsistencies in what has been measured in published research. More importantly, published research is not capturing what people consider to be important outcomes. It is measuring irrelevant outcomes, most often with inadequate outcome measures. We are getting a poor representation in published literature of what it is to live with ME/CFS and experience the impact of ME intervention. The outcomes element here is a significant part of the work.

**Chair:** When is your paper going to be published?

**Kirsty Haywood:** It is under review at the moment. The full document will be available on the BRAME website.

**Chair:** Will you let us have an advance copy? We would not use it publicly, but we may wish to draw on it for some of the content in the questionnaires.

**Kirsty Haywood:** I am more than happy to do that.

**Jane Colby:** I also think that that is important. One of the things I remember that you found, was that few of the outcome measures were the same as any others. There was no standardisation across lots of different studies that were being compared and analysed. In fact, that cannot be done. It is not like for like.

**Kirsty Haywood:** The real issue was that there was a clear lack of guidance in the assessment of outcomes in ME/CFS. There was zero standardisation of what was being measured, and the measures that were being used were terrible. They had poor psychometric properties, which meant that the confidence that could be placed in what was measured and reported was challenging.

**Jane Colby:** That is a vital publication. We have been waiting so long for it.

**Kirsty Haywood:** I know—I apologise.

**Chair:** We look forward to receiving it.

**Sue Waddle:** I want to pick up on what Joy and Jane have said about children, and parents who are frightened to report what has happened to their children. Is it possible for some sort of anonymity to be granted to people who are prepared to give evidence?

**Chair:** Yes. I can give the assurance that we will not name anybody. There is almost certainly no need to name any individual. If we do feel it necessary, we would not dream of doing it without their express consent.

**Joy Birdsey:** We need this. I can tell you honestly that there are a lot of mums in absolute fear of children's services and clinics. It is frightening to be on the end of the phone listening to these mums.

**Chair:** We will not betray any confidences.

**Paul Davis:** I want to point out that a lot of people with ME will be boycotting the services set up following the CMO report. I came here today—I do not know whether it is appropriate at this point, but we have had several communications from Yorkshire, and some of the people would not go to the Seacroft Centre in Leeds, as they do not think that it is relevant to ME.

**Chair:** I hope that we will pick that up through our questionnaire.

**Paul Davis:** They are saying that there is a roadmap that goes back to York review 1, and to literature by a certain school of psychiatrist. When the toothpaste is out of the tube, is it easy to get it back in?

**Chair:** We are trying to draw a line under things, not follow old misconceptions from the past.

**Peter Luff MP:** We are considering the terms of reference. How will you go about collecting data from the health authority?

**Chair:** Through questionnaires.

**Peter Luff MP:** Will you involve colleagues in the House of Commons in that process?

**Chair:** Yes.

**Peter Luff:** I would very much like to be party to that process.

**Chair:** You have just joined the group. Are there any other points? We have technically finished the terms of reference, but it is still open to discussion as it is an important matter.

We have not finally written or issued the questionnaires yet, but that will be done shortly. They will seek to elicit the information that we want. Heather has reminded me that we want to invite everybody—whether they are ME sufferers, carers or professionals—to submit suggestions for specific questions that could be asked in the survey. The deadline for receiving those ideas is 5 May. We intend to prepare and issue the final questionnaires on 12 May. We are open for suggestions until 5 May.

**Alan Gold:** Today is 1 April. Do you think that 5 May gives sufficient time?

**Chair:** It will have to.

**Alan Gold:** People are ill. I do not think that it is sufficient.

**Chair:** I am aware of that. The timetable may seem demanding, but if we are to complete not even the publication of the report, but the evidence-taking process by the beginning of the summer recess, we cannot slip past those dates. We will run out of time.

**Kirsty Haywood:** I appreciate your concern about getting the survey out and ensuring that we access what should be important information to inform on services provided for people with ME/CFS. However, there are real challenges to the time scale and the way that it challenges recognised, good-quality survey research. The time scale is unacceptable. We should be moving towards a world of patient involvement within research, and that means an evolution in the way that research has been undertaken and recognising the needs, capabilities and limitations of people with ME/CFS who contribute to this programme of work. We could argue whether the deadline of 5 May for people to submit questionnaires is too a short time, but certainly a week to turn around a questionnaire to the final questionnaire means that there is no time for piloting. Piloting the questionnaire is essential to ensure that our evidence is good-quality and will make a difference to what we understand in the provision of care for people with ME/CFS. I am concerned that the foundations for the survey are limited. That will inevitably mean that the data we receive has such poor foundations that it will be difficult to analyse or have any credible result.

**Chair:** I take your points, but if we are going to have a realistic chance of doing anything with this before the next general election, we cannot allow much more time.

**Kirsty Haywood:** The risk is that we could end up with a piece of work that is so fatally flawed at the foundations that we may as well not have carried it out. Surely we should spend a little more time upfront to ensure that the questionnaire works. The questionnaire tries to cover a vast array of important issues. It is a significant questionnaire, and if we want responses to come back more quickly, perhaps we should identify narrower sections and produce a quicker questionnaire. We could then spend a little more time developing a more significant questionnaire that might take longer. I have a real concern about the methodology applied here.

**Chair:** The issue would be largely resolved by piloting. That would imply that we delay the process by at least two months.

**Kirsty Haywood:** If I were undertaking this programme, I would want a 12-month programme of work, which starts generating items and involving patients and researchers now, and would get the result at the end of a 12-month period. It is essential that appropriate time and resources are made available to the inquiry to ensure that it is a good-quality programme of work. Otherwise, we will be doing an injustice to what we are trying to achieve with this.

**Chair:** what do others think?

**Doris Jones:** It is a good idea. You say that you want feedback from individuals as well as groups. How will those individuals be notified of this inquiry? How will it take place?

**Chair:** It will be advertised on the website and announced in the press. We do not have the names and addresses or the resources to be able to circulate it to all the thousands of potential witnesses out there.

**Joy Birdsey:** I see where you are coming from. I have looked at the science and statistics. What scale are you going to do the research on? Will it be made easy to answer? How will it be presented? If it is presented properly, we have time. If it is not presented well statistically, it will all go to pot. There are people who have been waiting years and years. I have a daughter with

ME. She has had it since 1990. How much longer must she wait? She is also a scientist. How much longer must people wait if we go down your line?

**Chair:** We must be careful about which questions we want to have statistically significant answers to. There will be very few issues on which we can get that sort of data. Most information that we derive from the inquiry will inevitably be anecdotal in nature. That is unavoidable. It is not the sort of exercise that one might do in other circumstances.

**Andrew Stunell MP:** It is important to recognise the limitations of the inquiry. It is not going to be a Royal Commission with an enormous research team—it is made up of MPs. Perhaps they can co-opt some of their research staff and perhaps we can have help from some NGOs, but there is no big team behind this. Important as it is, I hope that people will not raise their expectations so high that they will be disappointed. That is something for the room to be aware of.

We must also be aware of the parliamentary timetable—I know that is why the programme has been drawn up in this way. Those with the timetable in front of them will see that the deadline for written evidence is 1 June. Oral hearings would be held in the middle of July. Shortly after that, Parliament rises and MPs disperse to their constituencies. They do not reassemble until October. If those oral hearings do not take place in July, they cannot take place until October or November. If we wind that timetable forward, it pushes the publication of the report to something like late December or early January. You might disagree.

**Chair:** No, I do not disagree.

**Andrew Stunell MP:** In all probability there will be a general election in May next year—it might even be earlier. If we are not careful, we may produce a well-polished piece of work that will sit on the shelf. MPs will be facing the electorate—some successfully, some unsuccessfully. The same applies to the Government. If we want any traction with the current ministerial team, it must be on their desks earlier than January 2009. I understand and applaud the desire to do it exceptionally thoroughly, but we also want a fairly quick win with a view to getting some ministerial recognition at an early date. I am not saying what the right answer is. Good as the points for delaying this are, we must be aware of the likely consequences of that in terms of the parliamentary timetable and the general election.

Some have suggested that there might not be enough time for people to give their views. There will be a written evidence opportunity, so even if the question that some would have liked to see has not got into the questionnaire, people can still make their points as written evidence and stir others up to make the same comments to the inquiry. I recognise that there is a tight spot between the deadline for people to submit potential questions, and the issuing of the final questionnaire. I do not want to be a spoil sport, but people should understand that a lot of suggested questions will not find their way into the questionnaire. If we produce a questionnaire with 123 questions, it will not work. It must focus on specific points to the exclusion of some others.

I suggest that we stick with the deadline for people putting in questions by May 5. Perhaps in consultation with our academic consultants we can see whether we can build in an extra week or two for compiling the questionnaire. We would prejudice the whole exercise if we do not get those oral hearings done in July and the report out early in the autumn. That would almost

certainly write off the work that we are doing from a political point of view, never mind scientific or academic points of view. I am sorry to have gone on, but it was important to set out those points.

**Chair:** The crucial date, which we must not miss, is the issue of the final survey on 26 May. That allows quite a lot of time for refining the draft. It does not conflict with the deadline for written evidence, as that is an issue of the terms of reference. There is plenty of time for people to respond in terms of written evidence. There are more than two months—about 14 weeks.

**Samantha Brown:** I am student. I am 24 years old and I have had ME for 10 years. I believe that the inquiry must be detailed. I have been waiting 10 years to be recognised as having ME, let alone anything else. It took me three years to be diagnosed. I have waited this long, so I can wait a bit longer. That is how I see it. This illness affects more than 300,000 people. I cannot believe that it has taken this long to get my voice heard. Only through the BBC did I get the chance to be here today. I suffer with this all the time. If you want some reality, come to my world—I will give you some reality. I have never been helped by anyone. Action for ME is fantastic, but I did not even know it was there. I tell people that I have ME. They reply “Oh, MS?”, “No, ME.” I think we need as much detail as possible.

**Chair:** Thank you.

**Paul Davis:** I am with Kirsty in that I think that May 5 will be a tight deadline. Today is 1 April. Will you be putting something out this week? We return to the point about whether the people who will comment have G93.9 or something else.

**Chair:** I am sorry, I do not quite get the question.

**Paul Davis:** The people who will reply to the survey on services, given that some services exclude people—

**Chair:** That is a separate issue. This invitation concludes on 5 May and is for suggestions about what should be incorporated in the questionnaire. The submission of written evidence that will cover the points that you raise is open until 30 June.

**Paul Davis:** But you understand that that is quite a bit to take in at one time for people with ME?

**Peter Luff MP:** I want to endorse Andrew’s perspective on this. I understand the passion of people who have ME to see all the facts exposed in great detail, but the price of that might be to have no influence on the debate. In my view, the report must be available well before the general election to ensure that the current Government—or the incoming one should there be a change of Government—take note of it. There will be massive pressure on public expenditure in the next Government. We must ensure that this issue is a priority for incoming Ministers, whether in the current Government or a new one. The only way to achieve that is by this timetable.

This questionnaire will not be dismissed by Government because the questions were not finely drafted enough—it will be about the overall political judgment from collating all the evidence. Not all the surveys will be returned. Many health authorities and primary care trusts will not return them. It will be a broad survey. You will not get the response you would like—I imagine that we will get a 30% to 40% response. A 50% response would be very good. It is going to be an imperfect survey. If we have perfect questions but imperfect samples, it will be just as easy to rubbish it. The really important point is that

people with ME have three months from today to submit written evidence. Those letters, e-mails and documents will make a powerful case for change. The survey is important and must be done as well as possible in the circumstances. It would be wonderful to have perfection, but the price of that may be a loss of influence.

**Chair:** Thank you Peter, I totally agree.

**Michelle Goldberg:** I am a sufferer of ME. I would like to make an important point. I have just completed an excellent disability training course with a gentleman called Richard Reiser, who is a consultant to Government Ministers. He is one of the top people in the country on disability. I would like to give some definitions that I think are important regarding the link with ME and disability, and the medical model, the charity model and the social model of disability. This will be brief—I will not go through the whole paper, but people are welcome to have a copy of it.

I would highly recommend that this group, and others, do this training course, as it gives an insight into the medical and political barriers that we face. I would like to change the perspective as we are going down a well-trodden and unproductive path because we are looking at the medical model. There is the medical model, the charity model and the social model of disability. In the social model of thinking, disabled people are seen as active members of society who expect to contribute their skills and gifts. That is defined by disabled people.

The problem that we face with the medical and social models is that society causes unnecessary problems by segregating, stereotyping, creating inaccessible environments and failing to recognise our needs and rights. We do not want to rely on charity for services that should be ours by right. We have everyday needs that include education, jobs, transport, housing, social life and access to services, and we cannot wait for a medical solution. We aim to remove the barriers that effectively prevent us from participating fully in society. We need a better allocation of resources on our terms, and that requires political support and power. Disability is a political and social issue that needs a political and social solution.

There is a lot more interesting information in this document. The approach is very one sided and does not take in the question of how long we have to wait. People have needs now. We cannot wait for somebody to sit in a debate. We are not a checkbox or a point of law. We are human beings with a range of limitations. Most of the problems we face are caused by the fact that society is designed to meet the needs of non-disabled people, although there is a question over what we call “disability.” I find this very strenuous. The discussion is going on a narrow medical political track and needs to be opened out.

**Chair:** It is by definition doing that. The “target” is about what the NHS currently offers sufferers with ME. We are not setting out to try and solve all the issues surrounding disability. You are right—there is a wider range of social and philosophical issues, but we cannot possibly attempt to solve those with this inquiry. This inquiry is intended to have limits, because only by limiting it to a specific issue can we derive any benefits.

**Michelle Goldberg:** I am not sure about that.

**Joy Birdsey:** I agree with Andrew Stunell and Peter Luff. As a group leader, it is up to me to get the questionnaires out to those in my group, and I

suggest that everybody does the same. It might not be as scientific as we would like, but if we can get it out there and debate it before the next general election, we will have a far better chance. I would like to see something really scientific in the pilot study, but I do not think that we have the time. I agree with Andrew and Peter—it is up to us to get it out there.

**Chair:** Thank you. That is helpful.

**Sue Waddle:** I want to say the same thing. We are in a politicised world, and ME is the most political illness I have ever come across. The young lady who has been ill for 10 years is not here, but on a personal level, my daughter has been ill for 12 years and could not possibly come and sit in a room like this. I have just as much stake in this as anybody else. I want this to move along. The Gibson inquiry was very interesting but it disappeared in a puff of smoke. It was—very unfairly I thought—denigrated at the recent judicial review. I would hate to see this survey denigrated in the same way. It is vital to get it out there before the general election and the political scene makes it disappear.

**Chair:** Thank you very much.

**Derek Pheby:** It is important for the survey to be focused. It is abundantly clear that it cannot solve all the problems, but I have concerns about the time scale. This is not a question of the best driving out the good, it is the possibly good driving out something that might be seriously flawed. It would be nice to achieve this timetable and for the whole thing to be finished by 12 October, but I am concerned that if we have a flawed report, the Department of Health is capable of pigeon-holing and stalling it for at least six months, as I know from bitter experience. We could easily lose all the time advantages that we might claim to gain in producing a report that is not as good as it could be, simply to save six months.

**Chair:** October 12 is the deadline for the production of the draft report, not the final one. One expects further refinement. The opportunity for submitting written evidence will be open for three months. We cannot afford to wait longer. The constricted timetable is for the production of the questionnaire and the response to it by trusts.

**Derek Pheby:** I understand that. I have been concerned with this issue for over 20 years. If we lose another six months it would not be too serious. Whatever happens next year, we are going to have an incoming Government who will have responsibilities in this area. It would be better to produce a really good report that whoever is in power cannot possibly ignore.

**Chair:** The point made by Peter and Andrew, which I endorse, is that we must produce a report to this time scale. If we leave it any longer, there will be no report on the table, or it will be so late that it will be forgotten. It will be two years into the next Parliament before anything is done.

**Sue Waddle:** People said in 2002 that the CMO's report could not be ignored. It has been ignored all the time and it was a good report.

**Derek Pheby:** It was a good report. We took a long time putting it together. It was not perfect as the necessary compromises had to be made. This will be a very quick—I will not say quick and dirty operation as that might be insulting—

**Chair:** A dirty operation that will have taken over a year by the time we have finished.

**Derek Pheby:** I appreciate that, but it would be a great shame if the report had serious flaws, which I cannot see how we can avoid given the tight time scale. We have the opportunity to do something good that could not be ignored by any Government.

**Joy Birdsey:** Who will you ask to put the questionnaires together? If it is put together by members here, there will be no quibble about it. If it is done by somebody who knows nothing about ME, perhaps your fears will come true.

**Chair:** The questionnaire will be put together by involving the parliamentarians on the panel, charities, and I would like to invite the representative from the Royal College of Nursing who I think will make a valuable input, especially in respect of eliciting responses from the trusts.

**Kirsty Haywood:** Thank you. I am a little confused about how many surveys we are talking about. Is there one survey that will be completed by service providers and/or one completed by patients? It is not clear whether there will be a patient survey and then questions for service providers. Some of the issues that we are struggling with relate to whether we want to get the service provider's view about what care has been provided and so on, and whether we are getting the views of patients. Those are two different areas.

**Chair:** There will be a patient survey, and a service provider survey. Two surveys.

**Kirsty Haywood:** Right. That is potentially even more challenging.

**Chair:** You don't join this group if you don't want trouble.

**Sue Waddle:** We need to make that trouble heard. We must carry on and keep the momentum going.

**Kirsty Haywood:** I hear what you say about getting the information out quickly and making people aware of it, but there is clear evidence-based guidance for how we develop and utilise questionnaires. An HTO report provides concrete evidence as to how we should do that.

**Sue Waddle:** That would be good from a research point of view, but this is a parliamentary process.

**Kirsty Haywood:** But if we produce evidence that is fatally flawed—

**Chair:** We will put the two things together.

**Paul Davis:** I would like to read out a comment from Sue Pemberton from the Leeds Seacroft Centre. There was a report stating that 90% of patients are being helped. This person said that first, the majority of those who attend probably do not have ME, and secondly that clinics are a dumping ground for GPs who have patients with unexplained symptoms. Thirdly, what does "help" mean? Is it little more than a chat?

**Chair:** That illustrates the problem that we will try to get at with this survey and the evidence that we collect. We all know that there are a great many problems about diagnosis as far as ME/CFS is concerned. We are particularly interested to know what the outcomes are from both a service provider's perspective, and from the patient.

**Alan Gold:** How will you get to the patient independently?

**Chair:** We will be dependent on the help of various ME associations up and down the country. By definition, we cannot know all the people who have ME.

**Alan Gold:** They all seem to support chronic fatigue syndrome, which in my opinion does not exist.

**Sue Waddle:** One advantage of the timetable is that the final survey issue date, 26 May, is the date of a conference run by Invest in ME—I am not sure, but I think that is the date. You might want to ask if you could distribute information at that conference. I do not have the details as I am not involved with Invest in ME. It is 29 May—that is even better.

**Chair:** That is a good idea. The information will be available.

**Doris Jones:** Will there be any feedback from patients in Scotland?

**Chair:** Scotland is a devolved Administration as far as health is concerned. It does its own thing. We are not trying to solve the problems of Scotland or Wales.

**Kirsty Haywood:** How are you going to identify the target population? How representative of the English population do you hope that will be?

**Chair:** The answer is, with difficulty. We are dependant on bodies such as the ME Association, Action for ME and all the local and regional societies.

**Kirsty Haywood:** There is an additional issue about that as it will be a patient-completed survey. People with ME/CFS cover a wide spectrum of abilities and there is a huge risk of getting responses from those patient representatives who are quite well, while those representing the more severe end of the spectrum will not be able to complete a questionnaire. We might not get responses that give a correct representation. That raises additional challenges for the way in which questionnaires are completed.

**Chair:** It raises a point about the construction of the questionnaire. We must have questions that elicit answers, at least to some degree, as to the severity of people's condition.

**Kirsty Haywood:** Absolutely. Therefore, it may be that in some cases, people would have to complete the questionnaire on behalf of their friend or relative.

**Andrew Stunell MP:** A number of reservations have been expressed about how we would find sufferers and whether the questionnaires will be filled in truthfully. People might have fears about confidentiality and so on. All those points are valid and legitimate, but I have not heard anyone suggest how we can overcome them. I return to my point: there are four or five MPs and researchers who might be able to help. By researchers I mean young graduates who assist MPs. There are also the charities. Those are the resources available, and we are not going to come out with PhDs as a result of a carefully done survey. We are trying to get a sufficient feel for the overall shape of issues and problems, so to present a Government Minister with a credible report that has the authority of being produced by MPs. There might be another operation, done by the University of Warwick or somewhere else, which can get a careful, demographically matched sample of people, have personal interviews and so on. This study is not that and it is never going to be. It cannot be.

**Chair:** That would cost several thousands and involve a large team.

**Andrew Stunell MP:** It would take two years. That study should be done, but we cannot pretend to the people in this room that we are going to undertake such a study now.

**Kirsty Haywood:** Those comments are correct, but it is important to have that debate. That is why we are here today. It is also important to highlight where the limitations of this review and survey lie. When you

respond to other parliamentarians, it must be clear where the limitations are. If we do not have that debate, we cannot make that judgment.

**Chair:** I assure you that we start with an uncomfortable awareness of our limitations.

**Sue Waddle:** You have an amazing resource in the House of Commons. MPs who are interested in ME will have colleagues who may or may not be interested, but who have constituents who complain regularly about the level of service provided. I do not know how you communicate with your colleagues, but perhaps you have some way of disseminating information about the 26 May deadline, and asking people to contact those constituents who have been in touch over the last few years to get them to fill in the questionnaire.

**Chair:** That is a good suggestion. Thank you.

**Joy Birdsey:** Numbers are not the problem—I sure that we will get over 1,000 responses. For statistical analysis that is brilliant. We need a broad view. Some of that might be anecdotal or biased, but I agree with what Andrew is saying. It is better to get something out now, and do the posh one later.

**Kirsty Haywood:** Only if Des will support a release of a significant resource to support that.

**Chair:** It would cost tens of thousands.

**Kirsty Haywood:** It would indeed, but it would be worthwhile.

**Chair:** I am sure it would.

We have discussed the timetable fairly exhaustively. I have not detected any amendments to it. I suggest that we do our level best to work to the timetable, bearing in mind that caveats that have been raised.

That is the inquiry launched. We have a press release prepared, which we will send out today or tomorrow together with the terms of reference. Our inquiry is on from this moment forth.

Is there any other business? We have a statement from the West Midlands ME group. Does anyone wish to speak to that?

**Annette Barclay:** I have a supplementary statement that Jill Piggott sent me last night. She asked if it could be passed around.

**Tony Britton:** I am from the ME Association. I received information this morning that the statement from the Warwickshire group is now supported by the group in Norfolk and by the Cambridge group. It is gathering support.

**Chair:** Is anyone here involved with this who can speak to the statement? I am a little unclear about what it intends to achieve.

**Andrew Stunell MP:** Shall we note it? It is helpful for us to see it, but it is not a matter on which to take an operational decision.

**Jill Cooper:** I come from Warwickshire, and I have spoken to some of these people. They want to point out that they are most unhappy about the conference in Milton Keynes that is again dominated by psychiatrists. That is their point.

**Chair:** We shall note that. It is a recurring theme.

**Jill Cooper:** It is the truth.

**Chair:** Let us move on to the Care Quality Commission's proposal to make NICE recommendations mandatory.

**Heather Walker:** This is a suggestion from Chris Harrison of BRAME, who has had to send her apologies. She has a lot of problems with family

illness at the moment, and asked us to put this on the agenda. If possible, she would like it to be raised as an issue when she can attend to speak about it. I have circulated an article that drew the matter to Chris's attention—it is the PULSE article. The concern is that NICE guidelines or guidance—we need to clarify which it is—might become mandatory for GPs. That is for all conditions, but the matter is not clear. There is a difference between guidelines and guidance. We are not sure how it links into ME.

**Joy Birdsey:** I have spoken to some GPs. They are concerned about this and say that the Government are interfering in medicine and that they find it increasingly difficult to work. That is what GPs in my area say—this has upset them and they feel that it is interference. Everybody must be treated as an individual. That is what some of our Medway practices say—does that help?

**Chair:** Not really—there is a general problem with NICE guidance. In some areas such as drugs, it is mandatory. If NICE recommends the use of a drug, primary care trusts are obliged to fund it. In other areas such as technology guidance, it is not mandatory. The guidance may be clear, but PCTs and trusts can ignore it completely. There is a grey area about the standing of NICE guidance. There might be quite a heated argument from both sides about whether NICE guidance or guidelines on ME, or any other service frameworks, should be made mandatory for GPs. There is also an issue about national service frameworks for major diseases—there is a cardiac NSF and so on. One of the potential outcome recommendations that might emerge from our inquiry could be to advocate a national service framework for ME. That would be sort of mandatory in that doctors would be expected to play their part, whether they objected or not. There would be a debate—I am not going to come down on one side or the other at the moment.

**Derek Pheby:** The problem with the NICE guidelines is that they can only be as good as the evidence base that NICE had to work with in the first place. The evidence base at the time was pretty inadequate. It takes around six years to develop NICE guidelines, and we are told that it can only review those guidelines once every three or four years. I am concerned that if the guidelines become mandatory, we would be imposing a sort of planning blight that would prevent any innovations in treatment for possible 10 years. There are people out there who could benefit from innovations, so I would be concerned about that proposal.

**Sue Waddle:** I think that we all would. The problem with the article is that it is not clear exactly what is being proposed. Perhaps we could come back that in another meeting.

**Heather Walker:** My understanding of this is patchy as I could not find out much about it apart from the PULSE article that has been circulated. I looked at the Care Quality Commission's website, and it seems to have had a consultation that ended in January. There is no outcome from that consultation in terms of everything that it tries to do in setting up the new body. It is unclear what will happen at the moment. Perhaps someone from CQC could speak at a future APPG once there is a clearer idea of what is going on.

**Sir Peter Spencer:** I was going to make that point. It would be helpful to get either Baroness Young or the new chief executive of the CQC to come to a future meeting.

**Annette Barclay:** I spoke to a representative from NICE at one of these meetings, and asked how NICE was intending to enforce the guidelines. He said that the hope was for the NICE guideline to be part of the scorecard that is filled in for every PCT. Each PCT would be marked on whether it followed NICE guidelines or not, and that would give it its end score.

**Andrew Stunell MP:** Let me pick up on the point that we might usefully get somebody from the CQC, or whoever, to present to the next meeting. Perhaps Des and I could put our heads together in the meantime as to whether there is a parliamentary question that we might ask on this issue. This is not about compelling GPs to offer a particular sort of treatment, it is about ensuring that they consider a regime when diagnosing and treating a patient. That is a little double-edged. Depending on the NICE guidelines, we might find that GPs were automatically going down one set of railway tracks. People in this room would clearly want them to go down more than one set when looking at the problems. It comes back to what the NICE guidelines will be once our inquiry is finished.

**Chair:** The NICE guidelines have been set.

**Andrew Stunell MP:** Yes, but they are not universally endorsed in this room. The degree of compulsion we want will depend on the validity of the guidelines that are introduced.

**Chair:** That is why it is a difficult issue. I do not have a fixed view.

**Andrew Stunell MP:** Sometimes we can.

**Chair:** Your suggestion of a parliamentary question is good. We must do that...

**Doris Jones:....**As the NICE guidelines currently stand, they recommend CVT and exercises for the majority of patients with mild or moderate ME or CFS. They have not been generally endorsed. Prior to the judicial review hearing, Annette and I carried out a survey of roughly 135 local ME/CFS groups, and 88.9% of the responses were in favour of the judicial review. They were very critical of the NICE guidelines. That is over 20,000 patients in total. Only 7.7% said that they were basically happy with the guidelines, and 3.4% were undecided or noncommittal as they had not consulted their members. That indicates an overwhelming lack of support for the guidelines and the implementation of the recommendations. It is a very critical review.

**Chair:** We really want to ask GPs to take ME seriously, but we should not dictate how they go about it.

**Jill Cooper:** Regarding taking ME seriously, first we do not know what most people have got according to the diagnostic criteria in the NICE guidelines. We do not really know what we are dealing with. The guidelines do not take ME, or any of the patients with that diagnosis, seriously. That is the problem.

**Andrew Stunell MP:** Nobody in this room disagrees with that point. Between us, we should ask a parliamentary question about the implications of this bit of information. We need someone at the next APPG who can speak with authority on where the process has got to. We should take that into

account when producing our report. We want to have a critique of the current system, and suggestions or recommendations for improvement. That is about as far as we can go today.

**Chair:** I agree. Are people happy with that? We need to set a date for the next meeting. I suggest June. Does anyone have anything against Wednesday 24 June?

**Michelle Goldberg:** I have one last point. I have been asked to raise this matter by Ciaran, and I am not sure whether it has been addressed. It is about a letter he sent to Heather, which was received 10 March. It deals with the code of conduct. He wanted to bring to the attention of the committee that all attendees are bound by the same set of rules.

**Chair:** Thank you. Finally, the girl at the back, Samantha Brown, who stood up and made an impassioned speech to the meeting when we were discussing the terms of reference of the inquiry is an ME sufferer. The TV crew are making a film about her and her problems for the Politics Show.

Thank you all for your attendance.