Extract from Health Committee meeting 1 March 2005

The Convener: Part 5 of the bill deals with infection with hepatitis C as a result of NHS treatment. In taking evidence this afternoon, our focus is on the bill, which proposes a legal basis for the existing system of ex gratia payments. The committee will hold a further separate evidence session to examine the case for a public inquiry; that session, of course, will involve representatives of the Scottish haemophilia forum and the Minister for Health and Community Care. I remind witnesses and members not to stray into that area today, because we are dealing specifically with what is in the bill.

I welcome Philip Dolan, chairman, and GRO-A of the Scottish haemophilia forum and Frank Maguire, who is the legal adviser to the forum. I invite Philip Dolan to make a brief introductory statement, which I ask him to confine to five minutes.

Philip Dolan (Scottish Haemophilia Forum): Thank you for the opportunity to speak to the committee. This is the first forum at which we have been able to discuss our concerns about the Skipton Fund. The committee has received our submission, which I do not intend to go over, other than to highlight a few points. We have concerns about the Skipton Fund.

Frank Maguire will speak on the legal aspects of our concerns about the bill, of which you have given us a copy. He is much better equipped to deal with the legal aspects than we are.

It seems that the minister will have the opportunity to lodge amendments. Perhaps I am misreading the information that I have—no doubt you will put me right about that. We have always expressed our concern that the Skipton Fund seems to discriminate against the dependants of the people who died prior to 29 August 2003. We think that that is unfair and we do not know why the decision on it was reached. I am the only person here who attended all three of the meetings about Skipton that were held in London and there are no minutes of the meetings. We are concerned about how a record is held of how Skipton has come to decisions.

We have concerns about the fact that the appeals panel will lack any involvement from haematologists, who are the people who have been most involved with all those who have developed hepatitis C as a result of receiving blood products or blood transfusions. That is a concern, especially given the fact that the Skipton Fund deals only with those who acquired hepatitis C through NHS blood products or transfusions.

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That is all that I will say at this stage, but I am happy to answer questions. Mr Maguire will be able to deal with the legal aspects.

The Convener: I do not want extensive or lengthy opening statements. If Mr Maguire can restrict his statement to no more than a minute or two, we can bring out the other issues in questioning.

Frank Maguire (Scottish Haemophilia Forum): As a general point, let me state that we welcome section 24 of the bill, which will give Scottish ministers the scope and power to provide for a scheme that is more amenable to people in Scotland. I have a lot of experience of how the Skipton Fund has operated for people in Scotland since it started in July last year. First, the scheme is based very much on written applications. Many people, including many of my clients, find the forms intimidating and difficult to complete, which is a big disincentive. However, I think that section 24 will give Scottish ministers the scope to provide for claims to be presented orally. It should also mean that the scheme can have a presence in Scotland so that people can have a face-to-face discussion if they want to inquire what they should do with their form and what information they need to provide on it, or if they do not understand the scheme's requirements. At the moment, the fact that the Skipton Fund is based in London makes things extremely difficult.

Secondly, no appeals procedure has yet been put in place for the scheme. Applications have been refused, but there is no mechanism whereby my clients and others can appeal those decisions. Another problem with the appeals system concerns the question whether lawyers and others will need to travel to London to make their case or whether the appeals panel will sit in Scotland. Either way, there is a difficulty. Obviously, it would be difficult and impractical—and, indeed, costly—for many of my clients to travel down to London for an appeal, but requiring all those lawyers to come up here will also have a cost implication. However, there is something to be said for having an appeals procedure in Scotland. Section 24 will give Scottish ministers scope to do that.

As well as those general points about section 24, I hope to be able to highlight, in response to questioning, some specific points about the terms in the bill, some of which are contradictory, inconsistent and inaccurate. I will go through those issues as and when we are asked questions.

Janis Hughes (Glasgow Rutherglen) (Lab): The appeals panel is dealt with in some detail in the Scottish haemophilia forum's submission, which highlights a concern about the absence of a

Col 1680

requirement for a haematologist on the appeals panel. I think that the stipulation is that the panel must have a GP and a hepatologist. Given the issue with blood transfusions, I can understand why people might see a need for a haematologist to play an important role on the appeals panel, but could not a GP play that role, given that GPs look after patients throughout their illness?

Philip Dolan: Very few GPs have had direct involvement with hepatitis C. Some GPs will have been involved, but that is not true of the majority. For most people with haemophilia, their first application form to the Skipton Fund will have been filled in by the United Kingdom Haemophilia Centre Directors Organisation. Often, a haematologist will have been involved in that process, because virtually everyone who has developed hepatitis C got it through a blood transfusion. Therefore, the process generally involves some contact with a haematologist.

There is a question over whether a GP could deal with stage 2 applications to the Skipton Fund, because even haematologists find it difficult to work out the equation that determines whether someone reaches that stage. Therefore, there is a role for haematologists. One GP to whom I spoke recently was completely at a loss when they were asked by a patient to fill out the form.

The United Kingdom Haemophilia Centre Directors Organisation says that it has been involved in little or no discussion during the process even though it is the main organisation and most people who have developed hepatitis C are people with haemophilia. We have no idea why a GP was put on the appeals panel; I have also raised questions about how the other members of the board are recruited.

GRO-A **(Scottish Haemophilia Forum):** As haemophiliacs, we do not have a lot of contact with our GPs. We go straight to a centre for treatment. When I go to see my GP about anything we usually have a discussion about how things are, but GPs are not really up to speed on what is going on.

Shona Robison: The first of my two questions is on the point that is made in your evidence, and the evidence from the Royal College of Nursing, that the committee should examine section 24(1)(c) of the bill, which refers to those who

"did not die before 29th August 2003."

You suggest that that cut-off date disadvantages families and partners, who have no access to compensatory payments from any fund or legal process. Will you confirm that the Scottish haemophilia forum is calling for that provision to be amended or deleted from the bill to avoid the arbitrary cut-off date for those relatives who will miss out because the person who died of hepatitis C happened to die before 29 August 2003?

Col 1681

Has the Scottish haemophilia forum done any work on the number of families who are concerned about or caught up by that arbitrary date and who have therefore missed out on payments? Have any costings been done on what it would cost to include those people? That is my first question.

The Convener: We will deal with that question first.

Philip Dolan: We do not know the figures because of the need for confidentiality and so on, but hepatitis C has been an issue since the birth of the Scottish Parliament in 1999. Why choose 2003 and not 1999? Why discriminate, given that there are only a limited number of cases? It is complete discrimination against us.

GRO-A

GRO-A The fact that one has to be registered is another example of discrimination.

Initially the forum was concerned only with haemophilia, but in the course of our work we have taken on board other people who contracted hepatitis C through blood transfusions, who do not have an umbrella organisation to represent them. Frank Maguire has had more dealings with that group.

Frank Maguire: I will give an example. I have two death certificates here. On the first, the cause of death is hepatic failure and septic shock and the date of death is 7 May 2003. On the other, the cause of death is hepatitis C-related liver disease and the date of death is 4 September 2003. I see no difference between those cases. The date of death is pure chance and nobody has any control over it, but in one case the payment was made and in the other it was not. That puts the matter in stark contrast.

I have handled nine fatal cases; four of the people in those cases died in the period before 29 August 2003. It is quite hard for some of my clients to accept that they have gone through all the suffering because they were infected by the hepatitis C virus through a blood product or a blood transfusion and that because Parliament has only just got round to dealing with the issue, they are disadvantaged even though their pain and suffering are exactly the same as someone else's. That is the injustice. If we are dealing with numbers, and I have nine fatal cases out of 130 cases, and four of those people died before the date, we are not talking about an awful lot of money.

Col 1682

15:15

Shona Robison: The evidence from the Skipton Fund says:

"Activity in Skipton is now running at a low rate."

Mr Maguire said in his opening remarks that there was a disincentive because the scheme was based on written applications and the form was long. Do you think that the low rate of activity—I assume that that means a low rate of applications—relates directly to the amount of paperwork that a person has to fill out? Are your clients telling you that the process is preventing them from applying? Is the situation as stark as that?

Frank Maguire: I cannot deal with statistics, but I can tell you my experience. My impression is that although a lawyer is helping people, they are still having difficulty with the process. We are helping them with that. A vast number of people out there do not have a lawyer. The Skipton Fund does not like lawyers; it will not correspond with me. It will write to my client and my client has to come to me. I do not understand the reason for that, but that is what the Skipton Fund does. That is a disincentive, even for my clients who are using a lawyer. There is almost a disincentive to use a lawyer, because the Skipton Fund will not correspond with me.

There are several people out there who are struggling and trying as hard as they can to deal with the form. Not only do they have to fill in the form, they have to go and see someone and ask them to do something with the form. A lot of activity is required of the client.

There is a lack of information on the Skipton Fund. Where do people find out about it? How do they know what to do with the long form that they have to fill in? People sometimes find that their GP or medical adviser does not know about the fund either. I have a case in which it has taken from August last year until now to get the form filled in because the GP did not understand it and the consultant refused to deal with it because he was not getting paid; the form then went backwards and forwards to the Skipton Fund. We went to the fund and said that the consultant would not sign the form because he was not getting paid, and the fund said, "That's not our problem. You will have to pay for it." The client had no money to pay for it, so I wrote to the minister and he got involved. There are many bureaucratic systems in place that are potential disincentives.

Philip Dolan: This point might come up later, but I will mention it just now. Paragraph 3 of the Skipton Fund's submission is very misleading. First reading of that paragraph might give the impression that, of the four directors who were appointed to Skipton, two were from the Department of Health and two were the result of nominations from the Haemophilia Society. I have received an e-mail from the chief executive of the Haemophilia Society who assures members that the UK society was never asked to nominate persons to be appointed as directors.

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We have grave reservations about the closeness of the Skipton Fund, the Macfarlane Trust and the Department of Health. The chairman of the Skipton Fund, Peter Stevens, is one of the nominees of the Haemophilia Society to the Macfarlane Trust, but we certainly did not nominate him or any other person to the Skipton Fund. That raises questions about relationships. Mr Steven's term of office as a representative of the Haemophilia Society on Skipton finishes in July this year. A lot of things are going on. I want to be clear on the point that we were neither asked nor invited to make nominations to Skipton.

Dr Turner: I have two questions on the matter of filling in the form: one is on the form itself and the other is on the private nature of the company. I know of at least one person who is having great difficulty with filling in the form. How many consultant haematologists have said that they did not have time to fill in the forms? I understand that, in this case, they pleaded that the problem was one of workforce issues.

We heard earlier about someone who filled in the form as a private service and, because he was paid £200 to do it, the form was filled in a little bit more quickly. Consultants in the NHS do not seem to have the time to do that. From what you said, it seems that the length and complexity of the forms mean that it is not appropriate for GPs to complete them.

Frank Maguire: The consultants have to set aside time to fill in the forms. First, they have to see the person who has brought in the form to have it completed. They then have to set aside time to get out and look at the patient's notes, some of which are quite large. The consultant might then have to go back and talk to the person about their case. Consultants have to go through that procedure before they get down to filling in the form. If they are diligent, they want to get it right; they know how important that is to the patient. All of that has to be fitted into the work of a busy practice.

No one is saying to the consultant, "We will set aside time for you", or "We will pay for you to do this." Some consultants find the lack of payment quite galling. They are doing the work of filling in the forms, yet who gains a saving as a result? It is probably the private company. Skipton wants to keep down costs by making the process simple and by putting the burden of completing the report on to the consultant, who has to do it gratis. That saves the private company money and, in turn,

Col 1684

makes it more profitable. That is the dynamic of what is going on.

I agree that the form is difficult to complete. There is also an issue for consultants in terms of the time that they have to take to complete the forms and the fact that they have to make themselves available to do so. I emphasise again the fact that medical records are very large.

Philip Dolan: The haemophilia directors have been fairly helpful in relation to helping people to fill in the forms at stage 1. That said, it depends on the part of Scotland in which people reside. Some directors are pedantic about how they fill in the forms. We know of cases, certainly in this part of the world, in which people's forms went backwards and forwards between the consultant and Skipton and, at the end of it, people got no money. However, because the haemophilia director in another part of Scotland knows the patients, they can say that someone needs a payment and the payment is made.

Greater complications are involved in stage 2 payment applications. As I said earlier, I know from conversations that I have had with the haemophilia directors in Scotland that some of them have a great deal of difficulty in completing the second part of the application process, partly as a result of their trying to get meetings with hepatologists. I know of one case in which both the professionals work in the same hospital and yet an e-mail that was sent in November says that one can meet the other to discuss the filling in of the forms in February. I am talking about people who walk by each other in the link corridor of the hospital in question.

Dr Turner: I am concerned about the fact that a private company should have been formed in order to distribute the fund. I think that it was the Scottish haemophilia forum that went into detail about the private nature of the company. I do not understand why that had to happen. My understanding is that, under the Freedom of Information (Scotland) Act 2002, it is very difficult for a private company to give out information.

The Convener: Perhaps Mr Maguire can respond in respect of the difficulties that arise simply because Skipton Fund Ltd is a private company.

Frank Maguire: Questions arise because of the fact that it is a private company. What is in it for the private company? We do not know how much the directors are paid, how profit oriented they are or what their profit motive is, and whether they are being efficient because the company provides a public service or because they want to save money.

If I were to be cynical, I would say that—given the requirement for written applications, the

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practice of batting everything back to the patient, the avoidance of lawyers and the avoidance of other costs—Skipton is keeping the costs down so that its profit is higher. If the company gets involved in such things, its expenditure goes up, so its profit is obviously less. Whether I can get into that, or whether the company can reveal that, is a different matter altogether. The company keeps talking about judicial review, but such a review is normally conducted on an administrative body such as a local authority or a public body. There is a question mark over whether I could judicially review the actions of a private company, if only the private company and not the minister were involved. There is an obstacle involved when the Skipton Fund talks about judicial review.

Dr Turner: That is what I thought

The Convener: Witnesses from the Skipton Fund are coming later this afternoon. We hope that they will be here by 4.15, although there have been difficulties with their flight. I understand that they have now arrived, so we will be able to put some of those questions directly to the Skipton Fund representatives.

Mr McNeil: I am shocked to hear that consultants are being obstructive and that they are not being helpful. We know that, in other areas, consultants are an essential part of the network to get people who are suffering from certain conditions through the system and referred to self-help groups. I am really shocked and disappointed that that delay has arisen. I do not know whether the committee can do something about that with the minister to clear away some of those problems. It may be useful for us to get some more information about the form. How long does it take for the consultant and the person together to fill out the relevant part of the form?

GRO-A: Often they do not have to be together. The consultant has the information.

When I filled out the stage 1 application form, there was one page that the applicant had to fill in and the consultant filled in the rest. For the record, I would like to say that we have had no problems at Ninewells hospital in Dundee. The consultants there have been first class at getting the forms filled in.

Mr McNeil: Can you be more specific about where the problems lie? Which health boards are affected?

GRO-A: I believe that there is a problem in Edinburgh.

Mr McNeil: Where else?

Frank Maguire: There is a case in Glasgow.

Mr McNeil: There is one case in Glasgow. How many are there in Edinburgh?

Col 1686

GRO-A: I do not have a figure, but I know that there is a problem.

Mr McNeil: It would be useful if we could get some of those figures.

The Convener: Could you do some digging around and get some further information to the committee on that aspect of the issue?

Philip Dolan: Yes. There have certainly been individuals in Edinburgh who have had difficulty with the forms being batted backwards and forwards. We know that, in some instances, consultants took one and a half minutes to complete the stage 1 application form. In other cases, the process has taken months, because the consultants have wanted to go into greater detail. I can talk about individuals but, as you will appreciate, most people who have been involved have wanted to keep away because of the stigma that is attached to their condition.

The Convener: I appreciate that there is a difficulty, but it helps the committee if we can get as much information as possible about what is happening.

I would say the same to Mr Maguire. If you know of specific areas of Scotland or situations in which that specific problem has arisen, could you ferry that information to us? It would be gratefully received.

Frank Maguire: To be clear, I raised the matter with the minister and he took action on a specific case. However, it is a bit silly to have to go to the minister to get a form filled in.

Mr McNeil: The situation that you have described is shocking and not acceptable. We want to have an understanding of the extent of that situation so that we can put it right. Thankfully, we do not need to write to Dundee, because the consultants there may represent best practice, but we need to identify why that is not happening in other areas.

I presume that you have a copy of the submission from the Skipton Fund. Your own submission has been helpful to us in considering the evidence. You say that the two representatives from the Haemophilia Society who are directors were not nominated by the Haemophilia Society to the Skipton Fund. Do you have good links with them? Have they been able to raise and address some of the issues? Or is it the case that they have been of no effect and that you have had no contact with them?

Philip Dolan: I am a trustee of the Haemophilia Society and the matter has been discussed with the trustees.

The concerns about the appointment of the directors, which was done without consultation,

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have been discussed with the trustees of the Haemophilia Society. For the benefit of the representatives of the Skipton Fund, who have probably now arrived, I repeat what I said earlier: we have an e-mail from the chief executive of the Haemophilia Society—I will make the e-mail available—in which he confirms that the society was not consulted and did not make any appointment. We believe that the Haemophilia Society is having on-going conversation on the issue, but, unfortunately, the chief executive of the society could not be with us today to answer questions. We do not know why the Skipton Fund was set up—whether it was for reasons of speed or for some other reason—but we should have been consulted and had a say.

Mr McNeil: Is there any reason why you would not have nominated the two people concerned? Do you have objections to them? Do they have any association with the Haemophilia Society?

15:30

Philip Dolan: The Haemophilia Society nominated both of them for the Macfarlane Trust, on which people serve for a period of time. However, the Haemophilia Society might not wish to reappoint those people to the Macfarlane Trust in the future and may have preferred to appoint other persons to the Skipton Fund. The chief executive and chairman of the Macfarlane Trust were initially appointed to set up the Skipton Fund. The chairman of the Macfarlane Trust, who is with us today, is also the chairman of the Skipton Fund. Given the procedures in Scotland to ensure that everything is visible and up front, that relationship is rather close.

Mr McNeil: Given that we will question representatives of the Skipton Fund later on, and that you may not do so at this stage, do any other points jump out of the Skipton Fund submission, including the figures that have been provided, with which you disagree or to which you object?

Frank Maguire: My problem with the Skipton Fund is how it conducts itself. We have discussed the difficulty with forms and how the burden is put on to the patient. It would be of great assistance if the Scottish Legal Aid Board changed its policy of refusing automatically applications from people who want advice regarding the Skipton Fund.

The Convener: Does that happen even at the level of advice and assistance?

Frank Maguire: A person would get something—the initial £80-worth or whatever—but if more work needs to be done, the Scottish Legal Aid Board just says that the Skipton Fund deals with the matter and that is the end of the story. There is a constant struggle with the Scottish Legal Aid Board to get it to authorise increased

Col 1688

expenditure to cover more work on accessing medical records and assisting clients. That goes right through the system.

Philip Dolan: To answer Mr McNeil, the concern is why we need the Skipton Fund. Why could the function not have been carried out at arm's length from, or within, the Department for Work and Pensions? Only a limited time is available. Once all the applicants for the first and second phases have been dealt with, there will be only a trickle of people applying, as their condition worsens from chronic hepatitis into cirrhosis and cancer. The Skipton Fund seems to be an organisation that deals with paper—sending out forms, receiving them, sending out money and coming to decisions based on criteria that are not known to me or other people.

In two years' time, instead of having a large office in Westminster—the most expensive part of London—a confessional box in a church will be sufficient, because the body will need only a part-time worker. As Mr Maguire pointed out, we do not know how much of the money that the Skipton Fund was set up to pay to patients is being spent on administrative costs and rent. I do not know whether you are planning to consider the appeals system, which is one of our major concerns.

The Convener: You have made that point already. Mr Maguire mentioned specific issues that he wanted to raise. I invite him to take the opportunity to do so now.

Frank Maguire: With regard to compensation, we must consider what is best for people in Scotland. The system is not ideal, but we must be practical about it. It should be possible to access the system both in writing and face to face. There should be face-to-face access to advice. People should be able to go to an office in Scotland to ask someone questions, or another person should be able to do that for them. The face-to-face dimension is completely missing because the fund is based in England. It does not matter whether the system is run by the Skipton Fund or another body.

When people's claims are rejected, they must be given clear reasons, with appropriate reference to the evidence, for why that has happened. We do not get reasons—we are just given a little one-liner that says "refused". Why?

The Convener: That is similar to the way in which the Crown Office indicates that it is refusing to proceed.

Frank Maguire: Yes. I am concerned that, if we have an appeals procedure that is London focused, it will be based more on written communication and there will be an attempt to avoid oral representation. Oral representation is essential in any appeals procedure. A face-to-face

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question and answer session reveals much more than is contained in written documents and allows people to get right to the nub of the problem, without being misdirected in various ways. With face-to-face meetings, people understand why their important application has been turned down.

The system that we seek would ensure accessibility to both advice and decisions. Reasons for decisions and access to information would be provided. It would be helpful if that information were held here. There would also be an appeals procedure that was Scotland focused and accessible in Scotland. If the Skipton Fund can provide what we are seeking, that is fine. If it cannot, we must have our own system. If the number of applicants is declining, as has been indicated, such a system would not be very expensive. However, the benefits to people in Scotland would be great.

Dave Bissett: The Skipton Fund submission refers to payments of £20,000 and a further £25,000. No one has ever told us how those figures were calculated. Where did they come from? What do they mean? The Skipton Fund's advisers came up with an equation, based on liver tests, to work out whether someone should receive a second-phase payment. Any liver specialist will tell you that those tests do not necessarily mean that someone does not have cirrhosis or cancer—they are only a guide. Even if a good part of the liver is taken in a biopsy, it cannot provide 100 per cent certainty.

I qualify for the first section of payments, but not for the second. Although some of my readings are high, they do not fit into that category. I have probably had hep C for about 30 years. From the symptoms that I experience, I know that I have some sort of liver damage, but the tests do not show it. The equation that has been developed does not mean much to me. Over the years, even before hep C came into being, we were told that the tests were guides and that there were no guarantees. The fund intended to come up with a non-invasive test, but it was not able to do so. However, if it worked out an equation to determine who should get the second payment, could it not have worked out an equation to calculate what people were losing through ill health and stress?

GRO-A who is seriously ill and cannot work. He had his own business and is probably losing about £50,000 a year in earnings. He qualifies for the second payment, so he gets £45,000. The chap who runs the Skipton Fund probably gets more in his salary than GRO-A gets in compensation. Where do the figures come from? Did someone just decide that the figures sounded good and that by giving people £20,000 they could get rid of them? That is not satisfactory.

The Convener: We have a few minutes left in this session. I do not want to move off this topic if

Col 1690

people want to raise issues. I remind witnesses that we have the written submissions, so it is not necessary to repeat everything that is in them. Committee members have no more questions. Do you have any final comments on the bill?

Frank Maguire: I wish to address an important point on section 24, concerning eligibility. Section 24(2)(b) states that a person will not qualify if their sole or main residence was not Scotland when they applied for a payment or if, in the case of someone who died, their sole or main residence was not Scotland when they applied. I cannot see the logic of that. The issue should be that the conduct complained of happened in Scotland. No matter where you live after that, you should be paid if the NHS in Scotland infected you with hepatitis C.

Let us consider the practicalities if we keep that provision. I have cases the length and breadth of Scotland. Take the example of a baby in Shetland who was infected with hepatitis C virus. If as a teenager that person goes to England to get a job, their sole or main residence will be in England. In that instance, they will be disqualified. Why should that be? At the other end of the age spectrum, an elderly person might go to live with or near their children in England, France or elsewhere. By that fact, they will be disqualified. It is illogical that when making an application a person's sole or main residence must be in Scotland. That has no connection to what we are talking about. All that they should be required to prove is that, wherever they live, they were given a product or transfusion in Scotland and that it was administered by the NHS. Section 24(2)(b) should be removed from the bill.

In addition, there is a contradiction between what the Skipton Fund says and what section 24 says about people who receive money by way of another scheme or litigation—cases are proceeding on negligence grounds. Guidance from the Skipton Fund asks:

"Will any payments I have received from other schemes, or as a result of litigation, be deducted from the payments made to me by the Skipton Fund?"

to which the answer is, "No." However, section 24(3)(b) states that a scheme may

"provide that the making of a claim, or the receipt of a payment, under the scheme is not to prejudice the right of any person to institute or carry on proceedings ... (but may also provide for the taking account of payments under the scheme in such proceedings)".

That seems to say something different from the Skipton Fund. Perhaps section 24(3)(b) should be examined closely and amended.

Why was the cut-off date of 1 September 1991 picked? I cannot explain that. If it was chosen because it is believed that no infected blood was

Col 1691

in the system, I would like to see the evidence. We have never had an inquiry—we will not talk about that today—but because the issue has never been fully explored, how can we be satisfied that 1 September 1991 is the correct date? Where is the incontrovertible evidence? I have indications from clients that they were infected after that date. In any event, why not leave the question of whether you received hepatitis C from infected blood as the matter of proof? Whether you were infected in December 1991 or in 1993, you would still have to prove it. Leave it open and do not prejudge the issue.

I can submit those points in written form.

The Convener: You do not need to now, because you have put them on the record, unless you want to follow up with more detail. We have two minutes left. Do committee members want to ask questions on the last points that were raised?

Shona Robison: That is important evidence. I was aware of the issue around the date of 29 August 2003, but the important points that you make require further explanation, which I hope we will receive.

Helen Eadie (Dunfermline East) (Lab): Is the £15 million that the Executive has set aside adequate?

Frank Maguire: That is very hard to forecast. There are people in the system who do not know that they have hepatitis C. That is another problem, and it is why there is a problem with application. People cannot make an application if they do not know that they have the condition, but they still get disqualified for not making one. Those people in the system who do not know that they have hepatitis C are being discovered as and when they return for treatment, or if they die. The number of people concerned is unknown. We also do not know how many people will die of hepatitis C. Judging from the cases that I have dealt with, deaths have occurred in 2003 and 2004, and there will be some in 2005 and into the future, no doubt. That is difficult to assess.

£15 million may be set aside, but I hope that the Scottish ministers will recognise that there would need to be more if that fund were exhausted. I would not like ministers to keep within that £15 million by trying to keep expenditure down and doing various sorts of cost-cutting exercises. That would only go against the people who are trying to make a claim.

15:45

The Convener: I will allow Mr Dolan to come in very briefly, as we need to move on.

Philip Dolan: GRO-A raised the question of the £20,000 payments. The Scottish Parliament

Col 1692

set up an expert group under Lord Ross, which recommended a minimum sum of £50,000. We do not understand why that has not been implemented. Perhaps the committee is in a position to review that during its consideration of the bill. The concerns that we have expressed about the appeals system are important, and I know that you will be taking those concerns and our submission into account.

The Convener: I thank the three witnesses for coming along. Witnesses from the Skipton Fund will give evidence later. We now have to move into private session, as previously agreed. We have had to rejig our agenda because of late planes and so on. I will first suspend the meeting for a couple of minutes to allow the room to be cleared.

15:46

Meeting suspended until 15:49 and continued in private thereafter.

16:27

Meeting continued in public.

The Convener: I reconvene the meeting in public and welcome Peter Stevens, the chairman of the Skipton Fund, and Keith Foster, a scheme administrator of the Skipton Fund. We have heard evidence from representatives of the Scottish haemophilia forum. Mr Foster did not hear all of that evidence, but he heard a significant portion of it. I suspect that committee members will have questions arising out of that evidence. I ask one or other of the witnesses to make a brief statement about the Skipton Fund in connection with the legislative proposals that we are considering.

Peter Stevens (Skipton Fund Ltd): I apologise for delaying your proceedings, convener. The matter was out of my control.

The Convener: We understand.

Peter Stevens: The Skipton Fund began operations on 5 July last year, having been set up earlier in the year following discussions that have been going on since the announcement of the hepatitis C ex gratia payment scheme at the end of August 2003. Everything that has been done in setting up the scheme and in staffing it has been done in the interests of getting the payments made as quickly and efficiently as possible.

There are four directors of the fund who were all trustees of the Macfarlane Trust, which was invited by the Department of Health, on behalf of the health departments in the four Administrations, to put its resources, expertise and experience at the disposal of the departments to run the scheme. The directors have a job to do in signing off payments and I believe that we have already

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made well in excess of 80 per cent of the payments that the scheme will ever be required to make. That is all I wish to say at the moment.

16:30

The Convener: I thank you for being commendably brief.

Does Mr Foster want to add anything, or shall we go straight to questions?

Keith Foster (Skipton Fund Ltd): It is probably best to go straight to questions, but I will first explain my role. I came in as administrator at the start of the scheme, so questions on procedures are probably best directed to me, whereas questions on policy can be directed to Peter Stevens.

Shona Robison: My first questions relate to the status of the Skipton Fund. Will you confirm whether it is a private company? Concerns were raised earlier—you might have heard them—about whether, as a private company, you make a profit through the operation of the fund. Will you clarify that and whether the directors are paid or unpaid? Further to that, I ask you to tell me the breakdown of finances for the Skipton Fund—for example, administrative costs, office costs, the payments and the costs of appeal. I do not necessarily expect you to be able to answer that today, but you might be able to provide the information in writing, as it would be useful to have a breakdown of the fund's finances for those elements.

Secondly, I have questions about your written evidence. You say:

"Activity in Skipton is now running at a low rate."

We heard earlier that there are concerns about the length and complexity of the fund's application forms, which might put potential applicants off applying in the first place and might be one of the reasons for that low rate of activity. What is your view on that? Has that concern been raised with you?

Mr Stevens, you just said that 80 per cent of the payments that the scheme will be required to make have been made. Do you mean by that that you think that 80 per cent of the payments that you will ever make have been made or are you referring to 80 per cent of the payments that have been applied for to date? Will you clarify that point?

The Convener: The witnesses can decide between themselves who should answer which questions.

Peter Stevens: The Skipton Fund is a company limited by guarantee. It is our intention to minimise the profits and to make them as close to zero as possible so that we do not have to concern

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ourselves with profit distribution or tax. If there is a profit, it will be carried forward from one year to the next to pay for the following year's expenses and, in the long run, I anticipate that the company will be totally non-profit making.

At the moment, there is a slight uncertainty in everything to do with operating costs, because some VAT might be involved in services that the Macfarlane Trust supplies to the Skipton Fund, but HM Customs and Excise is taking a considerable amount of time to analyse the nature of the two operations and whether VAT payments will be required.

The directors give their services for free; there are no directors' fees. We have considered that directors might deserve a fee for the amount of time that they spend not performing directors' functions but coming into the office to process and sign off application forms, but no one has booked one yet.

Shona Robison asked me to amplify my statement that we have made more than 80 per cent of the payments that we will ever make—I emphasise "ever". Roughly 4,400 application forms have been sent out to people who have completed their registration. We are registering people at a rate of about seven a week—one a day—so it will be a long time before the initial estimates of between 6,000 and 8,000 applications are received. Indeed, I do not think that those figures will ever be reached.

When people register, they have no idea whether the application form will be complex. The registration form is very simple and the application form is even simpler for applicants. The bulk of the application form must be filled in by the claimant's clinician, because it is concerned with medical evidence; there is no other complexity in the form. The application process is simple and the form was designed so that it would not put anyone off applying.

That is all the information that I can give in answering the member's questions. Mr Foster will add something.

Keith Foster: I will leave a couple of spare forms with the clerk so that members can see them. The witnesses from the Scottish haemophilia forum made the point that the forms are complex and Shona Robison asked about that. However, the forms are not complicated for claimants, who need only fill in their name, address and national insurance number, sign the form and send it to us in a pre-paid envelope. All the work that needs to be done is then undertaken by the claimant's clinician.

The witnesses also expressed concern that there were difficulties in getting the forms completed. However, such cases tend to be

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isolated. I administer the scheme for the whole of the UK, so I can say clearly that the number of problems is small in relation to the number of claims that are being processed. Although such cases obviously present a big problem for individual claimants, the problem is not regarded as large globally. The chief medical officer has written to all consultants in a bulletin, to advise them of the existence of the Skipton Fund and to ask them to consider forms in that light.

Members might have encountered constituents who are having difficulties because GPs are being asked to fill in forms. We suggest that a consultant fill in the form whenever that is practical, but that does not always happen. Because of GPs' terms and conditions and their contracts with health authorities, fees might be charged. Also, GPs are not necessarily au fait with the details of the disease.

Shona Robison: Are you saying that you do not expect the £15 million that the Scottish Executive set aside to be claimed? You seem to be indicating that fewer applications than you expected have been made to date. How much of the £15 million has been claimed so far? What figure is represented by the 80 per cent of payments that you say that you have made?

Peter Stevens: Currently, Scottish stage 1 and 2 payments total roughly £8 million. If we were going to reach the figure of £15 million, which would be consistent with the entire scheme having around 8,000 applications, I would have expected that by now we would have heard from more than 6,000 people. However, we have heard from 4,500 people. I do not see where the other 3,500 applicants are. The scheme has been running for several months and has received quite a lot of publicity through the chief medical officer's circulars. We receive requests for new registrations at a rate of seven per week, as I said, and the figure has been falling gradually for about three or four months. I do not know where the other 3,500 applications would come from.

Shona Robison: Unless eligibility for payments is widened.

Kate Maclean (Dundee West) (Lab): I was not clear about Peter Stevens's response to Shona Robison's question about the fund's running costs. You said that the VAT issue is being sorted out, but notwithstanding that, what percentage of your budget goes on ex gratia payments and what percentage do you budget for running costs? You must have an idea of the approximate percentages. It would be interesting to know what they are, because there seems to be concern about the matter.

Peter Stevens: So far, we have paid out about £65 million in ex gratia payments. The fund's

Col 1696

running costs to date are less than a quarter of 1 per cent of the total figure.

Helen Eadie: Convener, should I ask all my questions now?

The Convener: Yes.

Helen Eadie: Why was not the Haemophilia Society invited to nominate individuals to the Skipton Fund's board? Why was there no correspondence with lawyers? I am raising issues that Frank Maguire mentioned.

Peter Stevens: I am sorry, but I did not catch your second question.

Helen Eadie: Why did the Skipton Fund decline to enter into correspondence with lawyers such as Frank Maguire who took on cases?

Is the Skipton Fund regarded as a public body under freedom of information legislation? Would it respond to requests for information in the same way as a public body would do?

Finally, in answer to Shona Robison's questions you said that information had been provided to consultants in a bulletin. We all receive bulletins and newsletters and it is not possible to read everything. Would it be better to provide such guidance to doctors in a direct letter? I do not think that a bulletin is an appropriate form of communication.

Peter Stevens: As I said, the composition of the board was designed simply to get things started and to get the job done quickly. As directors, we regard our appointments as being interim, and at some stage I am sure that we will be asked to stand down and perhaps a more representative board will be set up. We have no problem with that. It might be worth pointing out that the principal function of directors is to approve the making of payments. There are four directors, three of whom are Macfarlane Trust trustees who are resident in London, so we can get to the office quickly without having to spend time and money before we can perform our function. In other words, the directorship is a working job rather than a question of status.

In general we have not replied to lawyers' letters because we passed them back to the officials in the health departments of the four Administrations, who asked that they, rather than the fund, should enter into correspondence on legal matters. I stress that we act only as agents; we are not an independent body that has discretion over matters.

I understand that we are subject to the freedom of information legislation and would have to respond appropriately to requests, although I am sure that we would take guidance from officials in doing so.

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I take Helen Eadie's point about the communication of information. Again, information about the scheme and the Skipton Fund is in the hands of officials from the four Administrations, rather than in our hands. We do not have access to the process of sending circulars to doctors or consultants; that is a matter for the health departments of the four Administrations.

Mr McNeil: Is the 80 per cent achievement rate a UK figure? What is the figure in Scotland?

Keith Foster: That is an overall figure. I would have to calculate the Scottish figure. I will give some statistics that I prepared before I came here. Your paperwork talks about 581—

Mr McNeil: I have seen that somewhere.

Keith Foster: I am talking about the Smoking, Health and Social Care (Scotland) Bill and the related documentation, which says that Scotland has 581 hepatitis C sufferers. I do not know where you took that figure from, but at our last count, we had received 461 applications.

16:45

The Convener: That is not our figure; it is the Scottish Executive's. Any discrepancy is between the Executive and you.

Keith Foster: I was just making a comparison. The documentation talks about 580 people and 460 payments have been made.

Mr McNeil: There have been 460 claims.

Keith Foster: Yes. We have gone through those who knew about the scheme fairly quickly. The fund's concern, which Mr Stevens just touched on and Frank Maguire talked about, is about reaching people who were affected many years ago and do not necessarily know about the scheme, although it is hep C awareness year. The Skipton Fund has asked the Department of Health how it will promote the scheme to the wider public. We would like the devolved Assemblies to think about that, too.

It is vital not to miss people. The Haemophilia Society and the haemophilia world are close and have good contacts, but one of my big worries as an administrator is that people who were affected many years ago and are probably becoming elderly may not know about the scheme, so we need people to be advised of it by their GPs and others.

Mr McNeil: That information about the figures was useful. Will you provide us with figures for Scotland and the achievement rate here?

Keith Foster: Yes. That is no problem.

Mr McNeil: You said that the other figures were unrealistic, because you have received 460

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claims. In your experience, are cases under-reported? What figures would you expect?

Keith Foster: As I said, we have processed claims from people who are aware of the scheme. We must try to quantify who else out there should benefit from the scheme. We are beginning to see many claimants who are different from those who claimed at the start. Many now are elderly and have heard of the scheme only through word of mouth. Their infection dates are much earlier than the peak times of the 1970s and 80s. That is why those people's claims are appearing more slowly.

Mr McNeil: Have you no feel for the additional number?

Keith Foster: Mr Stevens said that when the fund started, the top figure that was talked about was 8,000 for the UK. That is probably too high. If we can have not so much a relaunch but the right emphasis in the medical world, the global figure might reach about 6,000 to 6,500.

Mr McNeil: That leads me to another line of questioning that I might as well run with. Have you allocated some of your budget to targeting those people and raising awareness? How will you fund that process?

Keith Foster: Unfortunately, our hands are tied. We have no budget for marketing, if that is the right word. We must approach the Department of Health for what we need. We are involved in the hepatitis C awareness programme, which is widely available through the internet. Only a week or so ago, we talked to the department about raising our profile again in the press, so that people more widely are aware of what we are doing.

Mr McNeil: I have a question about clinicians and medical evidence that I was going to skip but will not. How long does an average Scottish claim take?

Keith Foster: The question, "How long is a piece of string?" comes to mind. The whole process can take seven to 14 days, or it can take many months if the clinician spins it out. With regard to what was said earlier, it is true that applications come back much more quickly from certain pockets. Much depends on an individual's viewpoint on filling in the forms. As was highlighted earlier, there have been cases in which the Parliament had to step in to say to consultants, "This is part of your doctor-patient relationship. The forms need to be completed."

Mr McNeil: The earlier evidence about certain areas can be substantiated. Can you provide us with some of your information?

Keith Foster: No, I would not wish to do that.

Mr McNeil: Why not?

Col 1699

Keith Foster: That would isolate people who do not need to be isolated, because the problem has been solved.

Mr McNeil: So there are no current problems. The issue has been resolved.

Keith Foster: As far as I am aware, we have no outstanding applications from Scotland that are causing us problems.

Peter Stevens: We use the same form for people with haemophilia and people without haemophilia. Consultants who have to complete the application form on behalf of somebody with haemophilia—who will be somebody about whom they are well informed; they will know him or her quite well—say that it takes two or three minutes. However, it will take some time to complete the form for somebody without haemophilia who is rarely seen, whose hepatitis C is not active and who was infected through some form of hospital process perhaps 30 years ago. The issue is not the form itself, but digging out the paperwork and finding the records that will demonstrate the source, date and route of infection. The form itself is simple.

Mr McNeil: But there is a problem with people in some areas not prioritising the completion of the form. Is the fee a problem? It was suggested that because consultants are not given an appropriate fee, or if there is a dispute, the form is at the bottom of their list. A clinician can obstruct the whole process, which can prevent people who need the money from quickly receiving payouts. Where are those people?

Keith Foster: We know of a few, but they are not all in Scotland. There have been some in Scotland—

Mr McNeil: But not now.

Keith Foster: Not that I am aware of. There have been problems, but as far as I am aware they have been resolved. I do not know whether you have information that I do not have.

Mr McNeil: We may be able to give it to you.

Keith Foster: We always have a number of forms that are out being filled in and of course I do not know where all those forms are, but our overall impression is that there is no huge problem. There have been isolated pockets, not only in Scotland, where consultants have said, "I've got too many to do," which is a problem. There may be a problem with GPs completing forms if they are not happy to do so. That may be another area about which we are not entirely aware.

The Convener: You heard the end of Mr Maguire's evidence. Can I confirm from what you are saying that the decision on the 1991 cut-off was not taken by you?

Col 1700

Keith Foster: Correct.

The Convener: Can I also confirm that the decision to confine a person's right to make a claim to their residency in Scotland at the time of filling in the form was not taken by you?

Keith Foster: Correct.

The Convener: Mr Maguire also raised questions in respect of the appeal procedure. Was it set up by—

Keith Foster: The appeals process is still being set up by the Department of Health.

The Convener: Right. So it is outwith your bailiwick.

Keith Foster: We will administer it once it is in place.

The Convener: But you do not make decisions about it.

Keith Foster: No.

The Convener: I am trying to address the points that were raised. I am beginning to get a clear understanding of your role. Effectively, all policy decisions are made elsewhere. You simply administer them.

Keith Foster: We do what we are told.

Mike Rumbles: When do you envisage the appeals process being in operation?

Keith Foster: We would like it to be in operation as soon as possible but, unfortunately, we are in the hands of other people.

Mike Rumbles: Have you been given any indication?

Keith Foster: No.

Peter Stevens: I understand that there was a meeting yesterday between officials from the Scottish Executive Health Department and the Department of Health at which reference was made to the appeals process. I am told that the meeting was useful, but I have not yet received a report on it—I will get that tomorrow.

The Convener: Helen Eadie has a question. Is it one that these witnesses can answer?

Helen Eadie: My question is on a point that was raised by Frank Maguire. I do not know whether these witnesses can answer it. Can the Skipton Trust be judicially reviewed?

Peter Stevens: Presumably.

The Convener: But that has not happened.

Shona Robison: I have a point of information. In a letter to me dated 21 December, Andy Kerr, the Minister for Health and Community Care, stated that the employment of the appeals panel

Col 1701

would be done through the public appointments process and would take a few months to complete. We may want to tie him down on that.

I have a more direct question on an issue that I pursued earlier, although I do not know whether the witnesses will be able to answer it. As a manager and an administrator of the system, they are indicating that there may be money left in the system after everybody is paid. I am interested in that on behalf of those who are excluded from the scheme because their relatives did not die before 29 August 2003. As things stand, will there be enough money left in the system to widen the eligibility criteria to include those people?

Peter Stevens: If my view is right that we are heading towards—as Keith Foster said—6,000 to 6,500 eligible claimants rather than 8,000, the fact that the departments have put aside money based on 8,000 claimants would suggest that there will be unspent funds at some time. However, I do not know when it might be decided that progression from stage 1 to stage 2 has gone as expected and will not require a greater proportion of the budget than was originally estimated.

That will be up to the health departments.

Col 1702

The Convener: There are no further questions. The session has been helpful, although there have been many questions that you cannot answer. The fact that you are not in a position to answer them is in itself helpful to us. I am sorry that you had such a hard time getting here today.

Peter Stevens: It has been a pleasure.

The Convener: It must seem like an awful long journey for such a short time. Nevertheless, your attendance has been valuable and I thank you very much.

I ask for the room to be cleared as we move back into private session.

16:58

Meeting continued in private until 17:10.

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