HEALTH AND COMMUNITY CARE COMMITTEE

Wednesday 11 December 2002
(*Morning*)

Session 1

£5.00

Produced and published in Scotland on behalf of the Scottish Parliamentary Corporate Body by The Stationery Office Ltd.

Her Majesty's Stationery Office is independent of and separate from the company now
trading as The Stationery Office Ltd, which is responsible for printing and publishing
Scottish Parliamentary Corporate Body publications.

CONTENTS

Wednesday 11 December 2002

HEALTH AND COMMUNITY CARE COMMITTEE
33rd Meeting 2002, Session 1

CONVENER

*Mrs Margaret Smith (Edinburgh West) (LD)

DEPUTY CONVENER

*Margaret Jamieson (Kilmarnock and Loudoun) (Lab)

COMMITTEE MEMBERS

*Bill Butler (Glasgow Anniesland) (Lab)
*Dorothy-Grace Elder (Glasgow) (Ind)
Janis Hughes (Glasgow Rutherglen) (Lab)
*Mr John McAllion (Dundee East) (Lab)
*Shona Robison (North-East Scotland) (SNP)
*Mary Scanlon (Highlands and Islands) (Con)
*Nicola Sturgeon (Glasgow) (SNP)

COMMITTEE SUBSTITUTES

Brian Adam (North-East Scotland) (SNP)
Ian Jenkins (Tweeddale, Ettrick and Lauderdale) (LD)
Mr Tom McCabe (Hamilton South) (Lab)
Ben Wallace (North-East Scotland) (Con)

*attended

WITNESSES

Malcolm Chisholm (Minister for Health and Community Care)
Philip Dolan (The Haemophilia Society)
Lord Ross (Expert Group on Financial and other Assistance for NHS Injury)

CLERK TO THE COMMITTEE

Jennifer Smart

SENIOR ASSISTANT CLERK

Peter McGrath

ASSISTANT CLERK

Graeme Eliot

LOCATION

Committee Room 1

Scottish Parliament

Health and Community Care Committee

Wednesday 11 December 2002

(*Morning*)

[THE CONVENER *opened the meeting at 09:36*]

Item in Private

The Convener (Mrs Margaret Smith): Good morning. I welcome everyone to this meeting of the Health and Community Care Committee.

Our first item is a discussion on whether to discuss certain items in private. I suggest to the committee that we take two items in private. First, I suggest that we have a private discussion at the end of the meeting about part of item 3, which is on hepatitis C. We have an opportunity to hear evidence on hepatitis C this morning, before the committee draws its conclusions and makes them known later today if at all possible but otherwise as early as possible. The second item that I suggest we take in private is discussion of our draft report on genetically modified crops. Our usual practice is to discuss draft reports in private. Are we agreed?

Members *indicated agreement.*

Subordinate Legislation

Kava-kava in Food (Scotland) Regulations 2002 (SSI 2002/523)

The Convener: Item 2 is subordinate legislation. We have six negative instruments to consider. The first is the Kava-kava in Food (Scotland) Regulations 2002—that is obviously why we have such a big turnout of the public today. No members' comments have been received on the regulations, the Subordinate Legislation Committee has made no comments on them and no motion to annul has been lodged. The recommendation is that the committee does not wish to make any recommendation in relation to the instrument. Are we agreed?

Members *indicated agreement.*

Food Labelling Amendment (Scotland) Regulations 2002 (SSI 2002/524)

Road Traffic (NHS Charges) Amendment (No 2) (Scotland) Regulations 2002 (SSI 2002/528)

Community Care (Joint Working etc) (Scotland) Regulations 2002 (SSI 2002/533)

The Convener: No members' comments have been received on the instruments, the Subordinate Legislation Committee has made no comments on them and no motions to annul have been lodged. The recommendation is that the committee does not wish to make any recommendation in relation to the instruments. Are we agreed?

Members *indicated agreement.*

NHS Quality Improvement Scotland Order 2002 (SSI 2002/534)

NHS Quality Improvement Scotland (Transfer of Officers) Regulations 2002 (SSI 2002/535)

The Convener: Previously, the committee has shown some interest in the issue to which these instruments relate—Mary Scanlon in particular has made a number of comments on it. However, no members' comments have been received on the instruments, the Subordinate Legislation Committee has made no comments on them and no motions to annul have been lodged. The recommendation is that the committee does not wish to make any recommendation in relation to the instruments. Are we agreed?

Members *indicated agreement.*

Hepatitis C

The Convener: Item 3 is on hepatitis C. For some time, the committee has been considering the position of individuals who were infected with hepatitis C as a result of contaminated blood products and other health interventions. In October 2001, we published our report. One of the report's recommendations was that the Executive set up an expert group to consider not only financial assistance to those who had been affected but the wider issue of the national health service making no-fault compensation payments.

I am delighted that Lord Ross, the chair of that expert group on financial and other assistance for NHS injury, is with us. Thank you for attending, for your expert group's work and for your written submission, which we have in addition to the expert group's interim report. I suggest that you make a short statement to the committee, after which we will ask questions.

Lord Ross (Expert Group on Financial and other Assistance for NHS Injury): That is very kind of you. Needless to say, I am pleased to have the opportunity to appear before the committee. As you can imagine, I wish simply to support the contents of the preliminary report.

I stress that the report is only preliminary—I am sure that the committee appreciates that we are still working on the final report. I am also sure that you know from the preliminary report that a number of issues have been left over. No doubt they will appear in our final report, which we hope to present at the end of the year.

As the committee is aware, we made three preliminary recommendations. As far as I understand, the minister accepted recommendations 2 and 3 and said that they were already being implemented or that steps were being taken to implement them. The minister did not accept the main recommendation, which was for payments to be made to those who can demonstrate that they became infected with hepatitis C as a result of receiving blood or blood products from the NHS in Scotland.

That is all that I wish to say. Members have my written statement, but I thought that it might be helpful to indicate some additional views. If I can help by answering questions, I would be happy to do so.

The Convener: We will ask you questions on the basis of your preliminary report, but focus on financial and other assistance to those who have been infected with hepatitis C, rather than consider the broader question of no-fault compensation, on which you are still working. We might return to that at some point.

Bill Butler (Glasgow Anniesland) (Lab): Would you be so kind as to outline how you arrived at the lump-sum figures that are outlined in recommendation 1? Do those figures adequately take into account the level of loss, including psychological distress, that some sufferers experienced?

Lord Ross: I can tell you roughly how we did that exercise. We had the assistance of advisers, who are also the minister's advisers, and a lot of information on the sort of payments that had been made by the Macfarlane Trust. However, there is no precise way to arrive at a figure. Damages and compensation can never fully compensate anyone for their loss; in some cases, they are not much more than recognition that the recipient has suffered loss.

We recommended the initial lump sum of £10,000 because we considered that every person who had been infected with hepatitis C from blood or blood products deserved something for what is sometimes called the psychological effect.

Groups that represent those people also placed information before us, in addition to which some others and I had the benefit of meeting one or two individuals who had suffered. It was brought home clearly to us that once any sufferer has been told that they have been infected, even if they show no active symptoms, they are concerned about whether they may transmit hepatitis C to their families—their spouses or their children. They are anxious about whether their condition will deteriorate and what will happen if it does. That was brought home to us by one individual whom we met, who said that there was a social price to be paid. That individual had found that people who had been friendly before no longer wished to know them, and that there is public fear and stigma.

As the committee will no doubt have heard before, people with the condition also had problems getting mortgages, insurance and so on. We thought that everyone deserved something, and the £10,000 is simply a recognition of that.

09:45

Nicola Sturgeon (Glasgow) (SNP): Your supplementary written evidence goes into more detail about the number of people whom you estimate may have been infected by hepatitis C. You come to a figure of about 4,000, many of whom are already deceased. You say that the figures are based on "numerous assumptions" made by one of the advisers to the group. How robust are those figures?

Lord Ross: They are the best figures that we could get. As my written statement says, they are based on many assumptions. Those assumptions may be misplaced, but I repeat that they were the best figures that we could get. They are partly based on figures from England, which may be a criticism of them as the proportions will not necessarily be the same up here but, on the whole, we regard them as robust. The working group was reasonably satisfied that it was putting forward the worst-case scenario, and it did not think that there was any likelihood that the figures would be exceeded. In fact, the figures may well not be attained. That is all that I can say about the reliability or robustness of the figures.

Nicola Sturgeon: Are you equally confident about the estimate that the take-up rate among the people who are infected would be about 31 per cent?

Lord Ross: Again, we based that estimate on the information that we received, particularly from the Macfarlane Trust, and we have explained why we think that the take-up figure would be as low as 31 per cent. That might be a surprising figure, but many people who were infected do not know, and perhaps never will know, that they were infected. Some people who were infected may have died for reasons unconnected with the infection. That is why the figure is so low, and we are reasonably satisfied that that is a proper estimate.

Nicola Sturgeon: The report said that everyone infected with hepatitis C should get some form of financial assistance as a matter of principle. From what you have said, both today and in the expert group report, that appears to be an important principle. What is your response to the Minister for Health and Community Care's suggestion that assistance should be directed only at those who have suffered long-term harm or hardship?

Lord Ross: I do not agree with the minister. I do not think that I am speaking out of turn if I say that he was good enough to see me before the report was published and to tell me what his decision was going to be. From that discussion, my impression was that he was not very sympathetic to the idea that there is a psychological effect on everyone who develops the infection. We think that such an effect exists, which is where we differ from the minister. He is not as impressed by that aspect as the group, which unanimously concluded that everyone should get compensation. That said, there is no doubt that the people who are severely infected and have developed cirrhosis or liver cancer are the worst cases, and one would certainly want them to be compensated. We felt strongly that everyone should get a lump sum.

Mary Scanlon (Highlands and Islands) (Con): In point 12 of your written statement, you mention the initial lump sum of £10,000, which you say would be

> "a first step in righting the wrong done to these people".

Does that mean that you would be likely to overrun the estimated £89 million?

Lord Ross: No. Perhaps I could have expressed myself more clearly. I felt that the first step towards righting the wrong would be to give a lump sum to everybody who was infected. The next step would be to consider those who develop chronic hepatitis C, who would get an additional £40,000. After that, we would consider the worst cases. Those are the three suggested steps.

Mary Scanlon: Your preliminary report states that the second step would be to give

> "an additional lump sum of £40,000 to those who develop chronic hepatitis C."

What time scale do you envisage for that payment?

Lord Ross: I cannot give a time scale because it would depend on when sufferers develop additional symptoms. I stress that our figures are total figures that would not come from one year's budget but that would be spread over several years. I cannot tell you how many years because it would depend on when people develop the symptoms. Some people might develop symptoms quickly, but they might take years to develop in others.

Mary Scanlon: Are you recommending that, because people might develop chronic hepatitis C in 10 years' time, a sum of money should be set aside in a trust to make payments in, for example, 10 or 20 years' time?

Lord Ross: The mechanics of such a system would depend on the minister, of course. For example, he might want to pay money into a discretionary trust all in one go, or drip-feed the money into such a trust over successive years, as required. Our point is that if somebody gets the lump sum of £10,000 and goes on to develop chronic hepatitis C, he or she should get an additional £40,000.

Mary Scanlon: I am concerned about the time scale because we are discussing something that happened 14 years ago. We are talking about many people who are deceased but whose families still have a claim. I am concerned about the accuracy of medical records and about the litigation that is associated with claims, not just for the past but well into the future.

Lord Ross: I do not expect any litigation because the payments would be ex gratia payments from a discretionary trust. The supposition is that there will be no litigation because there is no legal liability on the national health service. We accept that the NHS has no legal liability, but we believe that it has a moral obligation. The cases should be an exception to the general rule that the NHS does not pay unless it has legal liability.

Mary Scanlon: So you are satisfied that those who would be entitled to the payments, including past cases, would be able to access them. I think that your report states that 2,800 of those who were infected are deceased. Are you satisfied that their families would still have the evidence to make out a claim?

Lord Ross: I do not know. The first paragraph of recommendation 1 states that payment should be made to

> "all people who can demonstrate, on the balance of probabilities, that they received blood … and were subsequently found to be infected."

I acknowledge that it might not be easy for some people to establish that. However, we decided that it would be necessary for anyone who claimed to show that, in all probability, they received infected blood and subsequently developed the condition.

Mary Scanlon: Many people who are unaware of their infection could be entitled to the payments. In some cases, other medical conditions may have taken their lives.

Lord Ross: That is right.

Dorothy-Grace Elder (Glasgow) (Ind): Your preliminary report pointed out that the cost would be between £62 million and a worst-case scenario of £89 million. However, you made it clear that the Scottish health budget has a £120 million surplus. Indeed, you referred in your written submission to the £40 million budget for the Holyrood building, which went wrong, but which is nevertheless being bailed out—that budget is now more than £300 million. Your submission has an almost puzzled tone about why the Minister for Health and Community Care did not decide to pay out right away when your report was issued.

One factor to which your submission refers is that Westminster has decided not to pay out to similar hepatitis C victims. You say:

> "However, there is no reason why a different view should not be taken in Scotland. Indeed that is something that can, and in appropriate cases, should happen when powers have been devolved."

Will you expand on that point? How strong a feature of the Executive's thinking was the argument that it should not pay out to the victims because England has not done so?

The Convener: Lord Ross can give his understanding of that issue.

Lord Ross: I cannot speak for the Executive, but my working group considered many matters and was aware that a different view had been taken in England. We all felt strongly that it would not be a good answer to our recommendations—although I do not know whether it has been put forward as an answer—to say that because it has been decided south of the border not to give compensation, we should do the same. We must think about what is appropriate for Scotland and we have the power to do so.

You said that there was some puzzlement in my paper as to why the minister did not accept our recommendation, but that is only partly true. I went out of my way to say that the working group recognises that the decision is political and is not for the group to make. We also appreciate that many competing demands are made on the health budget. That was why we insisted on being advised what the measures would cost. We did not want to make a firm recommendation if the figures appeared to us to be unreasonable. However, we felt that they were reasonable and that it ought to be possible for them to be accommodated in the health budget.

Dorothy-Grace Elder: So the group had a clear feeling that the minister was influenced by the fact that Westminster decided not to pay out.

Lord Ross: I would not say that. I do not know whether that matter weighed with the minister. We knew that that decision had been taken in England and, in case anyone said we should follow the same line, we wanted to make it clear that we felt we were perfectly entitled to take a different view.

Mary Scanlon: As the convener said at the beginning of the meeting, we intend to discuss the matter and to sign off on it today, but as we have only your preliminary report, I am worried that the committee might not have sufficient evidence. I know that this is a difficult question, but how much is the report that you will produce at the end of the year likely to change from the preliminary report? Is that final report likely to contain anything that is important, appropriate or significant to the committee's deliberations today?

Lord Ross: No, I do not think so. We have indicated that we still have to consider a number of issues. As you know, our remit was to report by the end of the year and I am hopeful that we will do so. Obviously, our final report is fairly far forward, although we have not concluded it yet. It would be wrong for me to disclose the direction that the working group is taking with that report. I do not think that anything in our final report will bear on the matter that we are discussing today. I anticipate—I put it no higher—that our final report will reinforce the preliminary report. We certainly have not reached any different views.

Mary Scanlon: So it is unlikely that there will be any changes or additional recommendations.

Lord Ross: None that will have a bearing on the issue that we are considering. There will be additional recommendations because we said that we would return to a number of issues that we highlighted in the preliminary report.

The Convener: Those issues are not related to the issue that we are considering.

Lord Ross: They are not related to that particular matter.

Nicola Sturgeon: I have a couple of points for clarity and for the record. One is to clarify that, although we have only the preliminary report, it is the final one on hepatitis C because the final report will deal with other issues.

Lord Ross: That is right.

Nicola Sturgeon: I want to be absolutely clear about the costing of the recommendations. Is it fair to say that £89 million would be the maximum cost to the Scottish Executive? The period over which sufferers would draw down the money is difficult to determine, but it might be several years.

Lord Ross: It will be over some years, yes.

Nicola Sturgeon: In your view, then, there would be no problem if the Scottish Executive decided to make the £89 million available over a period of years—three years, for example.

Lord Ross: That is correct.

Nicola Sturgeon: That would not cause the trust any problem in beginning to make payments.

Lord Ross: No, it would not. That is precisely right. The estimate is our best one. We cannot guarantee this—no one can—but on the information that we have, we regard £89 million as the maximum figure and it would be allocated over a number of years. I anticipate that, if a discretionary trust were set up, there would be no problem if the money were given to it over a number of years.

Nicola Sturgeon: I understand that that is what happened with the Macfarlane Trust.

Lord Ross: Absolutely.

10:00

Mr John McAllion (Dundee East) (Lab): Lord Ross, you mentioned that your advisers were the same as the Executive's advisers. From your discussions with the Minister for Health and Community Care, is it clear that he accepts the figures, especially the £89 million?

Lord Ross: I could not say that that is the case. When I met the minister, we did not go into detail about that. He certainly did not suggest to me that our figures were inadequate, but only he can say whether he has received any other advice on, or refinement of, our figures. He did not suggest to me that our figures were wrong.

Mr McAllion: You rightly point out that this is a devolved decision—it is a matter for the Scottish Parliament and the Scottish Executive. Did your panel consider the possibility that Westminster might not agree with the Parliament's decision and could use its powers over the social security budget to claw back payments by withdrawing benefit from people who receive payments?

Lord Ross: Any clawback would indeed depend on the United Kingdom Government. As I understand it, a derogation was granted in favour of the Macfarlane Trust, and one was certainly granted as far as CJD was concerned. A derogation would be one way of dealing with the matter. That is, as John McAllion says, within the power of the UK legislature.

Our committee being composed as it was, we felt that the argument about social security payments was a technical one. The minister may raise the issue later—he raised it with me. We did not think that it was right that people who we felt were entitled to some payment should be denied that payment because of an argument over which fund the money should come from.

Mr McAllion: It is entirely practical, in the devolved situation in which we find ourselves, for Scotland to make the payments and for a derogation to be granted, so that the money is not clawed back through social security.

Lord Ross: Yes. That is how it seemed to us.

Margaret Jamieson (Kilmarnock and Loudoun) (Lab): How would you respond to fears that the awarding of ex gratia payments to those infected by hepatitis C through blood or blood products would set a costly precedent, which could lead to claims from many other groups or individuals?

Lord Ross: Obviously, we thought of that possibility. It has been said that, if the award went through, we might find that people who had been in hospital and who had contracted some infection would claim that they, too, should be compensated. We did not think that that was really a risk, however. The Macfarlane Trust provision was introduced in 1988 and it did not lead to a flood of claims from other people who thought that they had been affected.

We are suggesting that ex gratia payments be made. As we say in our reports, there are other cases in which ex gratia payments have been allowed. Those are very few in number and are very special. They form exceptions to the general rule that the health service pays only where there is legal liability. We did not feel that a dangerous precedent would be set in this case any more than was the case with the Macfarlane Trust. This is a very special situation and experience shows that cases such as Macfarlane or the compensation of people with CJD have not led to a flood of further claims. We do not believe that an acceptance of what we are proposing would establish a precedent leading to a flood of other claims.

Nicola Sturgeon: I do not know whether you wish to comment on this. Since the publication of your preliminary report, it has been revealed that a number of haemophiliacs might also have been infected with new variant CJD through contaminated blood. Do you have any comment on the way in which that situation has been handled or on the delay in informing those patients?

Lord Ross: I do not think that I could comment on that. That matter has come to light since our report was published.

Shona Robison (North-East Scotland) (SNP): Let me ask a slightly different question. Do you think that that information lends weight to the argument for a compensation package, given that it is yet another psychological blow to the group of people about whom we are talking?

Lord Ross: I suppose that is right. There is provision for compensating people who contract CJD, which we have mentioned. However, as you rightly say, that news must be yet another source of anxiety for those who know that they have contracted the hepatitis C virus.

The Convener: Your third recommendation concerns legal aid. We seem to be talking about a group of people who have been let down by the legal system. Those whose cases come after 1988 have recourse to the Consumer Protection Act 1987, although that is a bizarre way in which to have to gain some kind of justice for contamination by a blood product. However, there is a history of problems in accessing legal aid for pursuing class actions. Our legal system does not seem to have stood up in comparison with the systems south of the border and elsewhere in the world. Can you give us a flavour of the kind of evidence that you took on that issue and of what you are suggesting, bearing in mind the fact that you have said that the minister appears to have accepted what you are suggesting?

Lord Ross: Yes, I can. I find myself in the unusual situation of having to say that, in relation to part of the legal system, people seem to do rather better south of the border than we do here. Nevertheless, that is true in the case of legal aid. The legal aid authority in England is different from the legal aid authority here. For example, in England the authority can grant a sort of interim legal aid certificate that covers all the work of preparing the case and getting medical reports. We cannot do that here, as legal aid can be granted only once probable cause has been established. Therefore, legal aid cannot be granted until all the preliminary inquiries have been made. The preliminary inquiries have to be covered by advice and assistance.

As we say in the report, we received evidence from the Scottish Legal Aid Board and solicitors that successive applications have to be made for funds to get new experts, to have the patient examined and to get the records collated. All those issues lead to successive applications being made. Sometimes they are granted; sometimes they are not. Our impression is that the process is much better in England, where people can be given an interim legal aid certificate to cover all that, so that they do not have to keep coming back to ask for additional money. For that to be done here would require primary legislation, as the Legal Aid (Scotland) Act 1986 provides that legal aid can be given only once probable cause is established.

We discussed the matter with the Scottish Legal Aid Board and felt that it must try to improve the giving of advice and assistance. That is what it is doing. It is developing a template to make it easier for solicitors who want to make applications electronically, for example, to speed up the process. Steps are being taken. They will not lead to a situation that is as good as the one in England. Nevertheless, it should be possible to improve the provision of legal aid.

We are satisfied that there is a problem of access, as you say, and that it is more difficult to get a clinical negligence case off the ground in Scotland than it is in England. That might be one reason why, as our figures show, far fewer actions are raised in Scotland. Our group includes solicitors who deal with such claims. As well as receiving evidence from solicitors, we have seen the Scottish Legal Aid Board and we are satisfied that the problem exists. That is why we have made certain suggestions for improvements.

One suggestion is that, instead of using probable cause as the test for an application for legal aid in such cases, the test that applies in criminal legal aid should be introduced. That test states that legal aid can be granted in the interests of justice. That would avoid having to establish probable cause before one could obtain a legal aid certificate. That is why we made the suggestion.

The Convener: Primary legislation would be required to make the system as good as the one in England.

Lord Ross: Yes.

The Convener: Your second recommendation is that the Scottish Executive should fund and develop other mechanisms for supporting people who suffer from hepatitis C. That has been the main thrust of the Executive's approach all along. The Executive has resisted the financial assistance route and has said that it would give assistance in other ways. Is such assistance being provided in practice or is the process still at the planning stage?

Lord Ross: Although I do not have a great deal of personal knowledge of the situation, I have spoken to people who suffer from the hepatitis C virus who said that they were not given enough information. That might have been some time ago, however. I am prepared to accept that steps are being taken to improve matters, as the minister said in his letter to me. We thought that it was important to highlight the need to provide assistance. If that is already being done, all well and good. The information that we received indicated that it was necessary.

The Convener: As there are no other questions, I thank Lord Ross for his evidence and for the work that he has done with the members of the expert group. I hope that he will convey to the group our good wishes and thanks.

Lord Ross: Thank you very much.

The Convener: Our next witness is Mr Dolan. We have met before. I hope that we will not need to keep meeting like this. Do you wish to make an opening statement before we ask questions?

Philip Dolan (Haemophilia Society): Yes, I would like to make a statement. I have a croaky voice and it is getting croakier as time goes on.

The Convener: Take the time to pour yourself a glass of water, if you want. Please do not feel rushed. I am afraid that we only have water.

Philip Dolan: That is all that I need today.

Dorothy-Grace Elder: We are all croaking.

The Convener: We are the Health and Community Care Committee—we should take things seriously.

Philip Dolan: Thank you for giving me the opportunity to meet the committee. I do not consider myself to be in the same mould as members of the Parliament, who are experienced politicians and debaters, or as people in the building across the road—the great orators of the General Assembly of the Church of Scotland. I speak to the committee as a member of the Haemophilia Society. I will endeavour to share with members our reaction to the expert group's report.

We welcome the report that was produced by the group that is chaired by Lord Ross. We have just had an elegant explanation of that report. As a member of the expert group, I am aware of the considerable discussions that took place about the situation for those who were infected with hepatitis C as a result of infected blood products or blood transfusions. We do not understand why the minister appears to have rejected the expert group's unanimous recommendation of compensation, even although the group's members have expertise in medicine, nursing, legal services, ethics and health service administration.

Yesterday, somebody with haemophilia and hepatitis C asked me why I was wasting my time speaking to the members of the Parliament, because, as I was told, "They don't listen." However, I come here with hope and faith that the Scottish Parliament supports and believes in the cause of compensation for those who have been infected with hepatitis C through blood products. I do not believe that the 80 MSPs from all parties who signed a motion on hepatitis C were wrong. I do not think that that was part of a political game of MSPs signing motions just for the sake of it. I would like to believe that they signed the motion because of their concern and because they recognised the injustice for people who have been infected with hepatitis C.

10:15

In October last year, I welcomed the committee's unanimous report following its inquiry into why people had been infected by hepatitis C through their national health service treatment. It is sad that, almost a year from that report's publication, Mr Chisholm has rejected its findings. The MSPs who signed the motion and the committee's members seem to have listened, so why is the Scottish Executive not listening?

In a recent debate in the House of Lords, Lord Hunt, who is a UK health minister, said:

> "There is little point in having devolution—certainly for NHS issues—unless the Scottish Executive and Parliament can come to their own view on such matters, as this Government do."—[*Official Report, House of Lords*, 21 November 2002; Vol 641, c 507.]

We welcomed the Health and Community Care Committee's support following the debate in the Scottish Parliament. We also welcomed the fact that the expert group would include people with hepatitis C and the expert group's preliminary report. The expert group, which Lord Ross chaired, took time to examine seriously the hepatitis C issues and how they affected people physically, socially and psychologically, before it reached its unanimous recommendation that there should be compensation. When the Minister for Health and Community Care welcomed the report on 6 November but seemed to dismiss its recommendations, I was astonished, disappointed and angry, like most people who are affected. What was the point of having an expert group then ignoring its main recommendations?

For people with haemophilia, that is yet another mountain to climb. For years, every time we have reached the top of a mountain, we have found that, when the cloud lifts, there is another mountain to climb. However, I—or perhaps we—do not believe that that is insurmountable. The

Executive cannot dismiss two unanimous reports and the support of MSPs. If the Parliament is willing and committed, it can find a financial solution and implement the expert group's recommendations. There should be no reason why Scotland cannot lead the way in providing justice for people who have been harmed through use of blood products.

I have loads and loads of pieces of paper but I do not think that the committee wants me to read them all out.

The Convener: How about us moving on to asking you questions?

Philip Dolan: Sure.

The Convener: If, at the end, you feel that we did not cover something, you can cover it in a short statement.

Shona Robison: You told the committee that the Haemophilia Society took a favourable view of the preliminary report. In fact, you put it more strongly: you said that the society supports the preliminary report. Will you say a little more about the report's recommendations that found most favour with the society? The compensation package is the key recommendation, but do you want to draw the committee's attention to anything else that the society felt strongly about?

Philip Dolan: We have focused on the main issue of compensation, for which we have battled for years. As Lord Ross explained, the figure that was given is just one figure. However, I do not believe that anyone can put a price on what the effect has been on people's health. Most people who have haemophilia and hepatitis C do not want money; we want our health. We ask why this happened to us. That is the main point.

Lord Ross referred to the recommendations. People who have tried to go through the legal system or get class action cases have been thwarted the whole way. Obviously, any change in the legal system would be beneficial, but the legal system has not benefited us.

When the committee produced its report in October last year, it recommended that compensation should be given at that time. That recommendation was made on the basis that financial provision should be made for those who were suffering so that they would not have to wait for a public inquiry, by which time they might be dead.

However, if the minister now rejects what we have said, there should be a public inquiry. Nowadays, many people agree that there should be a public inquiry because they have seen what has happened in America and other places where charges have been brought against people. For instance, after five years of investigation, the Canadian police recently charged four doctors from the blood transfusion service and a drugs company with clinical negligence.

Perhaps our situation should be seen in the same way as that of victims of a criminal offence, who can receive compensation. Last week, a well-known law lord in Westminster asked why, given that the Government does not need to pay money for victims of crime but still does, things should be any different for people with haemophilia.

Dorothy-Grace Elder: Mr Dolan, you may to some extent have answered my question. As people know, you have fought this case for many years. What will you do if, after all those attempts, the minister is still adamant that he will not pay out compensation? I know that some people from the Haemophilia Society and elsewhere are prepared to go into the long negotiations of suing the commercial companies in the United States that provided the bad blood products to Scotland. Are you prepared to go down that trail? How long might that take?

Philip Dolan: I think that the American lawyers who have been over here will represent only the limited group of people with haemophilia who got blood from a particular pharmaceutical company in America. As far as I understand it, all the cases in America that were based on the same complaint against that company have been settled out of court. The pharmaceutical company obviously assumed that, if the cases had gone to court, the compensation awarded would have been greater—something like 10 times greater. The American lawyers came over here not because they wanted to visit Scotland but because they are interested in the 30 per cent of any takings that they could receive. There is also that element.

Dorothy-Grace Elder: However, if the minister does not offer a proper settlement, you might be forced to devote more years of your life to this struggle. How many years—I know that it is quite a number—have you already devoted to it?

Philip Dolan: I do not want to say my age, but I feel as though I have been doing this for a lifetime. A few years back, the Westminster Government eventually decided to pay compensation to the surviving Japanese prisoners of war—most of the prisoners of war had died. From the way things are going just now, I suspect that most of us will be dead before compensation is awarded. The suggestion that appears in the media—I am sure that the minister will confirm whether it is correct—is that the folk who have reached a more serious stage will be like the prisoners of war, in that they will be given money just at the point at which they are dying. People need financial assistance now. There are issues relating to insurance, but the matter is not just about insurance. I can give examples of losses of earnings.

If the Health and Community Care Committee thinks that the issue is important, it can ask for a public inquiry or use rule 9.15 of the standing orders, which is on committee bills. As an all-party committee, it could take a bill to the Parliament. This session of Parliament is approaching the end of its life, but that does not prevent the resurrection of a bill after May.

The Convener: We hope that some life is left in us all.

Philip Dolan: Yes. A public inquiry would be ideal.

Dorothy-Grace Elder: Why has Britain never held a public inquiry, either by order of Westminster or the Scottish Parliament, but Ireland has?

Philip Dolan: I do not know. Perhaps there are too many skeletons in the cupboard that people do not want to come out. A public inquiry, chaired by Lord Phillips, was held on BSE. The report said that there had been secrecy in the establishment. People received awards as a result of that inquiry.

Dorothy-Grace Elder: Big business is also tied up in the matter. People have been infected by bad products from the US and elsewhere.

Philip Dolan: Yes. We know that faulty blood products from which people have contracted HIV, for example, came from prisoners at the Angola penitentiary in Louisiana. A doctor carried out trials, indicated a problem and suggested to the pharmaceutical company that it should stop what it was doing. He received his P45 as a reward. Cases have been recorded in Arkansas, where the previous President of the United States was governor.

Dorothy-Grace Elder: Yes. Clinton was governor when prisoners were bled in the Cummins unit and other jails. Blood licences had to be withdrawn.

The Convener: You mentioned that you had information about economic impacts on people in respect of loss of earnings. Will you tell us about that?

Philip Dolan: Yes. It should be recognised that the payment of sums of £50,000—that is, £10,000 and £40,000—for a middle category case will in many instances be well below what would otherwise be awarded in damages. People who lose their jobs as a result of their condition, for example, would lose future earnings. We could be talking about sums of up to £250,000.

The matter is not just about insurance; it is about loss of earnings. We have examples of people who have been in business as taxi drivers and long-distance drivers who could no longer drive as a result of hepatitis and fatigue. They have lost their houses and their families have broken up—such things have happened.

There is also an impact on people’s employment prospects. Suddenly, when people find out that you have hepatitis C, your promotion prospects or your future in your employment cease, whether it is in teaching or any other field of work. For instance, there are civilian workers in police offices who cannot say anything to their employer about the fact that they have hepatitis C. The police come in and say, “We’ve got another scumbag drug addict here with hep C.” That does not help.

10:30

On loss of earnings, people lose their employment; insurance and mortgages are additional factors. There was a meeting this week, which I am sure the minister will talk about, with insurance and mortgage companies. The mortgage companies say that there is no problem getting a mortgage and insurance companies say that the questions about hepatitis C and HIV will be removed from their forms. However, removing the questions from the forms does not preclude the fact that if you fail to disclose some medical information on your form, your insurance will, at the end of the day, be void. Most of us know that trying to get insurance is costly. Loadings mean that premiums are two, three or four times as much, or sufferers are told that the amount of money that they will have to pay is so much that it is not in their interest to pay it.

Margaret Jamieson: I take you back to the points that you made about loss of earnings. You said that when it is found out that people were hepatitis C sufferers, their employment is terminated or their promotional prospects are curtailed. Can you provide us with evidence that identifies the number of people who have found themselves in that situation? What action did they take against their employers? I ask because such people can complain to an employment tribunal if that is the reason why their employment has been terminated.

Philip Dolan: I cannot give specific examples of what people have done. Individuals have to make their own decisions and each person who faces such circumstances will, at the end of the day, determine whether he or she is prepared to go ahead and take action.

Margaret Jamieson: How many people out of the 4,000 that you used in the calculation would fall into the category of having been wrongfully dismissed?

Philip Dolan: I do not have the answer to that question. Margaret Jamieson mentioned 4,000 people; I find the statistics surprising. The author of the paper was Dr Kate Soldan, who is an epidemiologist, and her statistics related to England but were extrapolated to cover Scotland. The paper admits:

> "Many assumptions are used to generate these estimates - some of uncertain validity."

I do not know whether the statistics in the paper have been peer reviewed. The lady who compiled the paper now lives in France. The paper states that although the statistics are based on deceased people, there has been no adjustment to the level of fatality since 1995. Furthermore, the figures include people who died but not from hepatitis C—they might have died from a whole lot of other things. The figure of 4,000 represents a worst-case scenario; the actual figure might be only a quarter of that.

Shona Robison: I would like to take you back to your comments on mortgages and insurance. You say that we might get warm words that everything is okay and that questions about hepatitis C will be removed from forms, but you also say that that would make no difference because of the way in which claims operate when one refuses to include certain information. It is clear that you were making a serious point. What should the financial institutions and mortgage companies do to make removal of such questions a meaningful change that will help hepatitis C sufferers?

Philip Dolan: I do not have a solution; the actuaries and other people involved in that field make their own decisions. As Margaret Jamieson said, there is discrimination. Haemophiliacs are discriminated against but, of course, many other people are discriminated against by the insurance industry.

The member asked what the insurance companies could do. The Government could underwrite the companies with an adequate sum of money that would allow those who are affected to get insurance. Also, if their insurance is to be increased by a loading of two to three times the normal rate, the Government could pick up the tab. If it is not prepared to pick up the tab in that situation, it is unlikely that it will pick it up in others.

Sometimes it is not hard to find money. The Government found money to bail out a company called British Energy plc to the tune of about £800 million, and it has been able to find such money on several other occasions. In the worst-case scenario, the money that would be required to underwrite the insurance companies will amount to £89 million, which is a small amount in comparison to what the Government has paid out previously. As I said, no amount of money can be set against people's lives.

Mary Scanlon: If the Haemophilia Society was to accept the minister's argument about the level of costs suggested in its recommendations and had subsequently to prioritise those who received payments, at whom would it direct compensation?

Philip Dolan: It should not be an either/or situation. The report mentions £10,000 and a maximum of £40,000. That money goes only a small way towards compensating people who have lost many thousands of pounds in potential earnings because they were forced to give up their jobs. Some people would say that the money that was offered was a token gesture. The committee did not seem to take that view, and the Haemophilia Society assumed that the committee was recognising that harm had been done.

The media might be correct in its reporting that money will be paid out only to the oldest sufferers or to those who become most ill. If that is correct, payment at such times is a bit late for most people. They should get the money sooner so that they can help their relatives and families to cope. I would not like to have to decide to give money to one person but not to another. Hepatitis has a massive effect on a young person with a family and that family would need as much help as the family of an older sufferer. A young family has the same right to a house and the opportunity to live a full life.

The expert working group produced a figure that, because it is based on research that was done over a long period, should be taken seriously. If the statistics are correct, about 3,000 of the 4,000 people mentioned are already dead, although it might be difficult to determine whether they died of hepatitis.

Since 1988, people who receive blood transfusions have been subject to the provisions of the Consumer Protection Act 1987. Therefore, the number of people who are eligible for compensation is small. Although I keep referring to haemophilia, we must remember the people who have been infected through blood transfusions. That a woman can attend hospital for a hysterectomy, receive a blood transfusion, and leave the hospital with hepatitis must not be ignored. There is a range of causes.

Mary Scanlon: Therefore, in the light of past and present circumstances and future projections, you do not think that there will be priority categories—instead, everyone will be equal. I know that we must be pragmatic in the light of the minister's previous response, but you do not think that there is any order of priority.

Philip Dolan: The report should stand—it recommends that everyone who is affected should be treated. Why should one person receive treatment while another does not? Funding is limited and although it will not solve all problems, it might help to alleviate some of the current difficulties.

Nicola Sturgeon: The minister said that he might do something for people who are suffering from long-term harm or hardship. However, is not it difficult to define such terms? For example, although someone who has hepatitis C might not exhibit any physical symptoms, that person might be affected psychologically by the fact that they have the illness. Once we get into that sort of debate, there is a great danger that all that will happen is that we give rise to discrimination and create more unfairness than we get rid of.

Philip Dolan: That is correct.

Nicola Sturgeon: Do the payments that are recommended in the report—£10,000, £40,000 and the amounts that are calculated on the basis of common-law damages—provide adequate compensation for people who are affected?

Philip Dolan: They do not. After all, across the Irish sea, the minimum payments that were offered were between £200,000 and £300,000.

That said, no amount of money can compensate people for what has happened to them and the psychological effects that the illness has on their relationships. We must remember that the youngest person in Scotland with hepatitis C—certainly within the haemophilia population—is 16. He has a life in front of him. He became infected at a time when blood was supposed to be heat treated. In 1985, people assumed that that was the case, but blood products were not heat treated until 1987. The year that that guy first received treatment was the year in which he was infected with hepatitis C. That happened to a whole lot of people who are now teenagers; what will happen when they want to start relationships and have to tell people that they have hepatitis C? We have seen what has happened to people who were already in relationships, married and so on and became infected with hepatitis C. The partner says, “Right, I’m away”, and the relationship breaks up. One cannot know how people will relate to each other when they are suddenly faced with such a chronic situation. However, it is devastating for the people affected and for their families.

When I gave evidence to the committee a year past March, it was one of the first occasions on which I acknowledged that I had hepatitis C. A few weeks later, I met a friend of mine who said “I didn’t know you had hepatitis C. Does that mean that every time you come to the house we’ll have to sterilise our cups?” I know that he was being facetious, but that is the sort of comment that people who are affected receive all the time. Other people just do not understand. One of the reasons why I argued for a public inquiry some time ago was that it might have taken the stigma away from the situation, because at least people might find out that they will not catch hepatitis by touching people and so on.

I should add that the Scottish needs assessment programme report on hepatitis C that was published by the Government two years ago pointed out that there is a 5 per cent chance of the disease being sexually transmitted. There is a problem with people’s emotions about the disease and the way in which the public perceive it.

Nicola Sturgeon: Over the past couple of weeks we have learned that some haemophiliacs might have been infected with variant CJD. How do you think the Scottish National Blood Transfusion Service and the Scottish Executive have handled that information?

10:45

Philip Dolan: In some cases, the way in which people were told was quite harmful. Children, rather than their parents, received letters that stated “Dear patient, you might or might not have variant CJD”—although sometimes parents were the first people to open the letters. Some people did not receive letters and they do not know whether their letters have been lost in the post—250,000 letters are lost in the post every day.

The Minister for Health and Community Care said that he was not told about the situation until about four weeks before we learned of it. Why was information that was known for two years not disclosed? When the Scottish National Blood Transfusion Service gave evidence to the committee, that information must have been available to it. The matter has been handled badly.

Variant CJD is a problem that people will have to face. There is no test for it and if we believe everything that we hear, everyone who has eaten at a well-known burger house might have the disease in their system. I am bothered most by the fact that information was withheld; information has been withheld on a range of issues. We believed that the only place that used American blood products was the Royal hospital for sick children in Glasgow. We might have been wrong to assume that, but since American lawyers started to talk about knowing the batch numbers, the shipments and the hospitals to which the products went, a number of hospitals in Scotland have suddenly remembered that they used American blood products in the early ‘80s. The issue is how much information is being withheld. We believe in the committee system that operates here and we believe that the Parliament favours transparency and openness. We hope that the committee will eventually reach a decision on the matter.

Mr McAllion: Philip Dolan has touched on issues that range wider than the question of compensation. If the minister were to say this morning that he had changed his mind and that he intended to implement in full the recommendations of the expert panel, would that be the end of the matter? Would you continue to press for a public inquiry into all the other aspects of the problem?

Philip Dolan: In an ideal world, it would be important to hold a public inquiry. We know that Christmas is approaching, but if the minister were to come here today—

The Convener: If he comes wearing a red and white suit, we might have a clue about what he intends to do.

Philip Dolan: It would be very pleasant to know that the minister intended to implement in full the recommendations of the expert panel. However, as I said earlier, when we reach the top of one mountain there is still another to climb.

Not everyone would accept the figures that have been cited; some people are not happy about them, so a public inquiry would help. In Ireland, compensation was paid five years ago, but the public inquiry—which took two years—has only just been completed. Because of information that came to light at the end of the inquiry, there is talk of holding another inquiry into international drug companies' provision of products.

I would like to be as optimistic as Mr McAllion.

Mr McAllion: I am not optimistic.

Philip Dolan: I would like to be optimistic about the minister's intentions.

Mr McAllion: I have spent many years in politics learning not to be optimistic.

Dorothy-Grace Elder: Even if the full settlement were £50,000, that would not be a great amount of money. If the 16-year-old lad that you talked about got a job, £50,000 is what he might earn in two years. Why are you prepared to contemplate getting such a small amount? It is peanuts.

Philip Dolan: Lord Ross explained the reason for that. In my opinion, no amount of money will ever compensate sufferers, but at least it would represent recognition that something had gone wrong and it would be of some help. If you were to ask a variety of people how much sufferers should get, you would be amazed at some of the figures you would hear. I am not trying to put a figure on it, though.

Dorothy-Grace Elder: An MSP's yearly wage is £50,000.

Philip Dolan: Maybe we should all become MSPs.

The Convener: Recommendation 2 in the expert group's report deals with the position that the Executive has adopted to date, which is not to give financial assistance but to say that it will improve the standard of services, access to information and so on for hepatitis C sufferers. Has there been improvement in those services or is that recommendation still at the planning stage?

Recommendation 3 deals with the legal aid system, which appears to have let people down. Because of the date on which they were infected, consumer protection legislation cannot help those people. What are your thoughts on recommendation 3 of the expert group's report?

Philip Dolan: I do not have the document in front of me, so I am not sure what recommendation 2 is.

The Convener: Recommendation 2 reads:

> "The Scottish Executive should consider how it could fund and develop other mechanisms for supporting people who suffer from HCV".

Is that happening quickly enough, or is the Executive's claim that it is doing so simply rhetoric?

Philip Dolan: The recommendation goes on to mention counselling, provision of which is hit and miss; few hospitals provide adequate counselling services.

The Convener: You have just talked about letters flying through people's letterboxes telling them that they might have a fatal disease. There appears to be no question that those people will be invited in for counselling in advance of being told that they might have a fatal disease, so to say that counselling services are patchy seems to be a little too diplomatic.

Philip Dolan: That is correct, but I was thinking about the counselling services that are provided to some people. Little money is provided to ensure that that counselling is adequate.

Mr Chisholm talked about what used to be the Department of Social Security and is now called the Department for Work and Pensions. He said that if the awards that we have been discussing were made, people's benefits could be affected. I would counter that, however. When money was given to people by the Macfarlane Trust, the department that was responsible for benefits—whatever it was called at the time—did not have any difficulty in putting in place a waiver to allow that money to be accepted by those people. Such a waiver also applies to people who receive disability living allowance. I do not see the hurdle that Mr Chisholm talked about as being too high to get over.

The Convener: However, it is a political hurdle, because Westminster might take a different view to the Scottish Parliament.

Philip Dolan: Sure—but there are precedents for waivers.

The Convener: They are UK precedents.

Philip Dolan: Yes, because benefits are a reserved matter. However, if Westminster were willing, the matter could be resolved.

On legal aid, some years ago an Edinburgh solicitor wrote an article about the fact that he was being prevented from taking class action cases because of the failure of the Scottish Legal Aid Board to provide finance for them. Because the amount of money that can be made is so low, most sufferers find it hard to get a lawyer to help them. If the legal aid system were changed, that would help a lot. I think that that might be addressed in the final report.

The Convener: Is there anything else that you would like to say this morning?

Philip Dolan: If the minister does not accept the recommendations, I ask the Health and Community Care Committee to use its power to introduce a bill that would implement them or, at least, to push for a public inquiry. That would make the situation clearer, even if it took time.

The Convener: Thank you for your evidence.

10:56

Meeting suspended.

11:04

On resuming—

The Convener: Our next witnesses are Malcolm Chisholm, the Minister for Health and Community Care, and Mr Stock and Mr McLeod from the Scottish Executive health department. I welcome you all and ask the minister to make a short statement before we move on to questions.

Malcolm Chisholm (The Minister for Health and Community Care): Thank you, convener. We published the preliminary report of the expert group on financial and other support last month. You have already heard this morning from Lord Ross, who chaired the group, and from Philip Dolan of the Haemophilia Society, who was a member of the group. I thank Lord Ross and the members of the group for the work that they have done and we look forward to receiving the final report shortly.

It is useful to remind ourselves briefly of the group's remit. First, we asked it to look at our existing approach to no-fault compensation. In its preliminary report, it comments that that raises extensive and complex issues and that it cannot make meaningful recommendations at this stage. Secondly, we asked the group to advise whether improvements could be made to the existing system for handling fault-based compensation. That work continues and should be completed by the end of the year.

The expert group was also asked to look specifically at the situation of patients who have contracted hepatitis C from blood transfusion, or treatment with blood products, as part of the wider consideration. However, it decided, as you know, to do that first and separately and it has recommended a comprehensive scheme of ex gratia payments for that group.

We said in our response to the expert group's report that we share its concerns for those who, through no fault of their own, are suffering "serious long-term harm". Those are the words that the Health and Community Care Committee used in its report last year. We would very much like to find a way of doing something to help those people.

However, there are quite complex medical, legal and financial considerations. The way in which hepatitis C presents is variable. Finding a fair set of criteria for making payments and meeting people's needs is not necessarily straightforward. It is also clear that what the expert group is proposing involves a very large sum of money and that it would not necessarily focus help on those who need it most. We must take account of the costs of any payment scheme in the light of our other health priorities, which are vital to the people of Scotland.

We are looking very carefully at who needs help and at the best way to design a scheme and to structure payments so that the individuals involved benefit fully. There are two considerations. First, we must act within devolved powers and that might need clarification when it comes to the kind of payments that we are proposing. Secondly, we need to look at the interface with the social security system and devise a scheme that fits it as well as possible, avoiding a situation in which payments lead to social security payments' being withdrawn or reduced.

For the Macfarlane Trust and the Eileen Trust, which pay compensation on a UK basis to HIV sufferers, there is specific legislation that allows those payments to be disregarded for social security purposes. That might be more difficult for a specifically Scottish scheme. We are therefore considering with social security officials whether there are ways in which payments could be structured within existing legislation, for example through establishing some form of trust for individuals that would allow payments to be disregarded for social security purposes. My officials have met social security officials to consider those issues and are working with them to identify the best way forward. That will necessarily take some time, but I hope that the matters will be resolved very soon.

The expert group also asked us to fund and to develop additional mechanisms for supporting all people who suffer from hepatitis C. I am pleased to say that we have already done a considerable amount of work in that area. We are aware that one of the problems that people have is difficulty accessing financial services because of the perceived health risks that are involved.

Earlier this week, I met representatives from the Council of Mortgage Lenders and the Association of British Insurers. They recognised the issues faced by people infected with hepatitis C, but emphasised that, in general, insurance and other products should be available. In some cases, products may cost more to reflect the extra health risks involved, and it is important to ensure that people have the best information and advice to find the products that they need. The industry agreed to work with patient groups and us to try to improve the information and advice that are available. The ABI also said that it would issue advice soon that there should not be a specific hepatitis C question on insurance forms.

The Executive has started a range of other initiatives. We recently produced an information pack for professionals and a patient information leaflet on hepatitis C, which have been widely distributed within NHS Scotland, the drugs field and the Scottish Prison Service. In addition, we have offered £40,000 to the British Liver Trust and Mainliners this year to establish a hepatitis C resource centre for Scotland. The centre is intended to be a one-stop shop providing information on hepatitis C infection as well as details of who to contact about testing and treatment in Scotland. The project is expected to secure premises in Glasgow shortly and open early in 2003.

We are also in active discussions with the Health Education Board for Scotland and the Scottish centre for infection and environmental health to establish how any public information campaign on hepatitis C could best be handled. Building on recommendations from the joint health department and Royal College of Physicians of Edinburgh conference on hepatitis C, which was held on 4 July, the department is in active discussions with clinicians and patient representatives to examine the development of managed clinical networks for patients with hepatitis C. As members know, managed clinical networks have already demonstrated in other clinical areas that they can improve patient care.

In preparation for the July conference, we commissioned the SCIEH to undertake epidemiological modelling work. That is now being further developed and will provide us with much more robust data on the numbers who are affected with hepatitis C and, in particular, rates of disease progression, on which we can base future service planning.

In conclusion, I hope that those initiatives demonstrate that we recognise the needs of people infected with hepatitis C and that we are serious in trying to tackle them in the best way that we can. We shall continue to take the issues forward with urgency.

Nicola Sturgeon: All that you raised will be explored in the next wee while, but it is important that we are clear about the basis on which you decided to reject the recommendation of an expert group that you established, defined the remit for and picked the members of. Is it an objection of principle, or one based purely on financial implications? Do you agree with the principle underlying recommendation 1 of the expert group report, which is that everyone infected with hepatitis C in the NHS should get financial assistance to cover the inevitable stress, anxiety and social disadvantage that they suffer?

Malcolm Chisholm: As I said in my statement, we want to concentrate help on those who are suffering, in the words of last year's Health and Community Care report, "serious, long-term harm". That indicates that we want to target the support, and, fortunately, many people who contract hepatitis C either clear the virus or do not go on to develop the symptoms that the majority of people do. We need to concentrate help on those who are suffering serious, long-term harm. That is one issue, and we think that people understand that.

The objection is also related to financial considerations; I cannot pretend that that is not relevant. The reality is that the working group's estimates, which were accepted by Lord Ross, would have an impact on the health budget. I cannot disregard that. The Health and Community Care Committee put a proposal before the Finance Committee to take £89 million out of the health service during the next three years. I have talked to people in the health service about the subject. Like me, they are entirely sympathetic to hepatitis C sufferers and want to help those who are suffering long-term harm, but members can imagine the reaction that I would face from the health service if I spent that much money on the issue.

To give a bit of context to the amount that we are talking about, the cancer strategy involves £60 million over three years and the coronary heart disease and stroke strategy involves £40 million over three years. Those strategies have been widely welcomed throughout Scotland and are beginning to produce significant benefits for patients. My decision to target support at those who suffer long-term harm is partly for financial reasons, but partly because I think that that is the right thing to do.

11:15

The committee's report argues that we should follow the precedent of the Macfarlane Trust, but the people who received money through that trust were those who fell ill quickly, as happened with HIV in those days. So, if we follow precedent, the one analogous trust that has been set up was targeted at people who were suffering physically. I believe that, at the point at which physical suffering kicks in, help should be given, which is what I propose.

The third factor in the equation is our discussions with London. Members must realise that there are issues that must be sorted out if we are to get the outcome that we want.

The Convener: I want to clarify one point. You referred twice to the committee's report. The first recommendation in our report was:

> "We recommend that the Executive set up a mechanism for providing financial and other appropriate practical support to all hepatitis C sufferers who have contracted the virus".

The report then clarifies that further. Recommendation 3 states:

> "The level of financial assistance awarded to any claimant should be determined on the basis of need, having regard to the physical or psychological loss individually suffered".

So we did not simply focus on one group. We covered both groups.

Malcolm Chisholm: I know that, but by chance the words in my statement were the same as the words in the text of the committee's report.

Nicola Sturgeon: I am glad that you have cleared up that deliberate misrepresentation of the committee's report, which saves me making my first point. I have two supplementary questions that arise from what you have just said. As you have not questioned the expert group's estimate of the amount of money that would be required, I assume that you accept that it is roughly accurate. Earlier, Lord Ross said that the maximum total amount that the Scottish Executive would be required to pay would be £89 million. He also said that that sum would not be required to be made available in one year; it could be made available over a number of years.

The minister mentioned my proposal. He should read it because it does not suggest that the money should be taken from the health budget, but from across the Scottish Executive budget. That is one proposal as to how the money could be made available over three years. What work has the Scottish Executive done to examine ways in which the money could be made available? As the minister said, it is a large sum of money, although some people might think that, relative to other amounts of money that are spent on certain things, it is not so large.

Malcolm Chisholm: I am well aware of the recommendations in the committee's report, but I quoted from the body of the text.

I am going to repeat myself slightly, but there are three parts to what I am saying and the danger is that people will pull out one of them and say that my decision is only about resources or principles or London. There are three elements, but we cannot get away from the fact that there is a resource issue. I take your point that the figure would not be £89 million in one year, but it is fair to say that the funding would be front loaded because many people would claim quickly if the measure were carried through. We cannot separate out the issue of funding.

I have responsibility for the health budget and my decisions are made in that context. There are increased resources for health, but, as you know, on health issues we must make such decisions all the time because of the demands on the system. By chance, this afternoon you will ask for more money for mental health issues, which is another entirely worthy cause that I am pleased to champion generally. The last time that I was at the committee, members wanted more money for other services. All those demands are legitimate.

In health, one of the facts of life is that we have a great number of worthy demands. That must be part of our discussion and the people of Scotland would not understand if it were not. I wanted to note that. However, that is only one of the three issues that I want to talk about today.

The second issue is one of principle. We must decide whether everybody should get compensation or whether compensation should be focused on those who are suffering long-term physical harm. One positive thing is that, as hepatitis C does not develop in everybody as HIV used to do 10 to 15 years ago, many people can, fortunately, live healthy lives in spite of having the virus. Indeed, 20 per cent of people who contract the virus become clear of it altogether. The expert group's proposal was that everyone who contracts the virus should get money, but I think that it is better in principle to target our resources on those who are suffering long-term harm. That is the second part of what I want to say.

The third part is that, given the fact that the issue is interrelated with the social security system, we need to clarify what we as a devolved Administration can do. All those issues are being considered further in discussion with ministers and officials at Whitehall.

I hope that people will remember those three elements in our discussion today. We should not say that the issue is all about money or all about principle or all about London. All three elements are important and interact at various points.

Nicola Sturgeon: Before I ask my last question at this stage, I ask the minister to give a commitment that he will read the proposal that I have submitted. That proposal is worthy of consideration because it would have no impact on the revenue health budget.

The minister has continually used the term "serious, long-term harm". Will he define that? Does that harm relate purely to people who suffer physical harm, or would it cover people who have not yet developed physical symptoms but have perhaps been deeply affected psychologically by the fact that they have contracted hepatitis C? For example, earlier this morning, Philip Dolan mentioned a 16-year-old who has the anxiety and worry associated with being at a stage of his life where he is about to embark on relationships and has the concern about the possible sexual transmission of hepatitis C. Will the minister define what he means by serious, long-term harm?

Malcolm Chisholm: I refer to physical symptoms. I said that in my statement.

One of our main thrusts, which I mentioned in the debate earlier this year and to which I alluded in my statement today, is to put in place a range of measures to support everybody with hepatitis C—including the 16-year-old, whom I did not hear about because I was at a Cabinet meeting this morning. A broad range of help must be available. Indeed, the first role of the health service is to provide services and support in the broadest way possible for all who suffer from hepatitis C. That is why the second half of my statement was important. Obviously, I want to do everything possible for that 16-year-old and everybody else with hepatitis C.

The issue about whether everybody should get compensation because of what happened leads to the big debate about principle. The Parliament has been considering that debate over the past three and a half years. I know that some will argue about whether the NHS was at fault, but the committee's report did not flag that up as the ground for its argument. The committee found no evidence that there was fault on the part of the NHS. If the view is taken that everybody should get compensation, that leads to the more general argument that, whenever harm is done, everybody should get some compensation irrespective of whether we are at fault. However, in that case, it would be appropriate to talk about ex gratia payments rather than compensation.

That bigger argument must still be dealt with. I know that the committee and the expert group had the idea that they were simply following the precedent that was set by Macfarlane, but the reality is that that argument is still there. I am not pushing that argument hard, but I am saying that that is part of the discussion. I want to give help, but I want to target it at those suffering long-term harm, which I have said means physical symptoms.

Members might say that I have not accepted the report. It is clear that I have accepted that part of the report that refers to those suffering long-term harm. Perhaps the group to which the report refers in the third part of its financial recommendation could be extended. I am prepared to consider flexibly who might be included in that group. Today, I am stating the principle behind my approach. I would be quite sympathetic to considering whether that group does not have to be exactly what part C of the expert group's financial recommendation refers to. However, the group certainly includes all the people who are referred to in part C. The expert group made those distinctions.

The principle is that I want to target support. Under my proposal, perhaps not everybody with hepatitis C would receive help tomorrow, but they might receive it next year or the year after, depending on their medical condition. I accept that a difference of approach exists, which is partly a difference of principle, but that interrelates with the other factors to which I referred.

The Convener: Are you happy for me to read out part C of the expert group's recommendation 1, to clarify the situation for the people in the public gallery?

Malcolm Chisholm: Yes.

The Convener: You say that you want to target help at least on the group of people to which part C refers and potentially on more. Part C says that

> "those who subsequently suffer serious deterioration in physical condition because of their Hepatitis C infection e.g. cirrhosis, liver cancer or other similar serious condition(s), should be entitled to additional financial support (on an ongoing basis if necessary)"—

the expert group recommends that those people should also be given £50,000—

> "as may be assessed appropriate by the Trust. This financial support should be calculated on the same basis as common law damages, taking account of the payments"

that the expert group recommends should be made, but which you do not intend to make. That describes your group, and you say that you would be prepared to look beyond the envelope of that group.

Mr McAllion: You based your arguments partly on a comparison of the expert group's worst-case figure of £89 million with the three-year cancer strategy's £60 million cost or the three-year coronary heart disease and stroke strategy's £40 million cost. The implication is that £89 million is far too much money to be taken from the health budget. However, you have said that you intend to target ex gratia payments on some sufferers. What ballpark figure do you have in mind, if it is not in the range of the £62 million to £89 million that the expert group suggested? What can the health budget afford? Under your proposals, how much money will be made available to compensate at least some people?

Malcolm Chisholm: I have no definite figure in mind, but I cannot find the sums to which you referred. As I said, I am happy to be flexible about the number of people.

Mr McAllion: What sums can you find? If £62 million is too much, what is not too much?

Malcolm Chisholm: I am not giving a specific figure. I am saying that the health budget could not withstand such sums in a short period. However, I am happy to consider much smaller sums.

Mr McAllion: How much smaller?

Malcolm Chisholm: I have deliberately not calculated a figure, because that depends on many factors, such as the exact number of people who are included and how the discussions with the Government at Westminster go. To announce a particular sum would be rather premature.

Mr McAllion: You suggest that the health department has no idea how many people might fall into the third category, on which you are prepared to target ex gratia payments, and that you have no idea of the cost of that.

Malcolm Chisholm: I am not saying that. I am talking about much smaller sums of money, certainly in year 1. Given all the competing demands, it would be hard in one year to find more than, say, £10 million, but I do not have a specific figure in mind.

Mr McAllion: So there is a cash limit.

Malcolm Chisholm: I am happy to be flexible, but I am putting in the public domain the fact that figures such as those in the expert group’s report would have a serious effect on the health budget.

Mr McAllion: So you would accept £10 million each year for three years.

Malcolm Chisholm: That would remain difficult, but it is within the range that we could consider. The decision would depend on how much money people would receive, the number of people who are involved and other factors.

Mr McAllion: So there is a cash limit on the Executive’s compassion in dealing with this group of people.

Malcolm Chisholm: That is not a fair comment to make about a health budget. You could make that charge if I said that, much as I support mental health services, I could not give whatever sum somebody asks for in this afternoon’s debate. Another committee member could raise one of the many other worthy matters that the committee has discussed, such as pain services or epilepsy. We could go on until 12 o’clock with a list of things and with each item you could accuse me of lacking compassion because I was not giving any money to that issue, or because I was giving only £60 million to cancer services instead of £70 million. We know that more than £60 million is needed for those services.

However, the fact of life in the health department—and, I submit, in the Scottish Executive—is that we have to make choices. Sometimes we choose one thing and need to compromise. Although that means that we spend less money than we would like to on cancer, on ex gratia payments for hepatitis C or on mental health, it does not mean that we are lacking in compassion three times over. It just means that being in Government requires us to make choices.

11:30

Mr McAllion: It is about priorities. If the Executive decides that it does not want to make raising taxes in Scotland a top priority, everyone else—including groups such as this one—suffers down the line.

Malcolm Chisholm: John, you can pursue that argument if you want. If you are proposing that the Executive should use its tax-varying powers—

Mr McAllion: I have the power to propose that under the standing orders of the Scottish Parliament.

Malcolm Chisholm: Nevertheless, once we had spent the extra money thus raised, a few weeks down the line we would again be in the situation we are now. We would still need to make choices. I have to make choices every day in the health department; and I suggest that everyone in the Parliament must be in the business of making choices. If we are accused of lacking compassion every time that we do not give all the money that someone wants for some cause, I do not see how we can have a serious discussion about health or anything else.

Mr McAllion: But you are thinking about the figure of £30 million.

Malcolm Chisholm: I am not thinking of any figure in particular. Instead, I wanted to give the committee a rough idea of the figures that I was considering. However, I put a lot of health warnings around that because we have not started pursuing the matter from a particular sum of money. We have started with a principle. We will discuss the matter with the Westminster Government and proceed from there.

The Convener: Minister, you said that you are starting with a principle. However, the problem is that we are talking about a particular group of people. You say that you are prepared to go beyond those people, but you do not know how many will be involved. Moreover, we do not know what the impact of Westminster on the matter will be, and you cannot give us any figures. One of the reasons why we will ask you for more money this afternoon is that you have proactively introduced a piece of legislation that all committee members feel does not have enough resources attached to it. We did not introduce that legislation; you did.

I take your point that you must think about priorities. However, committee members unanimously produced a report that asked you to do one thing. We also asked you to set up an expert group, which you did; and that group has unanimously asked you to do exactly the same as we asked you to do. You have asked us not to accept our own opinion or the expert group's opinion, but instead to accept your position. However, you have not told us exactly whom you would help, exactly how much money you would attach to it or exactly what you would be able to get out of the Westminster Government.

You also said in passing that the debate was rather premature. I argue that it is not rather premature to the people who are suffering from hepatitis C. Although it would be nice to put our complete faith in you and give you the time that you need to take the matter forward, we are very keen to resolve the issue before the Parliament and the committee dissolve. After all, we have been working on the matter for a number of years.

Malcolm Chisholm: I have progressed the matter. However, unless we resolve the issue of the money and the London dimension—if that is what you want to call reserved and devolved matters and the social security aspect—no one will get anything. We are progressing discussions with the Westminster Government. We are the first Government in the history of the UK—if you want to put it that way—and certainly the first Government over the years that this has been an issue to make some movement on the matter. We have unlocked things and the ice has begun to melt.

However, as I have said, unless we can identify the money and resolve the issues that are of interest to the Scottish Executive and the Westminster Government, no one will get anything. It would be fine to say that we will give out all this money tomorrow, but we first have to address those two matters before anyone gets anything. I have begun that process.

Margaret Jamieson: I want to probe further about the on-going discussions with UK officials. You have indicated that your officials have met their Whitehall counterparts to discuss the implications that any ex gratia payments would have on social security payments and benefits. Do you have a time frame for concluding those discussions? When do you expect that you and your Westminster counterpart will talk? I know that paths have to be trod first by officials before ministers can follow, but time is running out.

Malcolm Chisholm: I do not follow those rules. I have spoken to ministers as well. I want the matter to be sorted tomorrow, but that is not under my control. I can have some degree of control of this end of the process, but the Government at Westminster has to do the things that it has to do in relation to the issue. People must acknowledge that there are two issues, both of which need to be explored by the Westminster Government: there is an issue with social security and an issue with devolved and reserved powers.

Margaret Jamieson: But you do not have a time limit.

Malcolm Chisholm: I do not know how I could have a time limit for the Westminster Government. I know that I used to be a member of it, but I do not have that kind of control over it.

Margaret Jamieson: Are UK ministers aware of the importance of the issue in Scotland?

Malcolm Chisholm: As I have spoken to several of them about it, I think that I could answer yes to that question.

Nicola Sturgeon: How tough are you being? I seem to remember you sitting before this committee discussing free personal care. You said that you were in delicate negotiations with Westminster about the potential clawback of attendance allowance, that we were to have faith in you and to trust you, and that everything would be okay. That ended with a complete climbdown and the clawback of the attendance allowance. Will you stand up for the will of this Parliament on this issue? Surely, as Scotland's Minister for Health and Community Care, you will not tolerate a situation in which the will of this Parliament, which is to provide justice for hepatitis C sufferers, is in effect subverted by the intransigence of Westminster officials or ministers.

Malcolm Chisholm: I would always support the will of this Parliament, although the precise will of Parliament on this issue in terms of what kind—

Nicola Sturgeon: Let us start with the will of the Health and Community Care Committee.

Malcolm Chisholm: We do not know whether the will of Parliament is inclined to what you are saying or to what I am saying. Assuming that the will of Parliament is to do something, of course I stand up for the will of Parliament—I will always do so.

Dorothy-Grace Elder: Is your reluctance to implement recommendation 1, on paying up in full, influenced by a perception that it would cause inequity in relation to English sufferers?

Malcolm Chisholm: We are a devolved Parliament and I am never influenced by the fact that something is being done differently at Westminster. That is self-evident from some of the things that we have done in Scotland in my portfolio.

Dorothy-Grace Elder: You referred to having discussions with ministers in Westminster about this subject. Have you discussed it with the Secretary of State for Health and with other relevant ministers? Were they enthusiastic about your coming to a proper settlement in Scotland, or were they reluctant, and did they point out that Westminster would then have to consider paying out in full? What was their attitude?

Malcolm Chisholm: The attitude of the UK Government is evident, because there was a debate at Westminster recently—I do not recall the precise day, but I think that it was in October—at which its view was made absolutely clear. I do not think that it is any great secret that it does not support going down either the route that Dorothy-Grace Elder advocates or the route that I advocate. That is clear.

Dorothy-Grace Elder: Was that made clear to you in meetings with those Westminster ministers?

Malcolm Chisholm: I do not think that it would be right to give a verbatim account of what individual ministers say to me, but it is clear from what has been said publicly that the Westminster Government does not support the policy. That is on the record at Westminster.

Dorothy-Grace Elder: Is the UK Government attempting to pull strings in Scotland to prevent a full pay-out, as Lord Ross described in his report?

Malcolm Chisholm: No, it is not pulling strings. In so far as we have devolved powers, we can do what we like. We have shown that in relation to more than one issue in this Parliament. The complication is that there is an interrelating social security dimension, but a further issue that has to be taken into account and to which thought must be given is the issue of devolved and reserved powers. If a matter is within devolved competence, we can do what we like. I do not think that I need to spend too much time here arguing that point, because what we have done, even just within my portfolio, has illustrated that point time and again.

Dorothy-Grace Elder: In his submission, Lord Ross says quite a lot about finance, which is a key issue, and points out that you have enough money to pay out. He mentions the surplus of £120 million in the Scottish health budget and the Scottish Executive's surplus of more than £700 million. In the light of that, why do you not simply pay out speedily, as Lord Ross recommends after years of study by various groups?

Malcolm Chisholm: I will become boring by repeating that I have made three different points, but you have homed in on one of those points—about money—which is fair enough. In health, the largest part of previous underspends consisted of money within boards' revenue and capital budgets. That money would perhaps be spent in April rather than in March. It did not lie around with no one knowing what to do with it—it simply slipped a bit and would perhaps be spent two months into the new financial year.

Perhaps a more fundamental point relates to the amount of effort that the Administration has put into addressing underspends over the past year. I cannot say today, on 11 December, what the underspend is in the health department or any other department, but I am confident that the underspend in the health department this year will be significantly less than it was last year. I must repeat that, even last year, it was not a case of people not knowing what to do with money. It was going to be spent on a capital project that had slipped or spent by a board in a revenue budget that had slipped slightly. As you know, no spare money is lying around in the health service that people do not have a clue what to do with. The opposite is true. It is in the nature of health that there are many more demands than we can meet.

Dorothy-Grace Elder: Lord Ross also makes the point that if the Executive thinks it necessary to find money, it finds it. He gives the example of the cost of the new Scottish Parliament building increasing from an estimated £40 million to more than £300 million and says that the Executive somehow managed to obtain money for that. Do you accept that there is a public perception, led by patients who have suffered, that you are dragging your feet on the issue and that you could find the money? Are you simply reluctant to pay out because of the implications for Westminster in that it would have to pay out to English sufferers?

Malcolm Chisholm: Not for the first time, I categorically deny that I would be influenced by the Westminster Government in the way that you describe.

On your first point, the Parliament building project has obviously been a disaster, but that is not the Executive's responsibility—I suppose that it is the collective responsibility of the Parliament. The Executive has not led on the Holyrood building—the project is steered by the Parliament and the Scottish Parliamentary Corporate Body in particular. We must all learn serious lessons from the project and we all wish that it had been handled better. Indeed, we all wish that it could be controlled now, but contracts have been signed. The reality is that we do not have a choice with much of that money, although we would like to have a choice.

Dorothy-Grace Elder: But you managed to make a choice. You managed to invest hundreds of millions—

Malcolm Chisholm: I am afraid that the contract was signed a long time—

Dorothy-Grace Elder: The patients had no choice—they were infected by the national health service.

Malcolm Chisholm: We are all in the Holyrood building together.

Dorothy-Grace Elder: Some of us will not be—thank God.

Malcolm Chisholm: I have had no more personal involvement in the matter than many committee members have had. The Holyrood project is a collective parliamentary project. A contract has been signed and money must be paid. There is no choice; if there were, I am sure that many of us would not want to spend—

Dorothy-Grace Elder: But money was found.

Malcolm Chisholm: We should make a distinction between where we have a choice and where we do not. We do not now have a choice in that area, which is regrettable, but that is a fact of life that we must accept; we cannot do anything about it.

The Convener: I would like to return to what was said about Westminster. In response to an allegation that Dorothy-Grace Elder put to you that you will do what Westminster tells you to do on the matter, you said that you would not be influenced by the Westminster Government in the way that she described.

To give credit where credit is due, it is obvious from what you have said that you will not do the same as Westminster is going to do, so we will see a different solution in Scotland. However, it is the case that, because Westminster is deciding not to go down that route, it can obstruct us in doing what we want to do—whether we go down the route that you are suggesting or whether we go down the route that the committee and Lord Ross are suggesting. It is not a question of your being politically influenced by Westminster, but it can practically obstruct the will of this parliamentary committee. On the basis of previous motions that were signed by the majority of members of this Parliament, I guess that the will of the Parliament would be at least to go down the route that you are suggesting, which is to take a different view from Westminster. Do you believe that the Westminster Government is being obstructive in not allowing specific legislation or derogation of some kind, as there has been in the past with the Macfarlane Trust?

11:45

Malcolm Chisholm: I do not think that Westminster is being obstructive, and what you said in that regard was premature. We obviously do not know what will transpire in the coming period, but Westminster has engaged at official level and is seriously looking at the issues. I have certainly had constructive conversations with more than one minister, so I do not think that it is fair to say what you are saying. You may have that fear or concern, but our Westminster colleagues are constructively looking at the issue. I must remind you that they are looking at two issues—the social security dimension and the complex issue of devolved and reserved powers.

The Convener: Could you expand a little more on the second of those two points?

Malcolm Chisholm: It is well known that social security is reserved under the Scotland Act 1998. I am flagging up the fact that the relationship between any payments and the social security system is an issue that Westminster colleagues are giving thought to. I am not saying that they have come to a conclusion on that, but it is right to put that into the public domain as an area that is part of what they are considering.

The Convener: This might be a premature question. Given that specific legislation had to go through the Westminster Parliament on previous occasions to give the Macfarlane Trust and other bodies their power, do you think that such legislation would be required again?

Malcolm Chisholm: I said in my opening statement that I hope that we can deal with that problem in another way. That is obviously a matter for the Westminster Government, because there is no precedent for social security legislation or regulations being done on a non-UK basis.

Mary Scanlon: I would like to clarify a point that you made in your opening statement. You mentioned that you would set up an epidemiological group to look at the numbers affected. Do you disagree with the numbers outlined in Lord Ross's report, or can we take them as being accurate?

Malcolm Chisholm: I was referring to all people in Scotland who may have hepatitis C, in terms of the work that is being done by the Scottish centre for infection and environmental health. Lord Ross is referring to those who have contracted it from blood products or blood transfusions.

Mary Scanlon: Do you disagree with Lord Ross's figures for those who contracted hepatitis C from blood products?

Malcolm Chisholm: No. We accept the figures and financial estimates that he has published.

Mary Scanlon: The underspend has been discussed, as has health spending. Do you agree that the situation is unique and not the same as for cancer services, mental health services and personal care? A limited number of people must prove that they got a blood transfusion in 1987 and 1988 that contained bad blood. The expenditure involved is not on-going expenditure. Surely there is a principle at stake, as we are dealing with an injustice. Lord Ross says that the group

> "continues to believe that these payments are necessary to avoid a palpable injustice."

It should not be a question of whether the money is taken from mental health, for example. The issue should be viewed in a quite different light, because the case is unique and limited and involves a one-off payment.

Malcolm Chisholm: This case is obviously in a different category. Such a payment has never been made either from the health budget here or from the health budget at Westminster, except in the case of the Macfarlane Trust. That is what drives your argument and that of the expert group.

I was describing the practical realities of the situation with which I am confronted. The fact that the case of the hepatitis C sufferers might be in a different category does not make the choice any different from my point of view. I am trying to take account of, and to balance out, the three factors that I keep referring to, so that we can make progress. Ministers have to make choices in health and, more generally, in government. They will be criticised whatever choice they make. Although the committee criticises me for not going far enough financially and in principle, you can be sure that large sections of the health service and the public would attack me if I offered £89 million, because that would have significant implications. That is a fact of life. We might not like to face up to that fact, but it is so self-evident that it is not open for discussion.

The Convener: Is not it fair to say that members of Lord Ross's expert group—I am struggling to find their names—came from a broad spectrum in the health service and elsewhere? There is a general sense among people in Scotland that an injustice has been done. As far as we can make out, that was not the fault of the health service. Nevertheless, people are living with the consequences of that injustice. I put it to you that a payment to help those people to live with the consequences of the injustice that they have suffered would probably be acceptable to most Scots.

Malcolm Chisholm: As I have said, I intend to find money in the way that I have described. I do not disagree with your assertion. I can say with some conviction that people make extremely worthy demands of my budget. The fact that that happens to me almost every day of my life reflects the reality of health. Demands might be made for money for a new area or they might be made for more money for an existing area—such a demand will be made this afternoon in relation to mental health. Those demands are all worthy and most are very worthy. Being Minister for Health and Community Care—indeed, being any kind of minister—is about making choices. The fact that a demand is worthy does not mean that one has to accede to it in full, because whatever one does in health or, more generally, in government has an opportunity cost. That is a fact of life from which we cannot escape.

Mary Scanlon: The issue is not about whether more can be provided for mental health or cancer, for example. You keep moving away from the basic principle. An injustice has been done—that is what must be addressed. It is easy enough to hide under the health budget and to say that we need more for mental health and so on. We all know that. The present situation is unique and it affects a limited number of people. We are talking about an injustice. It is not simply a question of the opportunity cost and of comparisons within the existing health budget. The problem has not gone away in 14 years and it will not go away. I invite you to treat the issue as an injustice, rather than as an opportunity cost in disbursing the health budget.

Malcolm Chisholm: I am trying to do both. I am not saying anything controversial; I am simply describing a fact of political life. We do not want things to be the way they are.

Mary Scanlon: Do you agree that there has been an injustice?

Malcolm Chisholm: I have said that I want to advance the issue. I want to help those who are suffering serious, long-term harm—I know that some of you want to help a larger range of people than I am proposing to help. That is a reasonable principle to follow, given that there was no fault on the part of the NHS, which is certainly the view of the committee and the expert group, although others disagree. It therefore seems to me to be reasonable that those who are suffering harm should get financial help and not just the help that they will get from the health service and other services. That is a departure and the first time that a Scottish or UK Government has made such a move.

I do not think the principle should be that everyone should automatically get financial help because that would be a principle of compensation and fault. We should target resources on those who are suffering harm as a result of something that happened to them that was totally beyond their control. I want to help those people, who will increase in number over the years as more people suffer harm from having contracted hepatitis C in that way.

I am not against helping; I am modifying the principle to say, “Let’s help those who are suffering harm,” rather than offering blanket help for everyone, some of whom might have cleared the virus. There are two dimensions to what the expert group has recommended. Some of the people being helped might have cleared the virus. Also, a lot of the people that the expert group is proposing should be helped are no longer alive. I am not against the principle, but there are different ways of helping.

Mary Scanlon: I have a final small point. From what I am hearing, you agree with the principles and the addressing of the injustice described in Lord Ross’s report. From this morning’s meeting, I gather that the sum will be either £30 million—as John McAllion almost got out of you—or £89 million. You have accepted the principles outlined in the report. The issue is about how much you are prepared to pay.

Malcolm Chisholm: The whole of my previous answer was about varieties of principle.

The Convener: Oscillating principles.

Mr McAllion: Principles come in all varieties.

Malcolm Chisholm: It is a fair point. You can see analogies with the question of universal and targeted benefits that runs through 101 general political debates. I accept that this is different. The issue is the same however; are we going to focus help on those who are suffering harm, or are we going to spread it across the board to everyone who was affected, including to people who are no longer alive and those who might have cleared the virus, as the report recommends? The approaches are significantly different.

The Convener: We could go back to the definition of harm, but we will bypass that.

Mr McAllion: For the record—

The Convener: Sorry, but some people have been waiting patiently for some time.

Nicola Sturgeon: Minister, I cannot be the only person here who finds your evidence completely incredible. The report has been published for one month. You have had it for a lot longer than that, and yet, as far as I can tell, no progress has been made. All you can tell us today is that you cannot afford £89 million, although it is clear that you have not really explored all the ways in which that money could be found and over what time scale it could be paid.

You said that you will make payments to some, but you cannot tell us how many or who those people might be. You do not know how much money you can afford to implement even part of the report's recommendations. Surely you can see that people, especially those who are sitting behind you who have hepatitis C, look at you and think that all you are doing is indulging in delaying tactics and trying to string out the matter in the hope that it will go away.

Where there is a will, there is a way. Is the problem not just that do not have the will?

Malcolm Chisholm: I do not agree with anything that you have just said. In fact, there are so many points to disagree with that I will probably forget them all while I am trying to cover them.

There has been a great deal of activity since I was sitting before the committee only five weeks ago. However, that activity has been mainly focused on issues with the Westminster Government. Until we have resolved those issues, we are not going to get anywhere.

I have no wish to delay. I am the first person in the world to hope that the issue can be dealt with very quickly and that is certainly my intention. I am merely pointing out that different issues have to be sorted out.

The principle that I am enunciating of helping those who are suffering harm—in other words, those who need the most—is a good one. As I said, I am prepared to be flexible. I am not saying that I will help only a fixed number of people. I am outlining an approach to the problem that enables us to target help and use sums of money that we might find. I know that the committee does not like me making comparisons, but I am only describing the unavoidable facts of my budget. My intention is to make progress on the issue without delay, but the committee will understand that I do not have complete control. Some of the issues have to be sorted out with the Westminster Government.

12:00

Bill Butler: Do you accept that there is widespread disappointment that you feel unable to accept fully recommendation 1 of the report? You say that you will target roughly £30 million over the next three years on those who are suffering serious long-term harm. What guarantees can you offer to sufferers that you can make progress on what is within your control, including establishing criteria for that targeting and the managed clinical network, for example?

Can you give the committee a time scale? You say that you will continue to press the Westminster Government to consider and clarify the possible social security ramifications, but what is the time scale for that? Even though you can address the part of the problem that is covered by devolved powers, unless the reserved matter is sorted out quickly, there will be continual delays. You want to make progress and we want to make progress. When will progress be made?

Malcolm Chisholm: That follows on from my last answer. I want to make progress without delay, but I cannot speak for another Government on how long it will take to resolve some of the issues. I want to make progress between now and the end of the financial year, so that we can get something started in that time scale. That is my ambition and intention.

Bill Butler: We are glad to hear that, and it would be fine if that could be done through the usual channels. However, if that is not possible, would you be willing to take the problem to a joint committee? As you say, the sooner that the problem is sorted out, the sooner that progress can be made. You say that you want the issue to be sorted out by the end of this financial year, so are you willing to take it all the way?

Malcolm Chisholm: We have made progress in the five weeks that we have had so far. If we do not start making progress by the turn of the year, we will have to consider the different avenues that are open. We are talking about complex issues and, in relation to the point on devolved and reserved matters, completely new procedural territory for the Parliament. There are formal procedures for such matters in the Scotland Act 1998, but we hope that we can resolve the issues without it being necessary to use those procedures. However, it is important to flag up both dimensions. There is an issue about what we can do under our devolved powers and the social security ramifications of our proposals. I am prepared to follow all avenues, but until we have been through all the processes, it would be premature to say that I will pursue one in particular. The Westminster Government is being constructive, but I am impatient to make progress.

The Convener: Can you clarify what you are saying? Is it right that the only discussions that have taken place between your officials and Westminster officials were in the five weeks since the publication of the interim report from Lord Ross's committee and the day that you appeared before us? There were no discussions before that.

Malcolm Chisholm: No, that is not true. I had discussions before then, although the bulk of the work has been done in that period.

The Convener: For how long have general discussions on the principle been going on between Westminster and us?

Malcolm Chisholm: The report was produced only three months ago, so in a sense there was nothing to discuss before then. There have been discussions over that period, but the bulk of the detailed discussions have taken place since I last came to the Health and Community Care Committee.

The Convener: But up to three months of discussions have already taken place.

Malcolm Chisholm: The bulk of discussions have taken place since I came previously to the Health and Community Care Committee, but I had discussions with ministers before that.

Mr McAllion: The minister suggested in an earlier answer that the Health and Community Care Committee had agreed that the NHS was not at fault in the cases in question. I recall that we did not come to that conclusion. Our conclusion was that we would not pursue that issue and would focus on other issues. Could somebody set the record straight?

The Convener: Our decision was taken on the basis of the evidence that we had heard. The committee held a short-term inquiry on the issue and took a limited amount of evidence. Our feeling was that there was nothing to suggest to us that there had been negligence, but that there was a need for action and that action should be taken—[*Interruption.*] Please do not shout out from the public gallery. We are trying to do our best.

There was a need for action, so the committee decided that rather than go down the route of a public inquiry, which we believed would further delay financial and other assistance being given to people who had already waited for long enough, it would be best for us to concentrate proactively on the assistance and take that forward—[*Interruption.*] It would be fair to say that we did not take all the evidence that we might have done had we decided to pursue the negligence issue. Frankly, a public inquiry would have taken much longer. One of the reasons for our decision not to go down that route was that we wanted the matter of financial assistance to be dealt with in a shorter period of time.

Shona Robison: Before I ask my question, I want to take issue with something to which Malcolm Chisholm alluded. The minister suggested that the public would be against payment of compensation to people who have suffered an injustice by having been infected with hepatitis C. If he thinks back to when the Macfarlane Trust was established, the public did not express concern that money was being directed from other elements of the health service to the Macfarlane Trust. I do not think that there is any evidence to back up the minister's implication that his decisions are based on public opinion. Members of the public to whom I have spoken are extremely sympathetic to the plight of hepatitis C sufferers.

My question concerns mortgages and insurance. The minister said that he had had successful meetings with a number of companies and that a number of guarantees had been secured. I do not know whether the minister heard Philip Dolan's evidence, but it raised a number of concerns. For example, Philip Dolan said that the removal of a question about hepatitis C from insurance forms would in itself be meaningless, because claims could later be regarded as null and void because such information had not been included. Furthermore, he said—the minister alluded to this fact—that financial products might cost more for people who have hepatitis C. Given the situation and Philip Dolan's comments, will the Government underwrite the additional costs of insurance and mortgages for people with hepatitis C?

Malcolm Chisholm: I will answer the question, but obviously I must comment on the first point. I am trying to present a complex argument; that is why I keep going back to the three points. The expert group does not use the word compensation, although Shona Robison does. I support ex gratia payments. I cannot speak for the public, but I—

Shona Robison: You tried to do so earlier.

Malcolm Chisholm: I repeat the point that I made about the public. I am sure that a large number of the public would support ex gratia payments. My specific point was that the public would not understand it if I took £89 million—I was not referring to the sum of money that I am talking about now; I was talking about £89 million—out of the health budget. That is the simple point that I am making and it is based on conversations that I have had with people in the health service. I cannot speak for the whole health service or the whole public, but I think that that issue is part of the discussion. If we say that it is not part of the discussion, we are not facing up to the facts of the situation. I am sure that a large number of the public will want ex gratia payments to be made and I hope that that will not be misrepresented.

On the insurance question, Philip Dolan is right that just not having a question about hepatitis C does not deal with all the concerns that he and his group have. Philip Dolan was at the meeting with the insurance industry, as was Jeff Frew, who I think is sitting behind me—he certainly was at the beginning of the meeting. There not being a question about hepatitis C does not in itself solve the issues.

There are different premiums across the insurance industry and a range of factors. In that sense, there is no difference in principle between hepatitis C and many other issues. One of the concerns that Philip Dolan and others have raised is about the unavailability of insurance. The Association of British Insurers said that that should not happen. We have also addressed the issue of information and advice. We do not have the power to insist that the insurance industry does not charge different premiums for hepatitis C or for any other condition.

Shona Robison's question is another way of asking about financial support. The way to deal with the matter is through financial support rather than through a payment to the insurance industry. I accept the legitimate point that one of the extra costs that people with hepatitis C, and indeed people with other physical conditions, might have is an insurance cost. That can best be addressed by the support that I am describing.

Shona Robison: So are you looking actively at underwriting the duty—

Malcolm Chisholm: Well—

Shona Robison: Let me finish. The insurance companies say that there should not be a problem with providing insurance and mortgages, but clearly there is a problem. Making those products available might require underwriting from the Government, because of the risk that is involved. Are you considering that actively?

Malcolm Chisholm: My point is that many people might have to pay increased premiums. The Government cannot get involved in underwriting for a whole lot of different issues. It can take a general view about hepatitis C, as distinct from something else. That is what I have tried to outline in my approach. It would not be reasonable to expect a Government to start underwriting an extra premium for a particular condition, because extra premiums could apply in many different circumstances.

The Convener: Are there any further questions?

Dorothy-Grace Elder: I would like to make a small point of information. The young man who was asked to leave is Andrew Gunn, who was infected, aged 18 months, at the Royal hospital for sick children in Glasgow. Perhaps he could be invited back in.

The Convener: If someone disrupts a parliamentary committee meeting, they are asked to leave.

Margaret Jamieson: He was not asked to leave; he left of his own accord.

The Convener: The point is that, no matter what any individual's story, we are trying to get some sort of justice for people like Andrew Gunn.

Dorothy-Grace Elder: I appreciate that. I just wanted to mention him.

The Convener: We are trying to get on and do our job. We should move to the next set of questions.

I hope that the minister's office has made him aware that we want to raise with him concerns about the statement that was made a week or so ago about the letters that were received by many of the individuals about whom we have been talking this morning in relation to CJD. We have a couple of questions on that. Does the minister want to make a formal statement on that aspect before we ask our questions?

Malcolm Chisholm: I would like to fill in the background, because I looked into the matter when it became an issue last month. However, as I said at the time, I was not familiar with the issue until the beginning of last month. The key issue is the setting up of the CJD incidents panel, which was established in the early part of 2000. The panel was certainly set up before I became the Deputy Minister for Health and Community Care. It is an expert committee that was set up by all the UK health departments to give advice on situations in which someone with CJD might have given blood, and on transmissions in general.

The issue of surgical instruments was probably given the highest profile at that time. Members will remember that we banned tonsillectomies because of concerns about reusable instruments. We were ultra-precautionary on that issue and we are similarly precautionary now about blood products. Members have probably heard about recombinant clotting factor, which we import to avoid even any theoretical risks.

12:15

The expert CJD incidents panel was established to give advice and that is why it is removed, in a way, not just from politicians but from the health departments. The panel includes not just many clinicians, but ethicists, one of whom chairs the panel. The panel was set up to give advice on when people should be informed if the situation arose. A fine judgment is involved in that. I said at the beginning of November that I supported the haemophilia directors' desire to inform their patients, because it was right to do so. Indeed, the deputy chief medical officer also said that. However, part of the problem is that the experts took a long time to come to a view on that. We can see why, to some extent, that was a difficult decision for them, because it means that they must tell somebody who has received a blood transfusion or a blood product that there is a theoretical risk that they will contract variant CJD—nobody is known to have contracted it in that way—and that there is no test or cure for it.

I am frustrated about the fact that the experts—the clinicians and the ethicists—took so long to reach a decision, but I can understand to some extent why they found it a difficult decision to make. My prejudice is always in favour of transparency and I expressed that general view at the beginning of November. The experts have produced new draft guidance, which is contrary to their previous advice—that people should not be told—and which states that people should be told if the risks can be explained to them and if help and support can be given. However, that is just draft guidance and not the experts' official final verdict.

I have given the committee important background information. In a sense, everyone has been waiting for the expert group to give its advice. The politicians have not given a decision on the matter because it was decided back in 2000 that clinicians would refer to the expert group when they wanted advice on the situation.

The Convener: Would it be fair to say that, as well as politicians such as you being out of the decision-making loop, the clinical directors of the Scottish National Blood Transfusion Service would also be out of the loop in terms of knowing about what was going on and being involved in decisions on who should be told and how? The Health and Community Care Committee is coming from a particular position on this issue. On 14 March 2001, personnel from the SNBTS gave evidence to the committee but did not say anything about the fact that not only had contaminated blood products given people hepatitis C, but that there was the potential that those individuals had been infected with CJD. We wonder where the SNBTS fits into the access to information about the matter.

Malcolm Chisholm: You can take up that issue with the SNBTS's clinical directors, but they obviously had knowledge of the CJD issue.

The people who came to the fore at the beginning of November, when I first engaged with the issue, were the haemophilia directors, who had been waiting for advice from the CJD incidents panel. They had the same frustration as me about why the expert group had taken so long. They wanted to tell their patients. Both I and the deputy chief medical officer—who actually wrote to the haemophilia directors, which was appropriate because she is a clinician—said to the directors, "Go and tell your patients. If that is what you want to do, we fully support you. We urge you to do that—don't wait." That is what we said at the beginning of November, but the haemophilia directors waited for advice that was not forthcoming from the incidents panel.

I am pleased that we now have draft guidance. My department and I are urging the panel to produce the final guidance as soon as possible and without further delay.

That is the background to the problem. Some members might say that the decision to set up the CJD incidents panel in 2000 was wrong, but I understand why it was taken. The issue was not seen as a clear-cut one, in which transparency was good and not telling people was bad, although that is my general view on such matters and my view in this case. However, I understand why people agonised about the matter and thought that the issue was not clear cut or black and white. For example, some older people might have had to be told about a theoretical risk in relation to something for which there is no test and no cure.

The background and context are important, although they do not overcome my predisposition towards openness and transparency. The situation is genuinely complex, which is why an incidents panel containing clinicians and ethicists was set up.

Mary Scanlon: The issue has come to the fore in the past month, but for how long have we been testing blood for the theoretical risk of CJD?

Malcolm Chisholm: My point is that there is not a test.

Nicola Sturgeon: Obviously, we have different views about the delay. That aside, if the delay occurred because the decision makers were, understandably, agonising about whether to inform people and were trying to get the decision right, why, when people were eventually told, was it done in a careless and almost callous way? Letters that contained devastating information were sent out of the blue and, as we heard from Philip Dolan, some letters were sent directly to children. After all the agonising, the information was conveyed to people in a way that did nothing to be sensitive.

Malcolm Chisholm: Most people would think that the best group to deal with such matters would be their own clinicians, which in this case means the haemophilia directors. If you have concerns about the process, you should take them up with the haemophilia directors, although, if you wish, you can route those concerns through me. The letters were not written by me or my department. As the most appropriate way in which to inform people was through their own clinicians, the haemophilia directors had responsibility for sending the letters.

The Convener: I thank the minister. We will take a short comfort break before we move to the next item on the agenda.

12:23

Meeting suspended.

12:30

On resuming—

Petition

Epilepsy Service Provision (PE247)

The Convener: Agenda item 4 concerns petition PE247, in relation to which we have received a response from the Executive. I ask the clerks to produce for a future meeting a comparison between what we asked for and what we got back. In the interim, if members have any comments they could e-mail them to the clerks and we will discuss them at that meeting. Is that agreed?

Members *indicated agreement.*

Mary Scanlon: Can we contact Epilepsy Action Scotland for its comments?

The Convener: Yes.

Cancer Services

The Convener: If members have any points on agenda item 5, they should also e-mail them to the clerks and we will return to the issue at a future meeting. Is that agreed?

Members *indicated agreement.*

Meeting in Private

The Convener: Finally, although we did not intend to meet next week, I ask members to agree to meet in private to finalise our report on genetically modified crops. Is that agreed?

Members *indicated agreement.*

The Convener: That completes this morning's public business.

12:32

Meeting continued in private until 12:56.

Members who would like a printed copy of the *Official Report* to be forwarded to them should give notice at the Document Supply Centre.

No proofs of the *Official Report* can be supplied. Members who want to suggest corrections for the archive edition should mark them clearly in the daily edition, and send it to the Official Report, 375 High Street, Edinburgh EH99 1SP. Suggested corrections in any other form cannot be accepted.

The deadline for corrections to this edition is:

Monday 6 January 2003

Members who want reprints of their speeches (within one month of the date of publication) may obtain request forms and further details from the Central Distribution Office, the Document Supply Centre or the Official Report.

PRICES AND SUBSCRIPTION RATES

DAILY EDITIONS

Single copies: £5
Meetings of the Parliament annual subscriptions: £350.00

The archive edition of the *Official Report* of meetings of the Parliament, written answers and public meetings of committees will be published on CD-ROM.

WHAT'S HAPPENING IN THE SCOTTISH PARLIAMENT, compiled by the Scottish Parliament Information Centre, contains details of past and forthcoming business and of the work of committees and gives general information on legislation and other parliamentary activity.

Single copies: £3.75
Special issue price: £5
Annual subscriptions: £150.00

WRITTEN ANSWERS TO PARLIAMENTARY QUESTIONS weekly compilation

Single copies: £3.75
Annual subscriptions: £150.00

Standing orders will be accepted at the Document Supply Centre.

Published in Edinburgh by The Stationery Office Limited and available from:

The Stationery Office Bookshop
71 Lothian Road
Edinburgh EH3 9AZ
0131 228 4181 Fax 0131 622 7017

The Stationery Office Bookshops at:
123 Kingsway, London WC2B 6PQ
Tel 020 7242 6393 Fax 020 7242 6394
68-69 Bull Street, Birmingham B4 6AD
Tel 0121 236 9696 Fax 0121 236 9699
33 Wine Street, Bristol BS1 2BQ
Tel 01179 264306 Fax 01179 294515
9-21 Princess Street, Manchester M60 8AS
Tel 0161 834 7201 Fax 0161 833 0634
16 Arthur Street, Belfast BT1 4GD
Tel 028 9023 8451 Fax 028 9023 5401
The Stationery Office Oriel Bookshop,
18-19 High Street, Cardiff CF12BZ
Tel 029 2039 5548 Fax 029 2038 4347

The Stationery Office Scottish Parliament Documentation Helpline may be able to assist with additional information on publications of or about the Scottish Parliament, their availability and cost:

Telephone orders and inquiries
0870 606 5566

Fax orders
0870 606 5588

The Scottish Parliament Shop
George IV Bridge
EH99 1SP
Telephone orders 0131 348 5412

sp.info@scottish.parliament.uk

www.scottish.parliament.uk

Accredited Agents
(see Yellow Pages)

and through good booksellers

Printed in Scotland by The Stationery Office Limited

ISBN 0 338 000003 ISSN 1467-0178