HEALTH AND COMMUNITY CARE COMMITTEE

Wednesday 23 May 2001
(*Morning*)

Session 1

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HEALTH AND COMMUNITY CARE COMMITTEE
16th Meeting 2001, Session 1

CONVENER

*Mrs Margaret Smith (Edinburgh West) (LD)

DEPUTY CONVENER

*Margaret Jamieson (Kilmarnock and Loudoun) (Lab)

COMMITTEE MEMBERS

Dorothy-Grace Elder (Glasgow) (SNP)
*Janis Hughes (Glasgow Rutherglen) (Lab)
*Mr John McAllion (Dundee East) (Lab)
*Shona Robison (North-East Scotland) (SNP)
*Mary Scanlon (Highlands and Islands) (Con)
*Dr Richard Simpson (Ochil) (Lab)
*Nicola Sturgeon (Glasgow) (SNP)

*attended

WITNESSES

Susan Deacon (Minister for Health and Community Care)
Dr Aileen Keel (Deputy Chief Medical Officer)

CLERK TO THE COMMITTEE

Jennifer Smart

SENIOR ASSISTANT CLERKS

Irene Fleming
Peter McGrath

ASSISTANT CLERK

Joanna Hardy

LOCATION

Committee Room 2

Scottish Parliament

Health and Community Care Committee

Wednesday 23 May 2001

(*Morning*)

[THE CONVENER *opened the meeting at 09:32*]

The Convener (Mrs Margaret Smith): Good morning and welcome to the Health and Community Care Committee. Everybody must be thinking that this is just where they want to be on such a lovely, sunny morning. No doubt we could all be in lots of other places, but the meeting ahead of us is important. I welcome the Minister for Health and Community Care.

Under agenda item 1, we must decide whether we are happy to take item 4—consideration of our draft report and conclusions on the budget—in private. The committee's normal policy is to consider draft reports in private. Are we agreed to take the item in private?

Members *indicated agreement*.

Subordinate Legislation

The Convener: Agenda item 2 is the Gelatine (Intra-Community Trade) (Scotland) Regulations 2001 (SSI 2001/169). The instrument was circulated to members on 4 May 2001 and no comments have been received. The Subordinate Legislation Committee states that the points that it raised with the Food Standards Agency Scotland have been answered satisfactorily, so that committee is now happy with the regulations. No motion to annul has been lodged, so the recommendation is that the committee make no recommendation on the instrument. Is that agreed?

Members *indicated agreement*.

Haemophilia and Hepatitis C

The Convener: Agenda item 3, on haemophilia and hepatitis C, is the substantive part of our public business this morning. Committee members and others will recall that we have received two petitions on the subject. The first of those petitions, from the Haemophilia Society, concerned the need for a public inquiry into blood products and the fact that a number of haemophiliacs contracted hepatitis C from contaminated blood products. The second petition, from Mr Thomas McKissock, took a more general approach and concerned a number of people who contracted hepatitis C through a number of other national health service treatments.

The committee has taken evidence on the subject over a prolonged period. After we received the petitions, the Minister for Health and Community Care's department conducted an internal inquiry, which examined some of the issues. Further to that internal inquiry, we returned to the issue and have heard evidence from the Scottish National Blood Transfusion Service and the Haemophilia Society. As a result of that, we have asked the minister to give evidence again.

In the past few weeks, we have had a short debate in Parliament on hepatitis C. There has been much cross-party co-operation and concern in relation to the issue and a motion in the name of one member attracted much interest over a prolonged period. During the past year or so, the issue has attracted, quite rightly, a great deal of parliamentary and public interest.

Does the minister wish to begin with a statement or are you happy for us to go straight to questions?

The Minister for Health and Community Care (Susan Deacon): I am happy to go directly to questions. Perhaps it would be useful if I mentioned that with me are Doctor Aileen Keel, the deputy chief medical officer, and Christine Dora from the health department, who was one of the lead officials involved in compiling the report on hepatitis C and heat treatment, to which the convener referred. Any of us would be pleased to answer questions from the committee.

The Convener: Okay—I will kick off the questioning. The internal inquiry was set up, basically, to consider two key issues, the first of which was whether the Scottish National Blood Transfusion Service, or the health service in general, had been negligent in the process of giving people with haemophilia blood products that subsequently proved to be contaminated. Secondly, the inquiry was concerned with human interaction—how information was given to patients and the impact that that had on patients. It would be fair to say that, on the second point, the Haemophilia Society felt that your report had been "thin" and "incomplete". Philip Dolan, in his evidence to the committee, said:

> "The Scottish Executive's report wrote off the Haemophilia Society and the people who gave submissions in one paragraph. It dismissed us. The Executive did not invite us to give information."

Mr Dolan and others are concerned not only about the on-going issue of negligence or wider issues such as the possibility of screening, but about the manner in which clinicians dealt with patients and issued information to allow those patients to be part of a risk assessment of their treatment.

I refer the minister to a couple of telling quotations. One is from Philip Dolan, again, who said:

> "my case paper from 1979 tells me that I had non-A, non-B hepatitis then. It was not until the 1990s that somebody got round to telling me that I had been tested for that and that it was known that I had been infected."

Ken Peacock, who is also from the Haemophilia Society, said:

> "Like Phil Dolan, I was eventually told that I had hepatitis C in 1992. I was not told that I was going to be tested for it; I was told that I had it. I have severe haemophilia, but I can tell you something: when someone tells you that you have something like hepatitis C, your whole life changes.
>
> Even to this day, there are no warnings in treatment rooms. There are warnings on the packets, but I ask anyone on this committee: if you get a packet of pills from the doctor, how often do you read the wee bit of paper … People do not do that: the doctor prescribes the medication for people, and they take it."—[*Official Report, Health and Community Care Committee*, 14 March 2001; c 1631-1632, 1643.]

The health department report emphasised that warnings were given on the little piece of paper, but the witnesses said that some people do not take the tablets themselves—they receive treatment in hospitals. Again and again, the point came through in evidence that there was a risk involved in taking the blood products and a risk in not taking them. Clearly, some patients were not party to any discussion about the risks that they were taking and, as a result, those risks were imposed on them. Many people contend that that wider issue was not dealt with in the health department's internal report.

Will you comment on that? In addition, do you believe that changes have been made to the way in which clinicians deal with difficult subjects of that type?

Susan Deacon: You have raised a number of points, which I will work through.

First, I will go back to my first involvement with hepatitis C and haemophilia, which predates the

point that you mentioned. Because of my concerns about many of the questions and points that had been raised by a range of people—not least the Haemophilia Society—I decided, weeks into my period as minister, to investigate the matter.

Like the committee, I have read the evidence from the Haemophilia Society. I also met representatives of the society some time ago so that I could hear directly about the consequences for people who have been affected. There is unanimity among us all about the need to listen to and take forward the concerns that have been raised. That is why I proceeded with the inquiry that we discussed previously and which the convener mentioned today. The convener paraphrased the inquiry's remit, but it is worth putting that remit on record. As the convener said, it had two specific purposes. The first was:

"to examine evidence about the introduction of heat treatment in Scotland for Factor VIII in the mid 1980s, to assess whether patients in Scotland with haemophilia were exposed to the risks of the hepatitis C virus longer than they should have been, given the state of knowledge at the time".

The second was:

"to examine evidence about the information given to patients with haemophilia in the 1980s about the risks of contracting the hepatitis C virus from blood products."

I want to touch on the findings in relation to those two aspects of the remit. A thorough examination of the evidence was conducted. We sought to set out fully in the report the chronology of events. I am unaware of any substantive points of dispute that have been raised by anyone about the evidence that we set out. It is testament to our desire to be open on the matter that not only the report but a range of evidence and submissions that go with it have been published.

I am bound to refute the suggestion that haemophiliacs were not given an opportunity to take part. Nothing could be further from the truth. We were proactive in giving people the opportunity to make submissions and a range of individual haemophiliacs did so. Some specifically asked that those submissions should not be published—we respected that. The Haemophilia Society submitted views. I read the report carefully when I received it to ensure that the views of all concerned had been taken into account when it was compiled. If members of the committee take issue with specific points with regard to that, I would be happy to address their concerns. However, I am unaware of people having taken issue with the facts as they were set out.

The second issue that the convener raised was information. That is important, which is why it was a substantive aspect of the remit of the report. After extensive investigation and examination, the report concluded that there was no evidence of any policy by haemophilia centre directors deliberately to mislead patients in any way about the risks of hepatitis or to withhold information. I have said before to the committee and in chamber debates that I feel strongly that we must work continually to increase information and to improve the way in which it is made available to patients. The convener rightly pointed to information on medicines and so on. Over the years, standards and guidance have been raised and the regulatory framework in which we operate has changed; I am sure that that will continue to be the case. In saying that we found no evidence of any deliberate attempt to withhold information, I stress that that does not mean that there have not been improvements since nor that we should not continue to make improvements in future.

09:45

The Convener: We all know of cases where clinicians withhold information for what they consider to be good reasons, albeit that they may be misguided in doing so. Despite what you say, the evidence we have received from individuals and representatives of the Haemophilia Society is that, although there may not have been a systematic approach to withholding information, individuals not only were being tested without their knowledge but were being unknowingly infected. They were therefore at a small risk of infecting others. Do you feel that your report adequately covered the fact that, in certain cases, that happened?

The big question is about negligence. Although the vast majority of members of the committee have gone on record elsewhere to say that, to a large extent, the negligence issue has been answered by your report, there is I presume, negligence in failing to warn somebody about the effect of treatment. If decisions are taken without that warning being given, is not that a different form of negligence?

Susan Deacon: You asked whether the report that I commissioned addressed adequately the facts. In so far as I am able to reach a judgment about what is, by definition, historical information, I believe that the report does cover that area. It is worth reminding ourselves that we are dealing with events that took place, in some cases, more than 15 to 20 years ago. While considerable effort was made to examine, record and identify events during that period, it is extremely difficult for any of us to go further than the report went in recording the sort of information that was shared.

We discussed that when I attended the committee previously. Throughout the period in question, knowledge was developing and evolving. As far as I can see from the report, efforts were made to share knowledge of risk with patients.

However, while there was growing awareness that there was a risk—that was outlined in the report and discussed by the committee—exactly what that risk was was not known until later.

The convener also raised testing, which was not introduced until 1991. It is important to report that the general policy of current haemophilia centre directors is to inform patients who have been treated previously with blood products that they will be tested for hepatitis viruses and that the results will be discussed with them at their next review appointment, as is the case with all test results.

Margaret Jamieson (Kilmarnock and Loudoun) (Lab): You gave us information about hepatitis sufferers who are also haemophiliacs. There was another petition from Mr McKissock, who lives in Cumnock in the constituency of my colleague Cathy Jamieson. Sufferers such as Mr McKissock were not considered in your report because it is specific to haemophiliacs who have contracted hepatitis C. Will you explain why your report is so specific?

Susan Deacon: Margaret Jamieson has raised an important point. The report examined a specific issue, which I took seriously when it was first raised: the Scottish National Blood Transfusion Service should have done more than it did during the 1980s to reduce the risks to haemophiliacs being treated with blood products. The remit is specific on that point. I gave a clear commitment to examine the specific allegation that was made and that is what the report did.

That does not negate wider issues, not only for other haemophiliacs but, as Margaret Jamieson rightly said, for those who have been affected by blood transfusions and other medical treatment. That matter was recognised by several members in a parliamentary debate a few weeks ago. Mary Scanlon referred to it on several occasions. It is important to separate the two issues. The report is a thorough investigation of a specific allegation, but I am sure that this morning we shall touch on the much wider issues regarding others who have been affected adversely by medical treatment.

Margaret Jamieson: Mr McKissock is suffering greatly. I do not know the prognosis, but I know from Cathy Jamieson that he is in poor health. Obviously, his case is not alone. Will you consider such cases separately in an annexe to your report on haemophiliacs who have contracted hepatitis C? People need to know.

Susan Deacon: Cathy Jamieson has been active in bringing attention to Mr McKissock's case and I am aware of it. I wish to raise two strands in that regard. Successive Governments in the United Kingdom have generally held to the view that compensation is not offered in cases of non-negligent harm. Individuals have suffered adverse effects through medical treatment for various reasons. Any change to the position on compensation in general would have to be considered carefully and fully. We touched on that in a parliamentary debate a few weeks ago. If there are specific circumstances relating to Mr McKissock's case that ought to have been addressed more fully, I will consider them. However, I am not sure what could be added to a historical examination of the case—as distinct from the question of any future action.

Margaret Jamieson: You will recall that the committee asked for your report to cover haemophiliacs and non-haemophiliacs who had contracted hepatitis C. We have yet to receive any response explaining why you decided to consider only haemophiliacs.

Susan Deacon: The Executive officials may be able to comment further on the matter. However, with respect, the report did not confine itself to haemophiliacs. It examined the development of events and the treatment of blood and blood products during a specific period. That examination is relevant to anyone who received blood or blood products during that period.

Margaret Jamieson: But your report is on "Hepatitis C and the heat treatment of blood products for haemophiliacs in the mid-1980s", in relation to hepatitis C and the activated factor VIII product. It is clear that your report focuses only on haemophiliacs.

Susan Deacon: Perhaps Dr Keel can comment.

Dr Aileen Keel (Deputy Chief Medical Officer): The remit for the work was proposed by the Haemophilia Society, which was keen to explore whether any negligence was attributable to the SNBTS or any other part of the health service in trying to produce a hepatitis C-safe product in Scotland, and whether negligence had led to Scotland being slightly behind England in achieving that. The report concluded that that was not the case and that there were justifiable reasons why it took Scotland longer to get to the same point as England. In fact, Scotland overtook England, as a hepatitis C-safe product became available for all haemophiliacs in Scotland, which has never been the case down south.

The report's remit was governed by the Haemophilia Society's wishes. The society wanted an investigation into the possibility of negligence, and that is what the minister set her officials to carry out. The second strand of the Haemophilia Society's concern related to the provision of information, which the minister has already addressed.

Margaret Jamieson: So, you considered the issue because an organisation raised it, but the

views of individuals who raised the issue with the Parliament were not considered.

Susan Deacon: It is important to remember that a number of people who have been adversely affected through blood transfusions and the use of blood products fall outwith the specific scope of the report because the report examined in considerable detail the specific allegation that the SNBTS could and should have done more over a certain period with regard to the use of factor VIII. In no sense does that negate discussion of people in other circumstances who were affected; indeed, concern was expressed during the parliamentary debate that many different circumstances and cases were becoming muddled in the course of the debate. In contrast, the report is very clear about the cases and circumstances that it deals with. I stress again that I am not suggesting that the cases of other people who were affected, during other periods and through other treatments—the report was specifically on blood products and not blood transfusions—should not be included in the wider debate on whether compensation should be offered in cases of non-negligent harm.

10:00

Margaret Jamieson: Those who have contracted hepatitis C who are non-haemophiliacs feel that they have been forgotten in your report, although they believe that they have as just a cause to be addressed by the department as others have. The terminology that is used in the report suggests that they do not warrant a mention. That concern must be addressed. We must speak for everyone who is suffering from hepatitis C.

Nicola Sturgeon (Glasgow) (SNP): Let us return to the main question. The closer I come to this debate, the more strongly I feel that it should move beyond the issue of negligence and on to the question whether justice dictates that the people who have been affected by contaminated blood or blood products should receive some form of no-fault compensation or financial assistance.

This morning, you have reiterated the report's findings that there was no negligence and that there is no evidence that any haemophilia centre directors deliberately misled people. I am happy to accept that, but you also conceded that patients were not as well informed about the risks as they should have been at the time or as well informed as they might be today, following changes in practices. Does that add weight to the case for financial assistance? I hear what you are saying about things being different now—maybe they are. However, that gives no comfort to people who were infected in the 1980s. Their lives have been badly affected by what happened to them, which adds weight to the suggestion that they should be considered for some form of financial assistance.

I agree with you on the general principle that there should be no compensation for non-negligent harm. That is an important principle for a variety of reasons. Nevertheless, that principle has been departed from in certain well-defined situations in the past—notably in the case of HIV sufferers. Most people struggle to get their head round the difference in circumstances between somebody who was infected with HIV through contaminated blood and somebody who was infected with hepatitis C through contaminated blood. I would like your further comments on that. Why should those people not be considered for financial assistance?

Susan Deacon: I welcome the fact that Nicola Sturgeon has highlighted and recognised the distinction between the report that we have been discussing and cases that fall under the wider issue. It is important to keep making that distinction. People who fall outwith the scope of the report are by no means forgotten.

We live in a society in which improvements and advancements take place all the time, not least in medicine and clinical practice. We should not conduct a post hoc analysis of the events of 20 years ago and say that people could or should have acted differently, as they were acting within the knowledge and established practice that existed at that time. A false connection is being made in some of the points that Nicola Sturgeon is putting forward.

With regard to other cases in which financial compensation was offered following non-negligent harm, the MacFarlane Trust for HIV sufferers is the example of an exception that was made—

Nicola Sturgeon: Totally relevant.

Susan Deacon: It is, of course, relevant. It is important to stress that it is the only exception. It was made in a particular period by a previous Administration. Obviously, I cannot answer for that judgment. There has been much speculation and much discussion and analysis of why that judgment was reached. At the time that HIV/AIDS came to public notice, there were enormous and different reactions. A relatively small number of people were affected. As Nicola Sturgeon said in Parliament a couple of weeks ago, HIV infection was virtually a death sentence. Although I stress that I have no truck with this analysis, the prevailing view was that some people were the innocent victims of HIV infection, who had been infected not because of their lifestyle, but because they had received a blood transfusion. The decisions taken at that time were heavily value-laden and affected a much smaller number of people.

It is interesting that the same Administration did not extend that analysis or judgment beyond that specific group. The responsibility of any health minister in any Government or Parliament in discussing this issue is to consider all the ramifications of any change. We would have to be clear about why the change was being made and why the particular judgment had been reached. We would need to be clear about how any line would be drawn.

I refer back to the parliamentary debate a few weeks ago. If—on the basis of a political judgment rather than on the basis of specific legal challenges or of cases before the courts—a decision were made to offer compensation, where should the line be drawn? I am not sure that any of us know the answer to that question.

Nicola Sturgeon: I do not dispute any of that analysis of why the original decision was taken. However, the minister has hit the nail on the head. The question is: where should the line be drawn? I cannot understand the justification for drawing the line between HIV and hepatitis C. One person may have contracted HIV through contaminated blood and their life may have been absolutely devastated; that person now has access to financial assistance. Someone else—possibly on the same day, in the same hospital, and from the same batch of blood—may have contracted hepatitis C instead of HIV. That person's life has been devastated as well, perhaps just as much as that of the person with HIV, but that person is denied financial assistance. Whatever the reasons for it, that is a glaring iniquity. Does the minister not agree that that is indefensible?

Susan Deacon: I would be interested to hear from Nicola Sturgeon or other committee members where they would draw the line, and—

Nicola Sturgeon: What other cases are being pursued—

The Convener: Let us hear what the minister has to say.

Nicola Sturgeon: Well, people—

The Convener: No—let us hear what the minister has to say.

Susan Deacon: Are we talking about haemophiliacs? Margaret Jamieson has rightly pointed out that people who are not haemophiliacs have contracted infections through infected blood or blood products. Are we talking just about people who have been infected by blood and blood products? Or—following a point that Mary Scanlon raised in the debate—are we talking about people who have been infected through, for example, surgery? Are we talking just about people who have been infected by hepatitis C when that infection was not known about or understood? Or are we talking about the period when knowledge was emerging but treatment was not in place? Or are we talking, much more widely, about the many individuals who, sadly, are affected by medicines or medical treatments and have an adverse reaction as a consequence?

Nicola Sturgeon: Let us have that debate.

The Convener: Minister, when the committee first asked you, some months ago, to extend your original report, it was because we wanted to have that general debate.

I want to move on to a couple of—

Nicola Sturgeon: Can I just ask, very briefly—

The Convener: No, I want to move on to Janis Hughes and Mary Scanlon, who have questions related to compensation. I think that those questions will elicit the answers that we want from the minister.

Nicola Sturgeon: I doubt it.

Mary Scanlon (Highlands and Islands) (Con): I wanted to follow up on Margaret Jamieson's point. We often hear about the 317 people with haemophilia who have contracted hepatitis C through blood transfusions. How many people have contracted hepatitis C through routine blood transfusions or routine surgery, as Thomas McKissock did? Whatever the final outcome of the inquiry, will it apply equally to the Thomas McKissocks of this world? If not, could there not be a challenge based on the European convention on human rights? There would be discrimination between two groups equally affected by hepatitis C.

Susan Deacon: Mary Scanlon spoke about the outcome of an inquiry, but I am not entirely sure which inquiry she means. The report that we have discussed this morning has been completed. Were you talking about the committee's inquiry?

Mary Scanlon: Yes.

Susan Deacon: The Scottish Executive has made clear its general policy on this matter on a number of occasions. There are—as at any time—a range of individuals in a range of different circumstances whose cases are at various stages of consideration in the Scottish courts. It would not be for me to comment or speculate on any cases that are a matter for the courts.

One thing that has not been touched on this morning is that the Executive has made it clear that we will consider, carefully and constructively, the English court judgment from March, to see what the implications might be for any cases pending in Scotland. However, I stress—and I think that the committee will agree—that it is important not to prejudice the outcomes of any of those cases.

Mary Scanlon: I just wanted an idea of the scale of the problem. How many people are in Thomas McKissock's category?

Susan Deacon: I am looking to see whether my officials can give more precise figures than I can. We cannot know the answer for sure. One reason why it is possible to have a clearer picture of the number of haemophiliacs who are affected is that they are in regular touch with haemophilia centres, so the data for them are better. It is harder to know how many other people have been affected. Clearly, if they have actively raised their case, or taken legal action, we would know. I find it difficult to give you a precise answer.

Mary Scanlon: The parliamentary debate on 26 April resulted in acceptance of the Executive's amendment. The amended motion stated:

"That the Parliament notes the Report produced by the Executive in October 2000 on Hepatitis C and Heat Treatment of Blood Products for Haemophiliacs in the mid 1980s"

and

"further notes the continuing deliberations of the Health and Community Care Committee on this issue and the recent ruling of the English High Court in the case of a number of NHS patients who have been infected with hepatitis C through blood transfusions".

Is that a tacit indication that the Executive agrees—albeit in a judicial context—with the notion of compensation for those infected with hep C by blood transfusion? To what end did the Executive want the Parliament to note the report and the court judgment, if taken together they do not make the case for compensation? I am shocked by the figures for compensation, which range from £10,800 to more than £210,000.

10:15

The Convener: Those are the amounts that were awarded in the English High Court judgment, for a range of reasons.

Mary Scanlon: Yes.

Susan Deacon: Mary Scanlon is right to say that the Executive amendment to which she referred asked Parliament to note both the report on "Hepatitis C and Heat Treatment of Blood Products for Haemophiliacs in the mid 1980s" and the English High Court judgment. We asked the Parliament to note the report because we thought that it was right and appropriate to note the fact that an investigation into this issue had been carried out and a report published. We asked the Parliament to note the English High Court judgment in recognition of the fact that it may have implications for cases here in Scotland. Ever since the English judgment was made, we have made clear that we will consider fully, carefully and constructively its implications for Scotland.

The English judgment applied to a group of 114 people in very specific circumstances. They were considered fully in Mr Justice Burton's judgment, which is publicly available. I am sure that committee members have examined it. It would be inappropriate for me to comment further on specific cases, whether those affected by the English judgment or cases here, but I reiterate the commitment that Malcolm Chisholm gave in the parliamentary debate: the Executive is considering the English High Court judgment fully and carefully.

Mary Scanlon: If the Executive does not provide compensation in line with the English judgment, can we not expect similar court judgments to be made in Scotland? Are you taking that into account? Are you prepared for it?

Susan Deacon: It is self evident that no judgment made by an English court is binding in Scotland. However, a judgment made in an English court can be referred to by a Scottish court. For that reason it is right and proper for ministers to consider closely the implications that the English court judgment may have for Scotland. We will continue to do that. I am not sure that I have anything to add on that point.

Mary Scanlon: When will you conclude your consideration of the English judgment, which will clearly have an impact on Scotland? When can we expect a statement from you on that?

Susan Deacon: I repeat that we are actively considering this issue. We are taking advice from a range of sources and considering the various cases that are pending in Scotland, each of which is different. Today we have touched on some of the reasons for that; they are to do with cause and timing of infection. It is not always certain how a person was infected. It is important that we do not generalise in this area.

We have discussed the wider issue of compensation. It is important to note that, just as the Department of Health in England has said that it wants time to consider the wider implications of the judgment for the national health service, the Scottish Executive wants to take time to do that too.

Janis Hughes (Glasgow Rutherglen) (Lab): I agree with Nicola Sturgeon's point about moving away from negligence and towards no-fault compensation. You mentioned the fact that compensation is available through the Macfarlane Trust for those infected with HIV. I understand that a similar situation obtains with regard to CJD. If that is not the case, perhaps you could explain the situation. Given the fact that the judge in the English case ruled that liability is defect based and not fault based, would not offering compensation for non-negligent injury be more cost-effective

than the sort of litigation that took place in England? Do you agree that, being less expensive, that would be less likely to lead to the defensive medicine that was mentioned in the debate in the Parliament?

I understand that a Welsh ruling on vibration white finger had an effect on the situation for people claiming compensation for that ailment in Scotland. Perhaps you could comment on that, too.

Susan Deacon: I am not able to comment on the Welsh ruling on vibration white finger, but I wonder whether it involved compensation relating to NHS treatment rather than to people developing the condition for other reasons.

Janis Hughes: I mentioned it in the context of your comment about English rulings having no effect on what is decided in Scotland. Precedents are set elsewhere, particularly on health issues, that can have a bearing on the outcome of similar cases in Scots law.

Susan Deacon: Let me be clear about what I did and did not say. I did not use the phrase "no effect." What I said was that any decision taken in an English court—or any court outwith the Scottish legal system for that matter—is clearly not binding on a Scottish court. That is a statement of fact. I also said that it is open to a Scottish court to have regard to decisions made in courts elsewhere. Indeed, politicians can examine and consider judgments that have been made elsewhere to see what we consider the implications to be, either in policy terms or in strict legal terms. That is exactly what we are doing.

You asked me about variant CJD. I do not think that the approach that has been adopted to variant CJD is particularly relevant in this case, and I shall explain why. It is absolutely correct to say that, in recent months, subsequent to the publication of the Phillips report on the BSE inquiry, the UK Government and the Scottish Executive have worked in tandem on developing arrangements for compensation for victims and families who have been affected by variant CJD.

The important difference is that there is no suggestion that people who have been affected by variant CJD, however that has come about—and there is still some debate about that, even since the publication of the 16 volumes of the Phillips report—were affected because of problems with medical treatment. The causes of variant CJD are very different from the causes of hepatitis C infection in people who have been affected by treatment in the NHS. It is not a question of people being compensated for something that has happened because of something the NHS has done. That is an important difference.

I explicitly acknowledged earlier and in previous evidence to the committee that the debate on the wider issue that Janis Hughes has raised, which relates to no-fault compensation, is real and has gone on in health care systems and the medical profession for many years. I made clear the view that the Executive and successive UK Governments have taken. I note that few no-fault compensation schemes are in place in health care systems around the world and that such schemes attract considerable criticism where they exist. However, I do not deny that they are a legitimate matter for debate. In debating them, we must be fully cognisant of the consequences for clinical practice and patient care of such a major change.

Janis Hughes: I hear what you say about the difference between the situation for hepatitis C and that for CJD particularly, but in the late '80s CJD was transmitted to patients who were treated with growth hormone derived from pituitary glands. That situation involved people contracting CJD through treatment in the health service rather than through other means. Compensation is being paid to patients who contracted diseases that might have arisen from treatment in the health service. Given that we have accepted that we should aim for some form of no-fault compensation, why do you say that the door cannot be opened to patients who contracted hepatitis C?

Susan Deacon: I stress that at no stage have I said that we should move towards a no-fault compensation arrangement; I have said that we must consider each case on its merits. Such a process might include the report, which I conducted, on an issue that involved fault, but it might also include cases that might be affected by the recent English judgment which, as Janis Hughes said, moved away from fault and on to the terrain of defect.

I have not advocated moving away from the general principle, not least because if that were done enormous questions would have to be asked about how a judgment could be exercised on how widely the net would be cast. Whenever a change was made, it would raise as many, if not more, demands from others to make similar changes.

Margaret Jamieson made an important point at the beginning. I have the most enormous sympathy for the situation that haemophiliacs who have been affected are in. She is right to make the point that although not only haemophiliacs have been affected, that group has been particularly effective at raising the issues and raising awareness, so we have those people on our horizon. What about other people who are similarly affected and whom we may not have considered as much? I note again that any shift to a no-fault compensation arrangement would have an impact on patient care and clinical practice. The changes could not be made lightly.

Mr John McAllion (Dundee East) (Lab): I take the minister back to the parliamentary debate on hepatitis C in April and the Executive amendment that asked the Parliament to note the Executive's report and the English judgment and called on the Executive

"to examine constructively the implications of"

the English judgment. What did the Executive mean by "constructively"?

Susan Deacon: By "constructively" I would mean that we would conduct our examination in an open-minded way and that we would not prejudge our decision. Should we consider that the judgment has a bearing on action that we should take, we would be prepared to deal with that.

Mr McAllion: It strikes me that if the Executive amendment that day had simply called on the Executive to examine the implications of the English judgment, the Executive may have found it difficult to deliver the votes for that amendment, because members were looking for a positive response from the Executive to the English judgment. The word "constructively" allowed members to interpret the Executive amendment in that way. Do you believe that that was a factor?

10:30

Susan Deacon: I can answer only for what the Executive is doing in this area, which is what I have sought to do this morning. We all have an obligation to ensure that, in our political debates, we do not lose sight of the complex human, technical and legal issues that we are dealing with. We could never have done full justice to the issue in an hour-long debate in the chamber. I have given a commitment to take the time and effort to examine fully and constructively this complex issue. Mr Justice Burton's judgment goes to hundreds of pages, so it is right and proper that we examine it carefully and constructively. I cannot speculate on the interpretation that others might put on the commitments that we have made.

Mr McAllion: No, but on behalf of the Executive you are not ruling out a positive response to the petition to examine the case for compensation that we are considering, in light of the English judgment. That is not ruled out, and I take it that neither is it ruled in.

Susan Deacon: I hope that I have made clear this morning the many different issues and circumstances that arise and how different different cases are. Throughout, I have sought to make a constructive and I hope appropriate and proportionate response to each case on its merits as it has been brought to me. That is what I will continue to do.

Nicola Sturgeon: The point that John McAllion raised is important. The Executive amendment was welcomed across the chamber, but it was welcomed because it raised an expectation that there may be movement in the Government's position. If that turns out not to be the case and those expectations are dashed, the minister should be aware that the matter will be returned to in Parliament. The issue will not go away.

My question goes to the nub of the issue, which is, as the minister said, where we draw the line on no-fault compensation. A line is drawn at the moment. I accept that there is a debate to be had about where the line should be drawn, but to have that debate, there has first to be an acceptance that where it is drawn now might not be correct.

The position that I go back to is that at the moment the line divides people who contracted one devastating disease through contaminated blood from those who contracted another devastating disease through contaminated blood. Where the line is drawn now simply is not defensible. A concession that that may be the case would allow us to move to a constructive discussion about where the line should properly be drawn and preserve the important general principle to which the minister has repeatedly alluded. Can the minister move in that direction and allow us to have that constructive discussion?

Susan Deacon: I am disappointed that Nicola Sturgeon speaks in terms of concessions and raising expectations. I made the point firmly a moment ago that complex human, technical and legal issues are involved. It is important that we do not distort that with some of the more pejorative terminology that politicians are apt to use.

I have been explicit about and consistent in my approach on this issue: I have said that we have examined specific cases and circumstances that have been brought before us, such as the allegation that was made about SNBTS in the 1980s. I have been clear that we are examining the implications of the English judgment for cases in Scotland and that we continue to adhere to the general principle that compensation is not offered for non-negligent harm. That is a clear statement of the position and suggesting otherwise does a disservice to the sensitivities of the debate.

Nicola Sturgeon: I assure the minister that it was not my intention to use pejorative language. I am sorry to labour the point, but we are now at the heart of the issue. The general principle is not in dispute. I support it. It exists for a good reason, but it has already been moved away from in the case of those who have contracted HIV. Having moved away from that principle in well-defined circumstances, we should debate whether the line is properly drawn. I do not think that it is. It cannot be defended. It would do a service to the debate if we discussed where the line should be drawn. I

fear that the minister has an intransigent attitude today. I had hoped that we had moved beyond that in parliamentary debates.

Susan Deacon: The use of "intransigent" is pejorative. I stress that I have sought actively to take forward such issues and I give the committee a commitment that I shall continue to do so. I am pleased that Nicola Sturgeon endorsed the general principle of compensation not being offered in cases of non-negligent harm. People generally adhere to that view. That is important to note, because at the same time Nicola Sturgeon seemed to be asking me to move away from that general principle.

Nicola Sturgeon: You have already moved away from it.

Susan Deacon: I repeat that I am pleased that Nicola Sturgeon agrees with the general principle. I agree with it. One case was considered by a Conservative Administration under specific circumstances in the 1980s, before most of us in the room were involved in politics or elected public office. I have sought to speculate about the basis on which such a decision was made. One case was an exception to the principle.

The fact that the committee is considering the matter is welcome. It is a tribute to the Scottish Parliament and devolution that we have an opportunity to air such issues. No one has been prevented from having the debate. Nicola Sturgeon asked where the line is to be drawn. I should be interested to hear her answer. She is not happy with where the line is drawn at the moment, so I should be genuinely interested to know where members of the committee think it should be drawn. I have been explicit.

Nicola Sturgeon: Will the minister concede that the line is perhaps not drawn at the right place at the moment?

Susan Deacon: I have made my position clear. Any further comments on my part will not add to the discussion.

The Convener: It is up to the committee to make its position clear when the report is published.

Shona Robison (North-East Scotland) (SNP): The minister said that she is reluctant to comment on specific cases and that she does not want to prejudice the outcome of the inquiry into the English judgment. Although the judgment runs to many pages, we are all aware of the key quotations. For example, on page 4 of his judgment, Justice Burton said:

"This trial has concerned the claims of 114 Claimants for recovery of damages arising out of their infection with Hepatitis C from **blood and blood products** through blood transfusions from 1 March 1988."

Minister, do you accept in principle that the English case applies both to blood transfusion and to blood product transfusion?

Susan Deacon: Will Shona Robison repeat her last question?

Shona Robison: Do you accept in principle, from what Justice Burton said, that the English case seems to apply to both blood transfusion and blood product transfusion?

Susan Deacon: I am bound to say that it is not for me to interpret what one line in a long and complex judgment in an English court might mean for us here—that would be irresponsible of me.

Shona Robison: With due respect, I am sure that in your discussions about the implications of that English judgment, that line will be at the front of your mind and the minds of your colleagues who are discussing the matter. It is a key line in the judgment—it is there in black and white and it refers clearly to blood products. All that I am asking of you is to say whether you agree that the statement refers clearly to blood-product transfusion rather than only to blood transfusion. How else could you interpret it?

Susan Deacon: I stress that it would be irresponsible of me to take one line from a court judgment and place an interpretation on it. I am happy to repeat the assurance that I have given in Parliament, to the committee and in response to John McAllion's question, which is that we are considering fully, carefully and constructively the implications of the full judgment. That is the right thing for us to do.

Shona Robison: Will you confirm whether you have discussed that aspect of the judgment?

Susan Deacon: I repeat that we are considering the judgment and its full implications. We are doing so constructively and with an open mind.

Shona Robison: You described the contacts that you have spoken to about the judgment. Who are those contacts?

Susan Deacon: On any matter of Executive policy, ministers will always seek advice from a range of sources. I speak in general terms, but that would typically include the minister's department and officials more widely throughout the Executive. A matter such as this also has legal and financial implications. As ministers, we will seek any advice that we consider necessary to enable us to take the right decision. That would be the case with any decision that ministers were faced with.

Margaret Jamieson: Your report said:

"given the level of scientific knowledge at the time, the SNBTS could not have eliminated the risk any sooner than it did."

The wording is similar to that which is used in the Consumer Protection Act 1987. Are you aware that that act failed as a defence in the recent judgment in England? Given that the judgment and your report appear to be mutually exclusive, are you suggesting that similar litigation would fail in Scotland, or that your report is flawed?

Susan Deacon: I hope that Margaret Jamieson will appreciate that I am being consistent with my previous responses when I say that it is not appropriate at this stage for me to comment on that judgment or its implications for Scotland. I make the general point that Margaret Jamieson is right to highlight that the core of that judgment and the debate that we are having is the question of how to deal with risk in the NHS, which is a huge and sensitive issue.

Margaret Jamieson: Will the minister advise us whether, and when, an appeal will be lodged by our colleagues down south?

Susan Deacon: The Department of Health has indicated that it is not appealing against the decision—it made an announcement to that effect.

Mr McAllion: We have discussed the restricted nature of the Executive inquiry and report. One aspect that has not so far been touched on is the fact that the inquiry was internal to the Executive and was not held in public. Given that the founding principles of the Parliament are openness, accessibility and accountability, will you comment on whether there is a case for a public inquiry? Given the earlier discussion, will you tell the committee whether the remit for such an inquiry should be broader, to include non-haemophiliacs and blood transfusions as well as blood-product transfusions?

Susan Deacon: Members will be aware that, since the Scottish Executive came into being, we have been asked to look back at a number of issues—historical incidents or practices that relate to a past period—especially in my area of responsibility. Often, I face calls for full public inquiries into those and other areas. In each case, I have to judge what I believe would be the appropriate level of examination and investigation. In this instance, I judged that it would be possible for us to conduct a thorough fact-finding exercise. John McAllion rightly looks to the Executive to achieve openness. I support openness and openness was achieved by publishing the facts fully as we found them and the evidence that had been gathered as part the inquiry.

As I said, I am not aware that anybody has challenged the substantive facts or evidence in the report. This morning, several members indicated that they see no reason to demur from the report's general conclusions. I believe, therefore, that there was an appropriate level of examination. The fact that the committee and Parliament are discussing the issues is, arguably, every bit as effective in achieving high standards of openness as would be the somewhat protracted, cumbersome and legalistic mechanism of a public inquiry. That is a general view.

10:45

Mr McAllion: Others would disagree with that, and would think that there is a need for a public inquiry. Indeed, I have given evidence to the committee in support of a public inquiry. We have been told that other countries—such as Canada and the Republic of Ireland—have carried out public inquiries and awarded compensation. Will you comment on that? If a debate is needed on where the line should be drawn on compensation—as compared to HIV cases, which we discussed earlier—could that be part of a public inquiry's remit? Should the problem be addressed in that way? Impressive as the Health and Community Care Committee is, it does not have the resources to carry out the kind of public inquiry that is required.

Susan Deacon: I reiterate that the basis upon which we have examined the issues thus far has been appropriate and proportionate. Of course I am aware that others have suggested that an alternative approach should be adopted in this area, as in other areas, but I remain unconvinced that a full public inquiry of the type that has been described would necessarily be the best and most appropriate way for us to move forward.

Mr McAllion: The narrow remit that was given to the Executive inquiry was shown by the fact that it specifically mentioned hepatitis C. Hepatitis C was known to exist for a long time before it was designated as hepatitis C, as was non-A, non-B hepatitis. Evidence was simply never considered by the Executive inquiry. The matter needs to be investigated; that is surely another argument for a public inquiry. The evidence surrounding non-A, non-B hepatitis was not part of the Executive report.

Susan Deacon: I disagree with the construction that John McAllion has placed on the report, but I want to stick to the issue of process. The report thoroughly considered a specific issue in a specific period. The findings were published in an open and accessible way. I am not aware that anyone challenged the substantive findings or the presented facts. That speaks for itself.

As has been illustrated, many strands to the debate—from how individual cases are dealt with, to major policy issues about the management of risk in the NHS and in the medical profession—have wide-reaching implications for the future. There is not a single vehicle for debate that would

resolve such issues, but a multitude of different ways. I believe that there has been a higher level of openness in Scotland post-devolution than was the case pre-devolution. That applies both to the Executive and to Parliament.

Dr Richard Simpson (Ochil) (Lab): This morning's discussion has been interesting. I realise that the minister has had some difficulty holding the line on the fact that the HIV decision in the 1980s broke the principle of no-fault compensation for the health service. I do not want to pre-empt our report, but I believe that there is no negligence in respect of the heat treatment of blood and blood products, nor in respect of the alanine amino transferase testing for blood products, which is used in the production of factor VIII. However, there are questions to be asked about screening, which is why the decision was made in England and Wales about ALT screening of whole blood.

We have received an interesting document from the blood transfusion service. It quoted a leading authority, which said that at best, the introduction of ALT screening would result

"in a 30% reduction in PTH (post-transfusion hepatitis)"

and that

"donor losses would be limited to 1.5 to 3.0%."

At worst, there would have been no reduction in post-transfusion hepatitis and a donor loss of up to 15 per cent in some donor populations. That would have resulted in deaths and caused a massive problem for the entire blood transfusion system.

Does the minister agree that we must have a major discussion in Scotland about how to deal with risk management and compensation? The subscription on the primary care side for general practitioners has risen from £50 a year—as it was in the 1970s—to more than £2,000. That reflects the level of risk and compensation claims.

According to the Audit Commission report, the amount on the balance sheet for risk in the national health service in Scotland rose from £4 million in the mid-1990s, to £80 million in 1999. That shows how much the level of perceived risk of possible future compensation claims has escalated within the service. Rather than debating one case concerning haemophilia, should not we have a debate led by the minister, to discuss the whole system of risk management and no-fault compensation in the service?

I was dismayed by the fact that it took 12 years for the case of a child who was damaged badly at birth to be settled. How that family suffered. The average length of time for settlement is more than five years. Having held your inquiry, minister, would it not be better for us at this stage to reconsider the system in Scotland in the light of the escalating risk?

Susan Deacon: I certainly share the view that, in many respects, it is time to look to the future, rather than to the past. That is one of the reasons why I have never considered that it would be the best use of our time, energy and resources to spend more time inquiring into past events. Some of the bigger issues relate to future practice. How such a debate is conducted and when it should take place is not something that should be decided only by the Government. A debate on the management of risk, negligence and compensation in the health service has massive implications for patients, health professionals, and for the medical profession in particular.

Everybody who has a stake in the issues should have their voice heard about whether and how current arrangements should be changed, and about whether and how any such widespread debate should take place. Given that consistent and well-established principles have been in place since the inception of the NHS, opening up that area for debate could destabilise clinical practice. I hate to think that any of us would do anything that might lead to an increase in the degree of risk aversion within the service. People might not receive the treatment or care that they need if medical professionals are frightened of the risks that are involved, the action that might be taken and so on.

I have no difficulty in principle with saying that we need to discuss these matters further; indeed, that is precisely what we have been doing to some degree this morning. However, I should stress that many others—other than politicians—have a stake in the debate and that we should be sensitive to the fact that any debate could have a material effect on the delivery of treatment and care. Furthermore, I point out that if we open up the debate, it will be incumbent upon us to find answers, not just to raise questions. As I said to Nicola Sturgeon, it is easy to ask whether the line is in the wrong place, but I would come back with a question that no one has been brave enough to answer: if the line is not in the right place now, where will be the right place in future?

Dr Simpson: On the group that has petitioned the Parliament, the specifics are quite clear about its members' suffering as far as their daily activities and their ability to live life fully are concerned. I hope that, even if the Executive does not make a judgment on some form of compensation, it will move swiftly to provide those patients with the sort of support that they need, both in terms of counselling and in relation to specific difficulties that they have with insurance, mortgages and other matters. Through no fault of their own, those people have suffered from an adverse event in their medical treatment.

Susan Deacon: We ought to strive to provide support and assistance to the large number of people who have been affected by hepatitis C in many different circumstances. The problem is now a modern epidemic of significant proportions, and the Executive has been active. For example, a Scottish needs assessment programme report on hepatitis C has been published, and work has been undertaken nationally and locally to improve what is being done on the problem. Furthermore, our HIV health promotion strategy, which was published last year, was backed by £7 million of additional investment to examine any other measures that might prevent the transmission of blood-borne infections in health care, and among drug users and other groups. I hope that such practical steps show that the Executive has remained active.

The Convener: Will you answer Richard Simpson's specific point about some of the financial implications of the disease, which might affect the insurance industry, the mortgage industry and so on? Such issues might not be the easiest for you to deal with, because they relate to reserved matters. Let us put to one side the issue of financial compensation, and instead consider the financial implications for the people who must live with the disease. As minister, can you apply any pressure on the insurance and mortgage businesses to introduce an element of fairness in relation to the point that Richard Simpson raised?

Susan Deacon: You are right, convener, that as a minister in the devolved Scottish Executive, I have no powers to act in relation to regulation of the insurance industry or of the financial services sector, for example. It is worth noting—although it is always dangerous to speak for one's opposite number—that this is an area in which Alan Milburn has recently made a number of public statements, in particular on genetic testing, in which he made it clear that he and the UK Government want to examine the practices of the insurance industry. They want to do so to ensure that—again, it is dangerous for me to paraphrase the words of another minister—people get fair treatment from the insurance industry. They want to ensure that people are not prejudiced by the fact that they either have, or it has been predicted by genetic testing that they will develop, a particular condition that could adversely affect how they are treated in relation to financial matters.

11:00

The Convener: I want to finish on a point of clarification about an issue that was raised by the Haemophilia Society. When you gave evidence to us on the issue at the tail end of last year, you said in relation to the Haemophilia Society:

"I am happy to meet it again".

However, representatives of the society then approached the committee and said that you had refused to meet them. Will you clarify whether you intend to meet that society and are still happy to meet its representatives? From this morning's discussion and from recent debates on the subject, a number of issues appear to have arisen over the past six months, not least the court judgment in England. Could you clarify that you are happy to meet members of the Haemophilia Society?

Susan Deacon: If members look at the *Official Report*, they will see that what I in fact said when I appeared before the committee. I was asked:

"is the minister prepared to meet the Haemophilia Society",

My answer was:

"I am happy to meet it again to discuss either outstanding issues arising from the report or wider issues" —[*Official Report*, *Health and Community Care Committee*, 25 October 2000; c 1266.]

The approach that I subsequently received from the Haemophilia Society referred mainly to ground that had already been covered. I did not feel that meeting the society could add anything further to the discussion, as the Executive had published its report and made clear its position. There are times when parties have to agree to disagree and that was, in some respects, the position that we were in.

I repeat that I am always happy to meet groups; I regularly meet a wide range of groups. If I felt that there were specific issues that could usefully be addressed through such a meeting with the Haemophilia Society, I would be happy to take part in that, but both the society and I would need to be sure that we could usefully take matters forward in that way.

Nicola Sturgeon: Surely, minister, if you are constructively considering the English court judgment, the Haemophilia Society would be a relevant group for you to take evidence and advice from. Can you give an assurance that it will be listened to in the review?

Susan Deacon: The society has been listened to previously, I have met some of its members and I will continue to do so.

Nicola Sturgeon: This is a new issue. The English court judgment brings a new angle to the situation. Can you give a commitment today that, should the Haemophilia Society wish to meet you, you will meet it specifically to discuss the implications of that judgment?

Susan Deacon: I think that I have answered that question. I have always said that, if there were new or outstanding issues to be addressed, which could usefully be addressed in that way, it would be done. I repeat that it does not always follow

that a meeting with a minister is the best way of taking matters forward. In our on-going deliberations it might, for example, be considered appropriate for further written contributions to be taken from the society, or for officials to meet its members, instead of or in addition to a meeting. I rule out none of those options. Our track record to date shows that we are very happy to take views and submissions from the Haemophilia Society or from other groups or individuals—one of the important points that has been raised today is that other groups and individuals are affected.

The Convener: We should wrap up this part of the meeting. We await with great interest the minister's constructive consideration of the English judgment, and I echo the points that were made by John McAllion, that this was exactly what the Parliament was looking for: a constructive, not intransigent, approach on the matter.

What has come out of this morning's discussion, and taking on board the minister's comments about looking forward, is the fact that wider issues need to be discussed, including the risk analysis issues that were mentioned by Richard Simpson. There might be some interest when we finally publish our report into the matter.

I thank the minister very much for giving evidence this morning.

11:05

Meeting adjourned until 11:10 and continued in private until 11:50.

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