Annex A

Transcript of Malcolm Chisholm's appearance before the Health Committee of the Scottish Parliament – 9 September 2003

Hepatitis C

16:12

The Convener: The minister will be joined for this agenda item by Andrew MacLeod, the head of the health planning and quality division in the Scottish Executive, and Bob Stock, the branch head of the health planning and quality division in the Scottish Executive. While we are waiting for the witnesses, I refer members to the background note that was circulated to them. Members might have received other material by e-mail and post and they might wish to refer to them, although they are not public documents.

I understand that the minister wants to make an opening statement.

Malcolm Chisholm: As I announced at the end of last month, I am pleased to bring good news to the committee about our proposed scheme. The United Kingdom Government has agreed that the Executive has the necessary powers under the Scotland Act 1998 to establish our proposed scheme. As members know, the Department of Health in Whitehall has stated that it will also establish a scheme. That means that we can get on with the detailed business of setting up our scheme.

We still need to ensure that the people who receive the payments do not lose social security benefits, but now that other parts of the UK are adopting a similar approach, I hope that that matter can be resolved without difficulty. There might be other advantages to the new situation and we will explore them.

I realise that the committee is concerned that matters are taking so long, and I share that concern. I hope that the discussions can be brought to a satisfactory conclusion, that the people affected will be able to receive the payments that we have proposed and that they will gain full benefit from them.

My final point is that it will take a little time to make the first payments. However, I want to make it clear that the start date of this particular scheme was the date of my announcement about it at the end of August; to be precise, Friday 29 August 2003.

16:15

The Convener: Committee members might want to ask more about the time that it will take to make payments.

The committee inherited the issue from the previous committee, which did sterling work on it. I understand that Lord Ross's expert group was set up by that committee to consider the issues and to

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advise. I also understand that the minister had that advice before him.

I hear the minister saying that he has good news, but it is so far from what Lord Ross recommended that I cannot believe that it is good news for those who have hepatitis C or for their surviving relatives and partners. Lord Ross recommended an initial sum of £10,000, and an additional lump sum of £40,000 to cover pain and suffering in those who develop chronic hepatitis C.

Importantly, Lord Ross's group recommended that the calculation for those who suffer serious deterioration in their physical condition—such as cirrhosis and liver cancer—because of hepatitis C infection should be made on the same basis as common-law damages, taking into account the two initial payments. Beneficiaries would not lose out, because they would inherit certain elements of that package, based on the Damages (Scotland) Act 1976.

I can understand why the minister does not want to call the payments compensation. That is a tricky legal word. The payment is an ex gratia payment. Why is the offer that is being made so far removed from what Lord Ross proposed? How was it calculated?

Malcolm Chisholm: That was discussed fully the last time that I came to the Health and Community Care Committee to discuss the issue. I fully accept that not everyone will agree, but I have to make a judgment about how health resources are to be allocated. In the previous session, there were implicit calls for more money.

We all know that there are many demands on the health service and I had to make a decision about the best form of ex gratia payment. The first principle was that it should go to those who are still alive and suffering, although I hope that my announcement of 29 August as the start date for the scheme reassures people that no one will be affected by the amount of time that it will take to get the administration of the scheme up and running. The main principle is that the money should go to those who are still alive and suffering.

The second judgment is about making a fair and reasonable payment to those people and weighing that against all the other demands on the health budget. That is the judgment that I had to make; Lord Ross and the expert group did not have to make that judgment because they were considering the issue in isolation.

The Convener: So the main issue was funding?

Malcolm Chisholm: That was one of the issues and I do not believe that there is anything very surprising about that. We would like to be able to give large sums of money for pay and ex gratia payments and all the other things that are

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necessary for the health service. I have no difficulty in saying that funding is a consideration, because we have to ensure that money is used effectively. However, I believe that the payment is fundamentally fair and reasonable.

The Convener: Are you saying that the payments of approximately £300,000 that are being made in Ireland are being made because they are prepared to put more money into the compensation—or whatever word you would use for it?

Malcolm Chisholm: I am glad that you raised that point. In Ireland, the Government and everyone else have agreed that wrongful practices were used. The payments in Ireland were compensation. We are making an ex gratia payment. I know that certain people are raising controversy about that, and the Health and Community Care Committee in the previous session of Parliament did not, in particular, express a different view. The payment that we are making is ex gratia and that is the difference between Scotland and Ireland. It is important that people understand that.

The Convener: I understand the difference between ex gratia payments and compensation.

My second point was about the fact that the ex gratia payment does not transfer to surviving family members. Is that not a bit mean, to say the least, given that you have been limited in the amount that you can pay? Why not, at least, let the payment be transferred to surviving family members?

Malcolm Chisholm: I understand that that point will also be made. However, we want to target the resources on those who are still living and suffering. Obviously, people will take different views on that issue. However, I think that the money that is available should be targeted on individuals who are still alive. That is a fair and reasonable approach.

Dr Turner: I know of someone who might come into the category of people who received blood products in the '70s and '80s. This person, who ought to receive payments for hepatitis C, has a very sick wife who needs to be looked after by him and is dependent on him. It would seem cruel if none of the hepatitis C money were to pass to that person, as they are unable to work and make money.

Malcolm Chisholm: Perhaps I missed something there. Assuming that the person to whom Dr Turner refers is in the eligible category, the payment will be made.

Dr Turner: They may not be—that is a separate issue. However, let us say that the person concerned is eligible to receive payment but is ill.

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What happens if there is a tragedy and someone who is caring for another member of his family, who depends on him, dies?

Malcolm Chisholm: I have said that the scheme starts on 29 August. If someone is now in the eligible category, they will receive the payment, irrespective of the circumstances that the member describes.

Dr Turner: So they will receive a one-off payment.

Malcolm Chisholm: Yes.

Dr Turner: However, if their health deteriorated they would not receive any extra payments and their family member would be left high and dry.

Malcolm Chisholm: I am very sympathetic to the people in the situation that Dr Turner describes, but she raises issues that are for the social security system and which I cannot resolve. I am sure that the sick individual in question would be entitled to other benefits. However, we must focus on the group of people to whom the scheme applies. The Parliament has certain responsibilities, but so does the Department for Work and Pensions.

The Convener: Notwithstanding this ex gratia payment, remedies will still be open in the civil courts.

Shona Robison: You said that the scheme starts on 29 August. Perhaps it should have been backdated to January, when you made the announcement. If someone does not live long enough to receive the payment but dies after 29 August, will their relatives get the benefit of it?

Malcolm Chisholm: That was the point of the August announcement, which gave a definitive commitment to establish the scheme. I do not want anyone to be anxious about whether they will receive a payment. If they are in an eligible category, they will get it.

Shona Robison: Will their relatives get it if they do not live long enough to receive it?

Malcolm Chisholm: Are you asking me directly about someone dying between now and the payment date?
Shona Robison: Yes.
Malcolm Chisholm: Their relatives will receive the payment.
Shona Robison: I have a question about the wider issue of relatives of hep C sufferers receiving money. Lord Ross recommended that they should. The financial package that he proposed, which included payments to relatives of deceased people, was worth £89 million. The package that you have announced is worth, I
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think, about £20 million—is that correct?
Malcolm Chisholm: We cannot be absolutely certain of the figure, because we do not know. Others may come forward, given the nature of hepatitis C. However, in terms of those who are registered with the Scottish Centre for Infection and Environmental Health, there are about—and I can be corrected—580 people, which works out at about £15 million, but we fully accept that the figure may be more than that because others may come forward. We are not saying that £15 million is the total amount, but that is the amount that we know we have to deal with initially.
Shona Robison: On those figures, out of around 500 families we are talking about around 150 who have lost relatives. Those were the figures that were before us previously. We are talking about a difference of £65 million to £70 million between the financial package that you are promoting and the package that was suggested by Lord Ross. This week, we learned that there is a £644 million underspend for this financial year, which is a significant amount of money. There is a moral obligation to the families. Rectifying the situation would amount to around 10 per cent of that underspend. Given the underspend figures that have come to light, and given that we are talking about one-off payments, is there not a moral imperative for your department to make a bid for some of the underspend, to give some recognition to the pain and suffering of the relatives of the deceased?
Malcolm Chisholm: Some people will make that point. I made my position on that clear earlier in the year, and from the point of view of my health budget I would not change my mind. I do not think that I should pre-empt what will be said about that budget on Thursday, but it would be fair to say—you will find this out on Thursday—that there is not a large amount of underspend lying around in the health department, and anything that is out there with the boards is very much committed. I am absolutely certain that you will not find anything that will meet your requirements.
People can always make competing arguments about the use of resources, but I have merely repeated today what I said before about the criteria that I use. First, I target the resources on those who are still alive, which I think people will understand. Secondly, I make what I regard to be a fair and reasonable ex gratia payment to those people.
Shona Robison: Do you appreciate how upsetting that is for the families? I have received correspondence, as I am sure others have. They want some recognition of what happened to their family members. Under this scheme, they will not get that. A one-off payment, which I suggest would be a good use of an element of the underspend
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that has been identified, would go some way—not all the way—to at least recognising what those families have gone through. Will you not reconsider?
Malcolm Chisholm: Shona Robison should wait until she hears what is said about health on Thursday, but I do not think that I am giving away any secrets when I say that the underspend is small in terms of what people expected in the past, which shows a well-managed budget. No doubt that will be repeated on Thursday when more information is available. However, I repeat the point that I made: we have to make hard choices all the time about the allocation of money.
You know as well as I do all the demands on the health budget. It is the nature of health. We all know about the increasing elderly population, big expansions in drug budgets and all the issues about doctors' hours that Duncan McNeil talked about recently. We know the demands on the health budget. Hard choices have to be made, and I think that the public will understand if we target the resources on those who are still living with hepatitis C as a result of blood products, and make them a fair and reasonable offer. However, that is a matter of judgment, and I accept that others will not agree with my judgment.
Mike Rumbles: Constituents who came to my surgery yesterday asked me the question that I am about to ask you, which you have gone part of the way towards answering. If someone had hepatitis C on 29 August, they need to come forward. What are the practicalities of the process? To whom do they come forward and what do they have to do to register a claim?
Secondly, you announced that the scheme in England would be the same or similar. To your knowledge, are the levels of ex gratia payments in England identical to those in Scotland?
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Malcolm Chisholm: I do not think that the second question is for me to answer; it is up to the UK Department of Health to make a statement about that matter when it is ready to do so.
On the first question, when we have finalised the arrangements, we will publicise them clearly and openly so that people know about them. I cannot outline every detail of those arrangements today. All that I am saying is that I now believe that we will be able to progress the matter quickly and will soon be in a position to produce the details of the scheme so that people can get their money.
Mike Rumbles: How will the situation be dealt with in the unfortunate circumstance that somebody dies between 29 August and the details of the scheme being announced?
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The Convener: That question has been answered. My understanding is that they will receive payments.
Malcolm Chisholm: In those circumstances, the family will get the money. People will understand the reasons for that.
The Convener: I want to ask about the situation in England. I understand that the minister cannot speak for the English, but should we anticipate that the settlement figures in England will mirror those in Scotland?
Malcolm Chisholm: I had not read the Department of Health press release as well as my official has done; I have been told that the notes in the press release stated that the payments would be the same. I did not think that the Department of Health had made that announcement yet. I knew that that was the intention, but I did not think that it had been announced and I did not think that it was my place to make the Department of Health's announcement for it. However, since it was in the footnotes of the press release, I can repeat it to the committee.
The Convener: Perhaps that is why the settlement figures are the same in Scotland. It might have been possible for the Scottish Minister for Health and Community Care to come to a different arrangement with the money that is available, but that would not have complied with the scheme in England. Is that an unfair inference for me to make?
Malcolm Chisholm: It would have been an entirely reasonable inference had England made its announcement in January and I had made mine in August, but since it was the other way round, some people might draw the opposite conclusion.
The Convener: We will see.
Mr McNeil: I have not been asked, but I agree that that is an unreasonable assertion to make. Despite the fact that concerns still exist about the scheme, the committee should take comfort in having achieved this result for hepatitis C victims in Scotland and having led the way for the whole of the UK. We should celebrate that achievement rather than denigrate it.
The Convener: I think that that is more of a comment than a question; we are here to ask questions.
Mr McNeil: Be happy.
The Convener: The point is being made by members of the public. I am not speaking personally; I am speaking from evidence that we have received from hepatitis C sufferers and their families. They are not happy. It is the committee's duty to put those points to the minister on behalf of the people.
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Mr Davidson: The minister visited the committee at its away day and on the journey back we heard him announce to the press that agreement had been reached within the UK devolution settlement. No mention was made of the fact that somebody from the Department for Work and Pensions had to comment on the potential clawback of benefits. When I got home that night, I discovered that I had received a flood of e-mails asking all sorts of questions. I had to respond and say that the minister had not commented on the matter and that they should be aware that it had to be dealt with. He has now talked about it. Where are we on the position of the Department for Work and Pensions? What difference might its current position make to the payments that are made?
Malcolm Chisholm: I repeat what I said in my opening statement, which was more or less what I said on the day. Now that the other parts of the UK are adopting a similar approach, I hope that the issue can be resolved without difficulty. That is certainly the view in Whitehall. We are talking about the technical arrangements and the details of the process rather than whether it can be done.
Obviously, there is still some work to be done on the social security side. Indeed, social security regulations may be required to bring the arrangements into effect. However, the key message that I am sending out today—in even stronger terms than I did on 29 August—is that there are no fundamental obstacles in the way of the scheme's being introduced.
Mr Davidson: I do not know whether you have had any negotiations directly about whether primary legislation will be needed at Westminster to change the position. Is your understanding that no deductions will be made if there is a United Kingdom agreement, or will there be some deductions?

Malcolm Chisholm: The intention is that there will not be any. There is a precedent for that in the Macfarlane Trust. I think that the assumption is that there will be social security regulations, which are reviewed regularly at Westminster. That would be the mechanism.
Mr Davidson: Presumably, if there is an interim clawback and the regulations are reviewed later, the arrangements will be put into effect retrospectively, from 29 August.
Malcolm Chisholm: That is one of the issues that we will take up with the Department for Work and Pensions, but that is certainly the intention.
Mr Davidson: My other question is about the Irish scheme, on which Christine Grahame has touched. Do you have any intention to set up a tribunal to deal with aspects of our scheme like the one they have in Ireland, which is called the
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Hepatitis C and HIV Compensation Tribunal? It does not sound as though you will do anything like that. Will there just be a flat statement and if someone qualifies, that is it, or will there be a tribunal system to challenge rulings?
Malcolm Chisholm: We already have arrangements for HIV payments. The Macfarlane Trust is the main body for those, although it is not the only one—there is the Eileen Trust as well—because there are two parts to those arrangements. That seems to be the most obvious model to use in a Scottish and UK context. The matter is still being discussed. I do not know the details of how the tribunal in Ireland works. In the first instance, we are thinking about the model of trust that we know. Discussions continue on that.
Helen Eadie: My question is related to the earlier one about the number of people involved in the hepatitis C cases. You will be aware of an instance in Fife of people being infected with hepatitis B. Will they be included in the scheme too?
Malcolm Chisholm: No, they will not be included.
Kate Maclean: My question is linked—tenuously, I have to say—to David Davidson's question on the Irish compensation tribunal. Like all members, I have had many representations from constituents, including from one in particular who, along with his two brothers, contracted hepatitis C from tainted blood products. Thanks to the Scottish Executive and, in particular, to the Health and Community Care Committee, for pursuing the issue of payments of any kind, such people are in a far better position than they were before, but it seems from the e-mails that I have received that people are quite unhappy about the level of compensation and the fact that there will be no retrospective payments.
From your earlier evidence it seems that the difference between Scotland and Ireland is that the money from the Scottish Executive is an ex gratia payment, whereas the money that is paid in Ireland is compensation, which necessitates setting up a tribunal to consider levels of compensation, and is far more complicated than an ex gratia payment. Has a definite line finally been drawn under the debate about the possibility of compensation? Some kind of public inquiry has been asked for, as people are concerned about some of the evidence and about the fact that medical records have been lost. Is there any possibility of opening up that debate again? It would be useful for individual MSPs to be able to say when they are dealing with constituents whether there is any hope of further developments in the saga, which has been going on for a considerable length of time.
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Malcolm Chisholm: The Health and Community Care Committee did not support a public inquiry, which is presumably what you are referring to. Throughout the previous parliamentary session the Executive's view on the matter was clear: if new evidence comes out, people can examine it and make a judgment on it. Like other committee members, I have seen the recent newspaper reports, although that is as far as it goes. Unless some very strong evidence emerges, I do not think that there is any reason to revisit the issue, given that the Executive and the Health and Community Care Committee took the view in the previous session that there should not be a public inquiry.
Kate Maclean: But you would not rule out such an inquiry if new and compelling evidence emerged.
Malcolm Chisholm: Obviously, if completely new evidence emerged, it would change the situation. However, I am not saying that that is the case.
Shona Robison: We must be careful and accurate about what the previous Health and Community Care Committee said about a public inquiry. I recollect that we said that a public inquiry was not the main issue at the time; instead, our main imperative was to resolve the issue of financial assistance. That is what the committee wanted to focus on. However, my recollection is that we left the door open for a public inquiry, particularly if new evidence emerged.
The issue of financial assistance has been resolved to some degree, although we still need to address some aspects about the level of compensation. I hope that the minister will meet organisations that represent hep C sufferers to discuss the matter. That said, sufficient questions about the whole episode remain unanswered. The Health and Community Care Committee's inquiry was able to pursue certain

questions only so far, and I think that the minister will agree that a committee inquiry is not as able to probe matters as a public inquiry. For example, there are questions about when the health service knew about hepatitis C as a virus and whether, after tests were introduced and heat treatment became available, there was a period of time when it knew that blood and blood products were contaminated. Such questions remain unanswered and up in the air for hep C sufferers. Moreover, as Kate Maclean has pointed out, it has now been alleged that hep C sufferers have not been able to obtain their medical records.

Having a public inquiry now would potentially allow hep C sufferers to have some of those questions answered. Although, as a Health and Community Care Committee member, I felt that a public inquiry was not the way to go at the time,

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because we wanted to get money into the pockets of people who were suffering, I think that it is now the right time to go down that route. Do you not accept that argument?

Malcolm Chisholm: I am not persuaded by the merits of that argument, although members might wish to pursue the point.

It is important that any new evidence that might have become available is produced so that it can be examined. However, the area is very complex. The reality is that a specific screening test was not introduced until 1991 and that although people knew about what was called non-A, non-B hepatitis, they might not have known about its exact longer-term effects. There were many issues to address. In fact, a critical issue was that doctors had to make a choice about giving certain blood products, because the alternative might well have meant death for the particular patient. I certainly cannot do justice now to the many complex issues that are involved.

If new evidence emerges, I am happy to consider it with an open mind. Indeed, Andrew Gunn, who is well known to members, phoned me today and I was happy to talk to him and tell him that any new evidence should be submitted for examination. At the moment, I have not seen anything that would make me change my general approach. I am sure that some members might wish to pursue the subject as a matter for discussion and debate. People must understand that my main focus is on ensuring that the money is paid out as quickly as possible to people who are suffering as a result of blood products.

The Convener: For the purposes of clarification, the article that appeared in *The Sunday Times* on 7 September—to which the minister might be referring among other things—mentions papers that refer to

"specific brands of blood-clotting agents during a monitoring project in the 1970s."

The article continues:

"The study, funded by what was then the Department of Health and Social Security (DHSS) found that 197 cases of hepatitis C were reported by haemophilia centre directors between 1974 and 1979."

In commenting on those papers, the Executive has stated:

"We are not currently aware of these documents and would not therefore wish to comment on them."

Has the minister now seen any of those documents?

Malcolm Chisholm: No, I have not seen the documents.

The Convener: I seek to separate the matter of the ex gratia scheme from the public inquiry. It will

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be up to the committee to decide whether to ask you back to discuss whether or not you would hold a public inquiry once those documents are in your hands and once you have considered them.

16:45

Malcolm Chisholm: I am open minded about it. Personally, I am quite happy to listen to any new evidence. It should be noted that all the products that we are talking about were licensed by the forerunner of the Medicines Control Agency—now the Medicines and Healthcare products Regulatory Agency—which operated under reserved powers. There might well be a question about whether the issue is for us or the Westminster Parliament. Without getting into that argument—

The Convener: Although you could take a view on that.

Malcolm Chisholm: In principle, I am quite happy to consider any new evidence, which is what I said to Andrew Gunn.

The Convener: Have you any idea when you might be in a position to tell the committee when you will have seen the documents that have been trailed in the newspapers?

Malcolm Chisholm: If somebody submits those documents, I am sure that people will be able to look at them.

The Convener: We can put out a call to *The Sunday Times*.

Mr Davidson: This point goes back to the days when Susan Deacon was Minister for Health and Community Care. Apparently, she made a statement that 20 people who had contracted hepatitis C as a

result of NHS blood-product use would be compensated under the terms of the Consumer Protection Act 1987. Have any such payments been made?

Malcolm Chisholm: I ask Bob Stock to give an update on what has been happening.

Bob Stock (Scottish Executive Health Department): No payments have been made, although offers have been made. Understandably, legal representatives of the patients involved are reluctant to accept any payments while the ex gratia scheme is still up in the air. They are holding back, and we are unable to resolve the matter in a lot of instances. It has also taken a lot of time to pull together medical records and so on.

The Convener: I thank the Minister for Health and Community Care, Mr MacLeod and Mr Stock. We will discuss next week whether we wish to take the matter any further, given the issues that have been raised today—and which have been left hanging to some extent. We will have to wait and see whether the documentation that we have been

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discussing reaches the minister. Is the committee content to wait?

Members *indicated agreement.*

The Convener: We will let members see any correspondence.

That concludes the public part of the meeting.