Scottish Parliament

Health and Community Care Committee

Tuesday 12 December 2000

(*Morning*)

[THE CONVENER *opened the meeting at 09:35*]

The Convener: I suggest that we write to the minister to reiterate the points that Mary Scanlon and Nicola Sturgeon have made, which echo the points that we made previously to the minister. As a result of those protestations, some months ago, we received forward work plans from the Executive. However, the clerk informs me that in reply to our most recent request for information, we received a bland paragraph about modernising the NHS, which gave no dates. We will pursue that matter.

Members will know that there have been difficulties in liaison between the committee and the Executive, which culminated in six or seven letters on hepatitis C going unanswered by the Executive, until the matter was raised with the minister personally. We will make the point again to the minister that it is impossible for a committee to feed into the process properly if it does not know what the Executive's plans are. We will ask for that information. In our first year, we were given a year-long work programme by the Executive, which was useful. However, for the committee's second year, that has not been forthcoming, despite our requests.

The Convener: We should note both that and the committee's support of the Executive's position that there should be no cross-subsidy of health services.

The next two petitions under consideration are PE45 from the West of Scotland Haemophilia Society and PE185 from GRO-A. We have also been contacted by the Haemophilia Society, which feels that the Government's response to a haemophilia inquiry was lacking. The society wishes to give a presentation on the matter to the committee. The report was published by the Executive on 22 October and considered by the committee on 25 October, when we questioned the Minister for Health and Community Care on the matter. The question for the committee is how we progress the issue.

11:00

Members will be aware of recent press reports about the screening of blood donations prior to transfusion. Although that is a slightly different matter, I was certainly concerned by a report in *The Scotsman*. The minister told us that it was impossible to check whether hepatitis C—non-A, non-B hepatitis, as it used to be known—had been heat-treated out of a blood donation, because the disease had not been classified with that name. The article in *The Scotsman*—backed up by extracts from minutes that were provided by regional managers of the Scottish National Blood Transfusion Service—claimed that during the 1980s, the service had a series of discussions about the presence of a non-A, non-B hepatitis, which was having an impact on people and was being screened for in other countries. At that time, the Scottish National Blood Transfusion Service wrote a letter to *The Lancet* on the issue.

At the tail end of last week, I asked the Scottish Parliament information centre to provide a research note on the matter, which members should have. Researchers have had a chance to review the documents that were supplied to *The Scotsman*, and I hope that members will find the briefing note useful when the committee comes to make a decision about petitions PE45 and PE185. Although the note refers to an earlier stage in the process from that which the committee discussed, it raises serious questions about whether it is a justifiable defence to claim that hepatitis C could not be screened out of donations because it was not called hepatitis C at the time. If it was known that a disease called non-A, non-B hepatitis was having a serious impact, surely the name of the disease is irrelevant; the point is that that impact existed.

I would like guidance from committee members on whether we wish to hear from the Haemophilia Society, which has asked to come and give evidence on the matter. We have taken oral evidence from the minister—if we ask the Haemophilia Society, we may consider asking the Scottish National Blood Transfusion Service and others, so that we can finalise our response to the petitions.

Nicola Sturgeon: A few unanswered questions surround the matter. Since the meeting at which we discussed hepatitis C with the minister, substantial new evidence has been produced. It is incumbent on the committee to deal with that. The first step should be to take evidence from the Haemophilia Society. We can decide what to do next after we have had asked the society questions on its evidence. We should talk to the blood transfusion service, and perhaps take evidence again from the minister.

In light of the evidence that is in the public domain, it is totally unsatisfactory that the matter should rest on an internal report—a report by the Executive on an Executive agency. While questions remain on that, it is incumbent on the committee to try to get some answers.

It is not for the committee to tell the Minister for Health and Community Care who she should see, but I would like this point to be noted. At the meeting that she attended, she said in answer to a question from an MSP that she would be happy to meet the Haemophilia Society again to discuss continuing concerns and new evidence. The society has since received a letter from her, in response to a request for a meeting, which said that she would not meet the society. That is unsatisfactory, and the committee should take note of that.

The Convener: That is a serious issue. As Nicola Sturgeon said, the minister told us that she would be willing to meet the Haemophilia Society again. As convener of this committee, I feel that that would be a reasonable thing for the minister to do in the circumstances. Committee members may have opinions on that—especially when we consider that the minister raised the point in evidence to us. What she said was welcomed by committee members.

Margaret Jamieson: To follow on from what Nicola Sturgeon said, I agree that we should take evidence from the Haemophilia Society. We should hear from the blood transfusion service too. To hear from one but not the other would serve no purpose.

Cathy Jamieson represented Mr GRO-A, who was unable to attend to discuss his petition. His situation was different and has not been considered in the inquiry by the Scottish Executive. If I recollect correctly, Mr GRO-A contracted hepatitis C through routine surgery. Cases such as his have been excluded from the inquiry. We should look into that, because a great number of individuals find themselves with hepatitis C through no fault of their own. Some have contracted it during the course of emergency treatment, not through the normal course of their treatment, which is the way that haemophiliacs have contracted it. We must consider sufferers of hepatitis C who are not haemophiliacs.

The Convener: Initially, we asked the Executive to include such people. The Executive ruled that out, but members seem to be suggesting that we should continue on that tack and ask the researchers to give us information on the acquisition of hepatitis C by non-haemophiliacs, so that we can get an idea of the extent of the problem and how it comes about. That might lead us on to consider the screening of blood products and other questions of hygiene.

Mary Scanlon: It is crucial that we take evidence. This issue has been with us for more than a decade and is not going to go away. We must listen to all the available evidence. I support asking the Haemophilia Society and the Scottish National Blood Transfusion Service to give evidence.

Dr Simpson: Can I be clear that we are confining our evidence taking to the question of screening? I assume that we are not going to go back over the old ground about heat treatments and so on. That has been covered adequately in the report. In relation to the new evidence about whether the blood should have been screened, we must decide whether the information was available and whether the screening test was appropriate and focused—in other words, that it did not produce too many false positives and false negatives. I would not support the committee broadening the inquiry to consider heat treatment.

The Convener: The Executive report examined heat treatment. If we have witnesses from the Haemophilia Society who do not believe that that report is adequate, I do not know how we can get the information from them without going back to the Executive's response on heat treatment.

Having said that, I believe that the Haemophilia Society will make some points to us about why it does not believe that that report is adequate and why it questions the reports findings. If the Scottish National Blood Transfusion Service is coming to give evidence, it would not be reasonable for members to feel that they were unable to ask questions about heat treatment, which is central to the Executive's report. We got at least one of the petitions because of that report.

Nicola Sturgeon and I have made the point that new evidence has come to us on screening. We will consider that issue afresh because it is a new development. How could we conduct an oral investigation effectively without asking questions about the main point of the Executive's report?

Dorothy-Grace Elder: We will find that a deal more evidence is produced.

It is surprising that the letter from *The Lancet* has not come to our attention earlier. The files of *The Scotsman* and other newspapers will produce information from the early 1980s. We have been told that hepatitis C was not identified until the early 1990s. That is the terminology that was used. However, we know now that it was called non-A, non-B hepatitis. I refer to comments that I made in the Health and Community Care Committee from October onwards. I remember clearly that in the early 1980s haematologists and the blood transfusion service were pleading for a few hundred thousand pounds to set up a heat treatment unit in Scotland. We must look back and examine the issue as rigorously as possible. We should call in the authors of the letter in the Lancet and haematologists who were serving at the time.

The Convener: I do not want to keep on interjecting on every comment made by committee members, but I think that the point that was raised earlier—that when we have heard evidence from the Haemophilia Society and the Scottish National Blood Transfusion Service, we must decide whether we believe that the report published by the Executive is adequate—covers all the issues. The question for the committee is how we proceed if we feel that it is not an adequate response. That leads us into whether the matter requires further work by the committee, the Executive or somebody else.

At this stage, it is not for the committee to redo all the work that has been done. Members are well aware of committees' limitations. It might be that other people are better placed to get answers. When we have heard evidence from the Haemophilia Society and the Scottish National Blood Transfusion Service, we will be better placed to judge whether the Executive's report is the final work that needs to be done to investigate the history of the matter.

Shona Robison: I agree that it would be impractical and unfair to constrain the discussion, so I support the convener's view that the discussion about the issues and the evidence should be wide ranging.

11:15

Hugh Henry: I think that everybody supports the principle that there should be further investigation of the broad issues. However, we are struggling to agree on, or even to understand, the terms of reference. I think that we should agree that the matter will return to our agenda and that there will be an inquiry. We can then try to draw up terms of reference. We should have a debate, based on the evidence and the arguments that we have heard this morning. The last thing that we should do is begin an inquiry when members have different ideas about what we are discussing. We all agree on the principle, but as this is such a sensitive issue, we should take a wee bit of time to sort out the terms of reference properly.

Nicola Sturgeon: I do not think that there is so much confusion about the terms of reference—the issue is quite simple. In response to what Richard Simpson said, I say that it is inconceivable that we could invite representatives from the Haemophilia Society to give evidence and then tell them that they can only discuss certain aspects of the matter. We should take evidence from the society on the points on which it disagrees with the Executive's report, or on which it thinks that the report has not been exhaustive and has not taken into account particular pieces of evidence. It would be fair to tell the society that we expect it to be quite focused so that we do not go back over matters that are not disputed by the Executive or the society. We should also ask about any new evidence—in relation to screening, for example—that was not examined for the report. If we agree to do that, what we are trying to achieve becomes clearer.

At the end of the process, we may conclude that the Executive report is fine—we can decide that once we have taken evidence. It may be that the only aspect that we will want to address is the new evidence about screening. However, it is inconceivable that we should tell the Haemophilia Society that it should give evidence only on the part of the issue that we want to hear about.

Irene Oldfather (Cunninghame South) (Lab): If I recollect correctly, the area of contention was the chronology of what happened. That information exists. In fact, we addressed much of that when Susan Deacon attended the committee. It is important that we do not try to conduct the investigation again and that we focus on one or two clear points on which we could make some progress. We received a lot of information in the report, and accepted much of it. The chronology of events was, however, the issue. We could ask about that and the new evidence on screenings.

The Convener: The other matter about which the Haemophilia Society is unhappy is how the report addressed the manner in which people were informed of risks in advance of treatment, and the manner in which people were dealt with after they contracted hepatitis C. The society will want to raise that as well.

The Executive's report was meant to deal with that, but committee members may recall that when the minister dealt with it, questions of confidentiality were raised. I do not know whether the Haemophilia Society believes that those issues can be overcome. The society will raise questions about the report's chronology and will discuss whether people were informed and, if so, how. We have not touched on that.

Dr Simpson: Will our clerks produce a note on the issues that members think should be raised? I remain concerned that we will try to repeat the inquiry. If we are to do that, we must appoint a special adviser, take evidence from absolutely everybody and do the task properly, but I do not think that that is our role. We should focus on our concerns. We can draw up a list, send it to the Haemophilia Society and find out whether the society agrees with it. I do not mind that. However, I do not wish us to go back into the entire inquiry again.

Nicola Sturgeon: We should take evidence from the Haemophilia Society about its concerns. Then, by all means, the clerks should draw up the note on the issues that the committee wants to progress with. We may think that some of the society's concerns are not justified. However, in fairness to the society, we must give it the opportunity to tell us about its disagreements with the report, what new evidence it has and what its concerns are. After that, we can boil down the issues.

The Convener: I agree. We have heard the minister speak to her report. The Haemophilia Society has intimated that it is not happy with the report. As things stand, if the minister refuses to meet members of the society—and that appears to be the situation—natural justice demands that we should hear from the Haemophilia Society. That will allow the society to put on record its thoughts about how the report has not gone far enough, which I think will relate to how information was passed on to the people involved. The society will be able to dispute points about chronology and other matters in the report. We must hear the other side of the argument, from the Haemophilia Society.

Hearing from the Scottish National Blood Transfusion Service would allow us to clarify some of the screening questions and any other issues that we may hear about from the Haemophilia Society. After that, the committee will have all the information that it will need on which to make decisions on the following questions. First, did the Executive's report go far enough? Secondly, do we want the Executive to do further work?

The screening issue has been brought up late in the day, so we could point that out to the Executive. Further work may be required on the question of non-haemophiliacs who have contracted hepatitis C. We would have to consider whether the committee should suggest that somebody—or ourselves—should take on further work. My gut reaction is that the committee would not do such work.

The committee can decide whether further work is required from the Executive or others only on the basis of evidence from the Haemophilia Society, the SNBTS and the minister. We would decide on an inquiry only when we had covered all the issues and had a chance to ask the main players about them. At the moment, we have heard only the minister's point of view, and we have had to take account of new developments.

I suggest that the committee undertakes to speak to the Haemophilia Society and the SNBTS. After receiving information from them, the committee will be able to decide how to proceed and whether further work is needed from anyone, including the committee. Our view is broad. We have two petitions that cover the haemophilia issue with the SNBTS, the ways in which people are acquiring hepatitis C and the manner in which we have dealt with blood products. The fact that we have two petitions on the matter has already broadened the issue out. Are there any comments from members?

Margaret Jamieson: If the Haemophilia Society could list the areas that concern it following the Executive's publication of its inquiry, we could cross-reference that with the areas that we have already dealt with. That would keep our work quite narrow, rather than rehashing what we have already dealt with.

Nicola Sturgeon: We have not dealt with anything. We have heard the minister give evidence on her report. As Margaret Jamieson said, we have heard one side of the story. Natural justice would suggest that we should hear the other side and give the Haemophilia Society—

Margaret Jamieson: We heard from the Haemophilia Society.

Nicola Sturgeon: Yes, but not in response to the report. We should give the Haemophilia Society the opportunity to respond. I agree that, after that, we have to focus on what we do next and on what progress we can make. However, to try to shut the debate down before we have heard one side of it is not fair.

Hugh Henry: The minister gave a commitment to the committee. She seems to be saying something different from what the Haemophilia Society is saying. It is reasonable for the committee to write to the minister to remind her of the commitment that was given to the committee and to indicate that we expect her to fulfil that commitment. In the event that that commitment is not fulfilled, it is within the competence of the committee to ask the minister to come back before us. At that point, we can undertake some of the functions that a meeting with the Haemophilia Society would have fulfilled. It is not right that the minister should make one statement to a committee and give a completely different message to the organisation that the commitment concerned.

On the general point that is raised in the petition, I wonder whether we are going way beyond the agenda item. On the basis of some of the evidence that has come forward, I think that there is an argument for retracing our steps on haemophilia. Perhaps we could conduct an investigation or produce a report. However, if we stick to the issue that is raised in the petition, that might not be possible. Correct me if I am wrong, but I believe that we are talking about a petition from Thomas McKissock.

The Convener: Yes, and one from the west of Scotland group of the Haemophilia Society.

Hugh Henry: The petition from GRO-A GRO-A deals with a specific issue. We need to determine what we will do about that. However, the other petition calls for a public inquiry. To some extent, we have been over that argument previously. If we think that it is legitimate to have a revolving inquiry in the committee and for us to rehash matters every time a decision is made, every petitioner will ask us to go over subjects again, even although we have already undertaken work. There is an argument for saying that new evidence on the issue should be examined carefully, but we need to separate what we have done from what we are trying to do. I think that the committee will create a rod for its own back on a range of issues if it starts rehashing work that it has already done.

Ben Wallace: I am not aware that we have closed our inquiry. Nicola Sturgeon is correct when she says that Susan Deacon used her time to talk about her report. We have not listened to the Haemophilia Society's opinion of the report. It would only be good manners, having heard from one side, to hear from the other. That is very important. When we have heard that, we can decide on a course of action.

11:30

Shona Robison: This is not just about the petitions—we agreed to discuss the letter from the Haemophilia Society at the same time as the petitions. The letter states that the society disagrees with the report and would like to bring its views to the committee. Anything short of allowing the Haemophilia Society to give evidence and voice its concerns would be totally inadequate. We should decide what to do after having heard the evidence. At this stage, all we need to do is to agree that we will listen to the views of the Haemophilia Society. There has been a suggestion that we listen to the views of the Scottish National Blood Transfusion Service at the same time. That seems reasonable. After we have heard that evidence, we can decide whether we should begin another inquiry.

Dorothy-Grace Elder: I do not agree with Hugh Henry that such a decision would compromise us in the future. The case is unusual. We cannot ignore the direct petitioners or the Haemophilia Society. I hope that this is a one-off, although it may not be. If necessary, we should make recommendations as to whether there should be compensation.

Dr Simpson: We have not decided what sort of evidence to take. We should ask the Haemophilia Society to detail in writing its objections to the report. All we have is a statement that the society is not happy with the people who carried out the inquiry. We need more details. The oral evidence should rest on questions that arise from the written evidence. We should also ask the society to present evidence on screening.

The Convener: I want to pull together the various suggestions for action. I did not recall—and nor did the clerk—that we had decided that, once we questioned the minister about hepatitis C, that would be the end of the matter. We asked her about several issues on that day; we took advantage of her presence to ask several questions because we had not had responses to six letters. Our final letter said that, if we did not receive a response, we would ask questions when the minister appeared before us to answer questions on other matters. That was why we took that approach.

I agree with the points made by Nicola Sturgeon, Hugh Henry and me. [*Laughter.*] I may change my mind, but not during a meeting. Given that the minister assured the committee that she would be happy to meet representatives of the Haemophilia Society, it would be perfectly reasonable for the committee to write to say that we expect her to honour that commitment. That would give the society a chance to discuss the issue with her face to face. Does the committee agree to that suggestion?

Members *indicated agreement.*

The Convener: The second point relates to the wider issue raised in the petition from Mr GRO-A, on hepatitis C being contracted by non-haemophiliacs through health treatment provided by the NHS. Is the committee happy to request a research note on that issue, so that we can revisit the matter at a future meeting?

Members *indicated agreement.*

The Convener: I suggest that we invite the Haemophilia Society and the Scottish National Blood Transfusion Service to give evidence. It would be reasonable for us to ask the Haemophilia Society to outline in advance its areas of disagreement with the report and the subjects that the society believes the report has not fully covered.

The Haemophilia Society is concerned about the secondary issue of the information available to patients not having been investigated as much as it could have been. Some of its concerns might be about not only the content of the report, but the breadth of the secondary part of the inquiry. If we ask the society to outline its concerns in writing, that would give us the opportunity to concentrate on the appropriate areas when taking oral evidence. It is important, with both the Haemophilia Society and the Scottish National Blood Transfusion Service, to use the new information that has been given to *The Scotsman* and to other parties on the screening programme. That links into the chronological aspects raised by Irene Oldfather.

Frankly, I do not believe that the committee will be able to carry out a full inquiry into the haemophilia and hepatitis C situations; we do not have the research resources to take on that task, although I mean no disrespect to the research resources that we have. However, after hearing the evidence from all sides, we will be better placed to say whether we believe that the Executive's report is adequate, whether the Executive should modify the report and whether other avenues, such as a full, independent public inquiry, should be pursued. The point at which the committee can make such decisions is after we have heard from the three major players. We have heard from the Executive, but we have not heard from the Haemophilia Society or the Scottish National Blood Transfusion Service. I suggest to the committee that that is the way in which we should proceed.

Dorothy-Grace Elder: We are going to invite the Haemophilia Society, but the petitioner is from the west of Scotland group of the Haemophilia Society. How do we work that out?

The Convener: When investigating petitions in the past, we have not always questioned the petitioner. We have taken on board the tone, spirit and letter of a petition and have then taken information and evidence from other people in order to arrive at a position. We can clarify this with the Haemophilia Society, but I presume that the west of Scotland group would be happy to be represented by the society, of which the group is an offshoot. There should not be a problem with that, but we can clarify the situation.

I will let Ben Wallace in, but I would like to get to a decision on this.

Ben Wallace: Many of us—including Hugh Henry and Irene Oldfather—supported Brian Adam when he called for an independent inquiry on hepatitis C. We ought therefore to continue with that, ensuring that we hear the minister's response before proceeding.

Hugh Henry: Can I respond to that?

The Convener: Yes—I think that you have to.

Hugh Henry: I do not think that we are arguing otherwise. We have been saying that the committee should not retrace the ground that it has already covered but should try to move on. I remind Ben Wallace that I said that we should move forward on the basis of some of the new evidence that has come to light.

Other issues flow from this matter, and not just on haemophilia. Will we be opening the door to any group that wants us to question Executive reports, regardless of the issue? We should consider issues of procedure. Nothing that I have said contradicts the views that I have expressed in committee or outside it.

The Convener: Let me clarify the matter for the committee. We are dealing with petitions that came to us in the normal way. The committee's response to the petition from the west of Scotland group of the Haemophilia Society was influenced by the fact that the Executive had intimated that it was going to commission an on-going report. Had that report not been undertaken, the committee might have taken a different approach to the petition, but we decided to wait for the Executive's response before we acted on the issue.

I suggest that the committee agrees to the course of action that I outlined a few minutes ago. Are there any objections to that course of action?

Dr Simpson: My objection is that the organisations that you will invite to give evidence are the two protagonists in the case—the Haemophilia Society, with its concerns over the report and the screening, and the Scottish National Blood Transfusion Service. I recommend that you, as the convener, also invite an independent expert, so that we can receive evidence from someone who is not directly engaged in the conflict.

The Convener: Do members have any problems with that?

Nicola Sturgeon: Although Richard Simpson may have the right idea, he is perhaps a bit ahead of the process, as that is a decision that we should make after we have heard the evidence from the Haemophilia Society and the blood transfusion service. At that stage, we can determine whether we require independent advice.

The Convener: Does the committee agree to the course of action that I suggested?

Members *indicated agreement.*

The Convener: We can revisit the situation when we have taken evidence.