The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 9 February 2016

Session 4

Tuesday 9 February 2016

CONTENTS

HEALTH AND SPORT COMMITTEE
9th Meeting 2016, Session 4

CONVENER

*Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

*Fiona McLeod (Strathkelvin and Bearsden) (SNP)

COMMITTEE MEMBERS

*Malcolm Chisholm (Edinburgh Northern and Leith) (Lab)
*Rhoda Grant (Highlands and Islands) (Lab)
*Colin Keir (Edinburgh Western) (SNP)
*Richard Lyle (Central Scotland) (SNP)
*Mike MacKenzie (Highlands and Islands) (SNP)
*Nanette Milne (North East Scotland) (Con)
*Dennis Robertson (Aberdeenshire West) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Gareth Brown (Scottish Government)
Philip Dolan (Scottish Infected Blood Forum)
Professor David Goldberg (Health Protection Scotland)
Shona Robison (Cabinet Secretary for Health, Wellbeing and Sport)
Bill Wright (Haemophilia Scotland)
Petra Wright (Hepatitis C Trust)

CLERK TO THE COMMITTEE

Jane Williams

LOCATION

The Robert Burns Room (CR1)

Scottish Parliament

Health and Sport Committee

Tuesday 9 February 2016

[The Convener opened the meeting at 09:32]

Decision on Taking Business in Private

The Convener (Duncan McNeil): Good morning, and welcome to the ninth meeting in 2016 of the Health and Sport Committee. As is usual at this point, I ask everyone to switch off their mobile phones because they can interfere with the sound system—they would certainly interfere with the committee's proceedings. You will notice that some of us are using tablet devices instead of hard copies of our papers.

Agenda item 1 is a decision on whether the committee will take in private item 5, which is consideration of the main themes arising from today's evidence on the final report of the Penrose inquiry. Do I have the committee's agreement to that?

Members *indicated agreement.*

The Convener: Thank you.

Penrose Inquiry

09:32

The Convener: We move to our second agenda item, on the final report of the Penrose inquiry. We will hear oral evidence on the report from Petra Wright. Should that be Bill Wright? No—it is Petra Wright.

Petra Wright (Hepatitis C Trust): We are not related.

Bill Wright (Haemophilia Scotland): Fond of her as I am, convener, we are not brother and sister, or whatever.

The Convener: Petra Wright is Scottish officer for the Hepatitis C Trust, Philip Dolan is the convener of the Scottish Infected Blood Forum, and Bill Wright is chair of Haemophilia Scotland. Welcome to you all. In the interests of time, we will move directly to questions. The first question is from Richard Lyle.

Richard Lyle (Central Scotland) (SNP): First, I thank you, convener, and the committee for holding this evidence session. I am sure that many people who have been affected by the issues that are being considered by the Penrose inquiry welcome it.

I have several questions, if you will allow me convener. First, however, we must have a short look at the history. In 1999, the then Scottish Executive announced an internal inquiry into contaminated blood. In 2000, the Health and Community Care Committee—this committee's predecessor—launched an inquiry. In 2004, the Skipton Fund was established. In 2006, the Heath Committee—again, a predecessor of this committee—called for a full public inquiry. In 2007, the Scottish Government confirmed that it would honour a manifesto commitment to hold a public inquiry, and in 2008, Lord Penrose was appointed to start the inquiry in January 2009. The Penrose inquiry's final report was published in 2013. It has taken 17 years to get to the current situation.

I welcome the three witnesses. I have a question for you. It has been said that the Penrose inquiry did not cover all the issues that were raised by the campaign. We have been given examples involving medical records, but there were other aspects of the disaster that were not covered. What is your view on what was not covered by the Penrose inquiry?

Bill Wright: The committee will be well aware that, among those of us who endured the six-year-long inquiry, the common phrase that was used was that it was a "whitewash". A six-year-long inquiry that cost £12 million but produced only one recommendation brings the whole inquiry system,

and the Inquiries Act 2005 and the Inquiries (Scotland) Rules 2007, into disrepute.

We believe that that is an issue that should be considered in a future session of Parliament—indeed, it stretches across the whole area of public consideration. In the recent trams inquiry, for example, the chairman had to alter the situation because the process had changed from being a non-judicial inquiry to a judicial inquiry in order that witnesses could be compelled.

The aspect that we have found most troubling is that, although the inquiry was six years long, there was a three-year gap between the end of the public hearings and publication of the report in March last year. Any reasonable person, when they are told that a public inquiry must be held transparently and funded by the taxpayer, would reasonably expect that the whole of the proceedings would be transparent.

I am very aware that the chairman was limited by the terms of the 2005 act because of what is called Maxwellisation, with which the committee may be more familiar in relation to the Chilcot inquiry. However, for three years we were left completely in the dark, wondering what was happening with all the to-ing and fro-ing between the chairman and his team and the witnesses who may well have been subjected to criticism in the first draft of the report. We simply do not know what was happening at that point, and we found that to be extremely frustrating and potentially time wasting. People died during that period from their infections.

We urge all parliamentarians, in looking to the next session of the Scottish Parliament, to consider examining the inquiry system as a whole and, if necessary, to consider making amendments to the 2005 act and the 2007 rules. However, that is for the future.

Philip Dolan (Scottish Infected Blood Forum): I agree with many of the things that Bill Wright has said. I have written a history of the subject, and I feel like I have been haunting this place and the corridors with the black and white tiles since 1999. What troubles and concerns me and members of the Scottish Infected Blood Forum, which—as I said in my submission—represents people who have been infected with hepatitis C, is that many people who wanted to be witnesses and to tell their stories were not heard. I have this morning distributed, for members to read later, the stories that some of the people who have been affected would have liked to have given to the inquiry. I am concerned about the way in which the Penrose inquiry treated that aspect.

The inquiry made no mention of missing medical records and people's batch numbers. There is nothing in the report about the fact that David Owen—Lord Owen—and Patrick Jenkin, both former health ministers at Westminster, found suddenly that documents that they had were, unfortunately, shredded by junior members of staff when they got to the Department of Health.

As I said in my submission, we expressed concern that the Penrose inquiry called only six victims as witnesses. Plenty of doctors, scientists and people from the Department of Health were called as witnesses, but where were the victims? I put on the record the fact that many people wanted to be core participants but that, at the end of the day, Lord Penrose allowed only six of those people to give evidence. The appeal was heard by Lord Penrose himself. It goes against natural justice for a judge to hear an appeal against his own decision.

Of even more concern was the fact that when the counsel who was talking about hepatitis C on my behalf said, "Mr Dolan has the sword of Damocles hanging over his head," Lord Penrose's response was, "You mean a feather duster." That is how dismissive he was: my having contracted hepatitis C was seen as nothing. We could say nothing: along with many other people, I sat in the background and was not allowed to say anything.

As I have said elsewhere, on the very first day Lord Penrose said in his initial statement that the inquiry was being funded by the national health service, and that therefore every pound spent on it was a pound that would be taken away from patient care, and that every time a doctor appeared at it, that was time away from the health service. He had nothing to say about the fact that, in the audience that day were a number of widows, widowers and families whose relatives had died. They did not seem to exist as far as the inquiry was concerned.

Two of the victims who were heard at the inquiry were heard because the legal people had taken a case under the Human Rights Act 1998, which meant that the Court of Session insisted that both were heard. Only four other victims were heard as witnesses.

On the first day I said that the inquiry was a whitewash, and on the last day I said that it was a whitewash. I have spent years and years, going back to the 1980s, campaigning to get justice. I do not mean just financial justice; justice is about getting an answer to why this happened, but the Penrose report does not provide that answer.

The Convener: I will let Petra Wright respond to the first question, and then I will take some supplementaries on the inquiry process. After that, I will allow the witnesses to make further comments.

Petra Wright: I was not personally involved in the Penrose inquiry, but I would like to comment on it.

Richard Lyle mentioned the length of time that the process has taken. We have been waiting for about 30 years, and it is 17 years since the inquiry process came along. I have hepatitis C. Despite costing so much, the inquiry produced only one recommendation that said, in effect, "Please go and test people and find those who have been infected." The Hepatitis C Trust has campaigned for more effective screening for years, so that we can find people who have hepatitis C. Even though only one recommendation was made, here we are almost a full year down the line and that one recommendation has still not been implemented. Time is short for people with hepatitis C.

09:45

The Convener: Do other members have questions on the process of the inquiry?

Malcolm Chisholm (Edinburgh Northern and Leith) (Lab): I also want to ask about something else, but I will stick to that issue for the moment.

I totally take on board what the witnesses have said and I understand your concerns about the inquiry process. The Haemophilia Scotland submission goes through various expectations. I am interested in expectations 2 and 4. In expectation 2, you say:

"The Penrose Inquiry has been reasonably successful at documenting the events of the disaster".

In expectation 4, you say that you are concerned because there was no criticism or apportionment of blame. On the first point, do all the witnesses agree that the inquiry was "reasonably successful" at documenting the events? Was there anything inaccurate? Part of your concern is that some things were omitted or not dealt with—for example, medical records—but your comment suggests that you are quite happy with what is there, or is that an overstatement? [*Interruption*.]

Bill Wright: No—

The Convener: Just a minute, Mr Wright. Do members have any other questions on the theme of the inquiry and its outcomes? No? Okay—go ahead, Mr Wright.

Bill Wright: In the time that was taken a substantial body of evidence was collected. Much of it was new evidence of which we had not previously been aware. The inquiry team secured and examined well over 100,000 documents and had about 89 days of oral hearings. Obviously, the team gathered a lot of facts. Whether the inquiry was then able to find some explanation for those facts is an entirely different matter. In the report of the Penrose inquiry, the word "could" appears very regularly throughout; it says, for example, that in the chairman's view certain steps "could" have been taken, rather than that they "should" have been taken.

Penrose gathered a body of evidence on much of the story, but he did not explain considerable amounts of it, such as what happened in relation to medical records and why United Kingdom civil servants attempted to render Crown immunity, which was an extremely savage tool to use against anybody who wanted to look into the matter. It was clear that UK civil servants at the time were feeling highly insecure about their position. There was no examination of that particular issue, for example, which indicates insecurity on the Government's part. As Philip Dolan mentioned, no evidence was taken from, for example, Dr David Owen. In fact, on the day when the report was released, a retired civil servant phoned us up because he was concerned about the manner in which the issue had been dealt with.

The answer to your question is that we did not get the complete picture, but we got a much bigger picture than we had had previously. However, once that body of evidence had been put together, not a great deal of judgment was exercised. There was no set of conclusions and there was but one single recommendation, which seems to be extremely odd, given the cost of the exercise and the time involved.

Philip Dolan: I feel most strongly about the fact that during the six years—or whatever length of time it was—the victims were not listened to, and that during the year or so for which Penrose listened to stuff, he did not hear from victims. How can we deal with the matter when the people who are affected have not been heard? There are hundreds and hundreds of stories. A number of people wanted to give evidence but were dismissed. Granted, an inquiry cannot go on forever, but people did not get an opportunity. For instance, if I had been given an opportunity to give evidence, it would have been an opportunity for the Penrose inquiry's legal team to question me and, equally, for the team that was representing people with hepatitis C to ask questions. However, I did not have that opportunity.

Some of the evidence that was given, even by the experts, was found to be wanting. For instance, on the first day, during discussion of the first two cases, there was a chart that showed that Mr X had a score of, let us say, 100, which the hepatologist expert witness said was a sign that he was a heavy drinker. I had to point out to counsel that a person does not get hepatitis C from being a heavy drinker: people get cirrhosis from that. The next case involved a minister—a

religious minister—who did not touch alcohol, and he had a score of 150.

It reminds me of days of old, when somebody who was discussing logic would say, "All dogs are hairy", and all that was needed for the whole argument to be defeated was for one person to come along and produce a non-hairy dog. The credibility of the evidence from that expert witness, who is also an adviser to the Skipton Fund, is questionable.

As I said, my concern is that people should be listened to. If I go to the doctor, he or she will listen, take notes and base their diagnosis and decision to take action on what they have heard, but that opportunity was not afforded to us. It was a waste of £12 million. As has been said, notes were taken, but what was in the report could have been recorded by somebody who was not a judge but was good at taking shorthand. The report seemed to me to be based on someone taking notes. A lot of money was wasted, and I do not know why all the lawyers and others were there if they were not going to speak for us.

The Convener: Richard Lyle will take us on to the next topic.

Richard Lyle: Thank you for sharing your experience with us, Mr Dolan. Sadly, I have heard the same from other sufferers all too often. Was it a weakness that the Penrose inquiry did not seek to apportion blame or establish liability? I have met many of the sufferers over the years and it has been put to me that no one was put in the dock, if I can use that phrase.

Philip Dolan: Many years ago, there was an inquiry about BSE in England, which was chaired by a Scottish judge. At the end, the inquiry came out and said that it blamed the chief medical officer for England and the chief civil servant—it named people. When there was an inquiry in Ireland, the two senior people from blood transfusion were named.

You are correct that blame should have been apportioned, because it was not the victims' fault. Many of our members—they are two thirds of the numbers involved—are people who got blood transfusions. They went into hospital looking to be cared for, but they suddenly found that they had a life-threatening condition. There was an opportunity to apportion blame, and that should have been done, whether it was apportioned to doctors or not.

When Malcolm Chisholm was health minister, he allowed people to get their medical records. People started phoning me up to say that they had got their medical records, but the batch numbers were missing. At first I thought that maybe that was due to bad administration in that hospital. However, I heard from people from all five hospitals in Scotland that dealt with haemophilia, and the same story came from all of them. The problem was not just a consultant somewhere; it had to have come from somewhere in central Government. That information was not around.

The finger is not pointing just at consultants. Most of us with haemophilia or hepatitis have great respect for and get on well with doctors. We have spent a lot of time in their company. The decision must have been made in some mysterious place, wherever it was.

Bill Wright: The question illustrates the shortcomings in the inquiry system that I alluded to. We can look at a number of inquiries. I understand that a former First Minister recently commented on this issue in relation to the Chilcot inquiry—there may well be indications that that inquiry is seeking to avoid apportioning blame—and there are similar issues with the Taylor inquiry into Hillsborough.

We have to look at what we want out of the inquiry system. Sadly, I agree that blame should be apportioned where it should be. However, if we are going to maintain an inquiry system that does that, we have to expect that witnesses may well adopt defensive rather than reflective positions when giving evidence, which means that conducting inquiries could become adversarial.

It depends on what we want an inquiry to achieve. Do we want to learn lessons? Do we want to apportion blame? Do we want to improve current practice? Unfortunately, a difficulty with the Penrose inquiry was that it was held so long after the damage was initially done that many of the witnesses had passed away. I am not just talking about our own folk—I am talking about some of the so-called expert witnesses as well. We have to look at the inquiry system in a fundamental way. The question is extremely valid, but the issue is not simply about apportioning blame. We must look at what we want out of the inquiry system as a whole.

Mr Chisholm spoke about expectations 2 and 4 in our submission. Philip Dolan spoke about expectation 3, which is

"That those affected would 'get their day in court'."

Frankly, the Penrose inquiry is increasingly being seen in the same manner as the Taylor inquiry into Hillsborough was seen. Families were dismissed from the Hillsborough inquiry. Years on, a panel was set up in Liverpool that finally gave families the opportunity to relate their stories and express their concerns. That has, of course, led to an altogether different outcome from the outcome of the Taylor inquiry. I see a lot of parallels between what happened with Penrose and what happened with the Taylor inquiry, which, it has pretty much been recognised, had a controversial outcome.

In future, we need to look at the purposes of an inquiry. The position that Lord Penrose adopted as chairman was very defensive of so-called suffering victims. Some of us would have been prepared to give our names and stand up and be counted. That did not happen. Apart from the fatal accident victims, the 13 people who appeared as witnesses were all given pseudonyms. If I had been one of those individuals, I would have been prepared to stand up and be counted, just as the expert witnesses were. It was very much them and us. Professional witnesses were exposed to taking the oath and giving evidence, whereas the approach to the evidence that patients gave was somewhat dismissive.

10:00

For example, a lot of assumptions were made about the consumption of alcohol among those who died from hepatitis C. However, the only way in which one can establish how much alcohol someone is consuming is to be with that individual every moment of every day. Particularly in the west of Scotland, doctors often make assumptions about alcohol on death certificates. Death certificates have been improved since this disaster took place. However, a number of approaches need to be taken in looking at the inquiry system and in following up the inquiry.

The Convener: Richard Lyle has a third and final question to move us on in this theme.

Richard Lyle: Dennis Robertson has a question, so I will let him in first.

Dennis Robertson (Aberdeenshire West) (SNP): It is just a quick supplementary question on death certificates. You are saying that the cause of death could have been hepatitis C or whatever but, because it was thought that the person had abused alcohol, that was what was on the certificate. However, we now have a much better system of recording cause on death certificates. Are you content with the new format of death certificates? Do you think that that will improve the recording of the facts surrounding the cause of someone's death?

Bill Wright: Some improvements have been made. Previously, anybody who was medically qualified could write a death certificate. However, the legacy for us has been considerable difficulties. To be honest, I am not familiar with the matter in detail and would have to write back to you about how we view it.

Petra Wright: Many deaths that were attributable to hepatitis C have been attributed to other things. Since hepatitis C became known about, evidence has emerged about areas apart from the liver that are affected by it. People who have died from cardiovascular disease, stroke and non-Hodgkin lymphoma will not have had hepatitis C on their death certificate. The number of deaths that have been attributed to hepatitis C is a lot lower than it should be.

Bill Wright: Could I follow up on that, please?

The Convener: Yes, but you are taking time from some of the other questions.

Bill Wright: It brings us to the next issue, convener, which is financial recognition.

There is a surprising frequency of death from cerebral brain haemorrhage being recorded on death certificates. Many victims died at what is called stage 1 with respect to financial recognition, but they died of cerebral brain haemorrhage. The most famous of them was Anita Roddick, who founded the Hepatitis C Trust. It is common for cerebral brain haemorrhage to be recorded on death certificates, but the problem that we have is the medical input to relate cerebral brain haemorrhage to hepatitis C. In the case of haemophilia, we have the difficulty that cerebral brain haemorrhage is a possible cause of death among people with bleeding disorders and it appears that there is an increased risk of cerebral brain haemorrhage when someone also has hepatitis C but, at the moment, in respect of financial recognition, that is not recognised.

The Convener: Some of that is reflected in the written evidence, of course, but it is good to get it on the record.

Philip Dolan: I want to pick up on one specific point. During the inquiry, when expert witnesses came in, there were three or four doctors who all sat close together giving evidence. They were asked about certain things concerning hepatitis during the 1970s and 1980s, and all three said in their evidence that they did not recall. I have put that in my submission. They may not recall that, but a few minutes later they could recall events from 10 years previous to that and 10 years afterwards. Every person, whether they have haemophilia or had a blood transfusion, will remember the day and the hour when they were told that they had hepatitis C and the impact that it had on them and their families.

It is not just about hepatitis. Any time someone is told bad news, they will remember it clearly. They may not understand what they are being told, but they will remember being told, so I find it surprising that those witnesses would make a statement like that. Maybe they had a loss of memory on that particular day, but I know when I was told. I know the day. At my age, I can remember the second world war being declared—I was sitting in the garden and I was about three years of age. There are things that you remember clearly.

Richard Lyle: I have been involved with the issue for the past few years. Last year, I had the opportunity to go and see the emotional and hard-hitting play "Factor 9", which conveyed to me the effect that hepatitis C has had on many sufferers. I acknowledge what Miss Wright said. People have been suffering for more than 30 years—far longer than the length of time that I mentioned earlier.

Last night on social media, many people were discussing today's committee meeting. I promised on social media that I would ask about one of the points that arose. I apologise if I am jumping ahead, convener, but people want closure on a Scottish settlement for financial support, as Bill Wright said. I am not going to put a figure on people's lives.

I am sure that all the witnesses are members of the contaminated blood financial support review group that has been established. I compliment the Cabinet Secretary for Health, Wellbeing and Sport on what she has done in recent months and I acknowledge the apology that the Scottish Government, the First Minister and the cabinet secretary gave to all sufferers when the Penrose report came out. The group is looking at recommendations. I do not want anyone to give me figures, but I understand that many people out there want closure now. We have had the inquiry and a lot of people called it a whitewash and are now saying, "Enough's enough. We've suffered for the past 17 years or 30 years and you've now come to recognise that we have a legitimate claim." I do not want to pre-empt other members' questions, but what do the witnesses think would give people a rightful closure on what they have suffered over a number of years?

The Convener: A rightful closure is a good start. What would be a rightful closure?

Bill Wright: That is a difficult question, because it will be different for every individual involved. Frankly, for some people, it is not money that matters. For many people, the apologies by the First Minister, the cabinet secretary and the Scottish National Blood Transfusion Service meant a great deal. Over the past year, we have made considerable progress.

In the case of haemophilia, considerable progress has also been made, because we now have a national haemophilia committee in order to avoid the circumstances that happened 30-odd years ago, and patient groups will be much more closely involved in the way in which haemophilia treatment and support are exercised. A number of steps have been taken, but the big question for many people is that of financial recognition, and I use that term advisedly because it is one that was drawn in by a legal official from the Government during the production of the review group's report.

We can live with the term because, if we go down the route of legal compensation, the story will continue for years and years. We do not want that. We want closure or as near to it as possible to try to get money to people as soon as possible. Each individual will have a different idea about the correct amount of money. If we were to treat every individual case by case, as in Ireland, we would wait another 10 years. In Ireland, 10 years on, cases are still being argued over in the courts. We do not want that. We want to get money to people tomorrow. We are aware of families in which it is likely that the infected partner will die and they want to pass away in the knowledge that their widows are properly looked after.

I must impress on the committee the need for urgency. The widows in this story are being treated really shoddily. I have spent a great deal of time sitting with them. I recently spent five and a half hours with one widow because of how shoddy the current arrangements are. I must impress on you in the strongest possible terms the need not to obstruct the process but to ensure that people who have lost loved ones do not have to wait another 17 years to get justice. We need the Government to move on the matter and make an early announcement so that the people who are in fear for their partners' lives at least know that, when they pass on, there will be some sound financial support for the people who are left behind.

I am sorry about that, but the matter is very dear to my heart.

Petra Wright: The recommendations that the review group made will go a long way to beginning the end for many people.

One of the big things for me was the silly stage 1 and stage 2 distinction. The number of people at stage 1 who have died or are unable to work because of the other medical issues that, as the evidence now shows, are caused by their hepatitis C is unrecognised. They get no help. We want to pursue that in widening the criteria for the Skipton Fund stage 2 payment so that more people can access an income and all the other benefits—if we can call them that—of having the impact of their hepatitis C on their health recognised.

I am talking about even small things, such as the stigma. At the public meeting in Perth to which I went, I spoke to one gentleman who was into his third generation of keeping a secret. He got hepatitis C from a blood transfusion. He and his wife had kept it from their son while he was growing up. The son had grown up and knew all about what had happened to his father but now that son had a son and the family was once again back to trying to keep that horrendous secret and keep the stigma away from the third generation.

10:15

Philip Dolan: Bill Wright is correct that some people do not necessarily want money; they want an explanation of why it happened. We have said all along that that is the case.

The committee has the Scottish Infected Blood Forum's note of dissent to the review group's report. The forum represents probably two thirds of the people who got hepatitis C, according to Lord Penrose's figures—if you believe in statistics at all. Our concern was around splitting up people into stage 1 and stage 2, which we believe should not be done. A lot of people who are in stage 1 are very ill.

The document that I gave to members earlier, which you can read at your leisure tomorrow or later, sets out the stories of people and the different types of experiences that they have had. One is the story of a lady whose husband had haemophilia. It depicts the impact on the whole family when he died. It is basic things such as, "If he had been alive, he would have walked my daughter down the aisle last year." Those are the sort of things that affect the wider family.

I hope that some members will be able to come to the event that we are holding in the Parliament building tomorrow night, where the stories will be told. People will appear via video film to tell their stories, and some stories will come from the scoping exercise, where people tell what happened to them. I am not a person who gets excessively emotional, but I feel as much about those stories as I do about anything else.

With regard to differentiating between one person and another because one happens to be deemed to be at stage 1 and the other at stage 2, I have nothing against people at stage 2 getting increased moneys. The issue is the creation of a difference between one person and another when their circumstances appear to be the same—they both have families, they both cannot talk about their condition, and all the rest of it. Those are important things.

The review group came out with a particular view, and in response we put out a note of dissent. We only recently discovered—after the review group's report was published—that the 10-page commentary that we had put in with the views of people on what they were going through had been left out. I understand that the reason why it was left out was that some parties in the review group had wanted it silenced. They did not want it to be published, so it seemed to be censored. I do not know which parties they were, but I know that an emphasis was to be put on people at stage 2 getting money. We have nothing against that, but the fact is that the majority of people are at stage 1 and those who are seeking financial support will get nothing.

The Convener: As you would expect, the committee gets into these kinds of situations all the time. This week, in fact, we will be speaking on matters on which a majority view and a minority view have been expressed. Having read the background papers for this session, I can see that there are differences and minority and majority views on this matter; indeed, we have heard them reflected today. As we try to develop that theme, I will give the witnesses an opportunity to come in.

We have mentioned closure, but for some, there can be no closure without the apportioning of blame and a real understanding of what happened. No matter whether they are generous or ungenerous, the financial arrangements will not satisfy everyone.

The point about the limitations with regard to those to whom support is provided has been well made, in relation not just to hep C but to some of the other conditions that have been mentioned. That point has still to be argued and won. I am no expert, but that is my observation.

I give all that as context, but I also have a follow-up question. On what issues do you believe that you can reach a majority opinion with people who have been involved in this matter for so long now? Are they currently in agreement? We know that the priority is to put in place arrangements for financial support. I can see that everybody agrees with that, so we can seek closure on it, but the question is how we get that closure before we deal with some of the other outstanding issues.

Philip Dolan: I agree, convener. You said in your opening remarks that committees have agreements and disagreements, but at least in the Scottish Parliament the views of those who dissent are openly recorded. Those kinds of views were not recorded in the review group report, despite the fact that we contributed to it.

As for closure, there are those who certainly do not want anything, but the fact is that the width of the gap and the distance between the financial arrangements suggested for those at stage 1 and those at stage 2 is not ideal. People are going to die. Recently, it was put to me that there is a new treatment for hepatitis C, and there will be some folk who will say that, as a result of that treatment, people will be clear of it. However, we know from the case of the nurse from Lanarkshire who was told that she was clear of Ebola—and, indeed, from talking to other people—that although a new drug might appear to leave someone clear of a disease, that disease can still reside in the body.

When Mr Chisholm was health secretary in the Parliament in 2004, all that he offered people at stage 1 or stage 2 was an ex gratia payment. He

and I might have been on opposite sides of the table in disagreeing on that, but he made the payment, and I was glad that that forced the Westminster Government to follow suit. That showed that we were at least doing things right in Scotland.

We have argued about the payment. In 2003, Lord Ross recommended £50,000, but that figure was never reached. At the moment, the review group has recommended that an extra £30,000 be given to people at stage 1. Those people got £20,000 in 2002 or 2003—or over 10 years ago—and £30,000 would only bring them up to the amount that Lord Ross recommended in 2003.

Lord Ross also recommended that the money would be for the harm caused to people by hepatitis C, so the review group's recommendation only takes us back to what was recommended more than 10 years ago. It is good to know that people at stage 2 are going to get considerably more money—even though it might still not be enough—but the fact is that if two people, one at stage 1 and one at stage 2, get some financial package, they will at least have some help to get on with their lives. If one gets nothing, they will be distraught. People do not know how they will be able to bury their loved one when they die, because they do not have any money.

The Convener: As the background paper makes clear, we are also talking about a complex set of arrangements. Does Mr Wright have a comment on that?

Bill Wright: The breakdown of stage 1 and stage 2 is difficult because, when the review group started its work, it did not start with a blank sheet. In effect, we were having to operate on the basis of Lord Ross's original recommendation to you, Mr Chisholm, when you were minister. Philip Dolan was on the Ross committee, which recommended the breakdown between stage 1 and stage 2. Of course, medical understanding has moved on since then, but Petra Wright would be in a better position than I am to talk about the extrahepatic effects.

We did not have the advantage of medical representation on the financial review group, and if there is any weakness in the review that we conducted, I suggest that that might be it. Nevertheless, we do not want to go back to a blank sheet. We think that it is better for everyone to have at least £30,000 in their bank account as a result of the review, which is what will happen if the recommendations are followed. I should also make the point that £30,000 is by no means a proposed ceiling. Under proposal 4, which relates to "Support and Assistance Grants", we recommend an increase in flexibility to draw on the scheme for, for example, funeral costs, whether someone is at stage 1 or stage 2 or is a widow or whatever.

This has not been mentioned yet, but it is worth recognising that 60 people were infected with both HIV and hepatitis C by the disaster, and 40 of them died. That element has been forgotten in the whole story. Those people were hit with a double whammy.

We are particularly keen that the HIV provisions be brought up to Scotland, because currently the administration of all the schemes takes place down south. There is no Scottish representation whatever on the Macfarlane Trust. We think that the whole thing needs to be administered from within Scotland. If HIV is included, we will be able to do that.

We and the Hepatitis C Trust supported the report because it built in flexibility. Bullet point 4 of proposal 5, on "Further work", says:

> "The current thresholds for Stage 1 and Stage 2 of the Skipton Fund should be the subject of a specific, evidence-based review".

That could encompass many of the concerns that Philip Dolan has raised about extrahepatic effects, but as I have said, Petra Wright is probably better qualified than I am to talk about that. We would like to draw in medical representation on the matter. There are considerations such as fatigue, which is an extremely common theme for people who are affected by hepatitis C, but it is difficult to provide evidence of that, because fatigue is self-reported rather than identified through blood samples or whatever. We need to find a way through that, for people who are at stage 1 but are no longer able to work because of the impact of the fatigue. The evidence is that such people simply do not have the energy to go to work every day.

Petra Wright: I can relate this to my first involvement with hepatitis C. When I was first diagnosed, my biggest symptom was that my memory seemed to have disappeared. I am going back to 2006, and to one of the first conferences that I attended. We were shown new magnetic resonance imaging scans of brains of people with hepatitis C, and we could see where the brain damage had occurred.

At the time, hepatitis C was known to cross the blood-brain barrier; the active hepatitis C virus had been found in the brain, post mortem. One of the first things that I learned about the disease was that it is systemic and affects multiple organs around the body. However, liver damage and cirrhosis were the first things that were recognised, and they seem to have taken precedence throughout. Indeed, hepatitis C is probably an incorrect name for the disease, as it relates too much to the liver.

As I have said, though, that was my first involvement—finding out that I was neither going mad nor suffering from early-onset Alzheimer's but that the reason why my memory had escaped me was due to hepatitis C. It was disturbing not to be able to remember things.

10:30

Another issue that has come up relates to Dame Anita Roddick's passing as a result of a cerebral haemorrhage not long after she was diagnosed. In the past year or so, a lot of evidence has come out about things that are now being linked to hepatitis C, such as cardiovascular disease, strokes, diabetes and other things that we are concerned about in Scotland. Kidneys can be affected, too; Natalie Cole had to get a kidney transplant as a result of hepatitis C. That range of issues seems to have been ignored to a great extent by the medical profession. I have heard of people being successfully cured of their hepatitis C infection, but then having to go along to their doctor with the other on-going factors. One lady told me that her general practitioner had said to her, "Well, I don't know. Your hepatitis C is cured but you are still suffering from these other things as well."

The latest sexual health and blood-borne virus framework that has been published by the Scottish Government, which covers the next five years, lists groups of people to whom priority should be given in terms of access to new drugs. Those groups are

"patients with F3/F4 hepatic fibrosis; and/or patients with severe extra-hepatic manifestations of hepatitis C; and/or patients with significant psychosocial morbidity as a consequence of hepatitis C".

There has therefore been some recognition by the medical profession of the other health issues that hepatitis C can bring, and I feel that reconvening the group and taking a deeper look at the issues will help not only the people in this disaster but the thousands of other people who got hepatitis C by other means. We could go a long way towards helping those people.

Malcolm Chisholm: I want to ask Philip Dolan a question to ensure that I completely understand his position. Is your main concern about the recommendation with regard to the £50,000 level, or are you still concerned about the distinction between stage 1 and stage 2?

Philip Dolan: Basically, we are concerned about the difference between stage 1 and stage 2; indeed, many members feel that there should be no stage 1 or stage 2. There might be some way of putting in place tiers of payment; however, the level of payment that people will be offered is seen as derisory. Many people who have started on this road feel that, at the end of everything—the Penrose inquiry and so on—they are no better off than they would have been if the recommendations of Lord Ross had been implemented in 2004. The majority of people will only ever get what Lord Ross recommended. They know that there were difficulties at times and difficulties elsewhere.

A lot of people want an explanation and some support to be put in place for people who have been affected. The setting up of the Scottish Infected Blood Forum created an opportunity for people who had contracted hepatitis C through blood transfusions to talk about their situation for the first time. Haemophilia has been around for a long time, and people knew about hepatitis, but people who had been infected through a blood transfusion felt stigmatised and unable to talk to anyone about it. One of our members, who was the guidance teacher at a big school, said that she was first diagnosed as having ME; however, when she was then told that she had hepatitis C, she was unable to talk to her fellow teachers, because she felt that they would assume that she was a drug addict. That is where the issue of the assumptions that people make comes in. There is a lot of that type of thing.

As for Malcolm Chisholm's question, a number of people are not interested in the money, but the majority are. I remember when I was campaigning and so on a doctor with whom I used to sit on tribunals telling me, "Oh, you shouldn't be campaigning about this. Doctors are good people—they don't make mistakes." That was fine but, when Mr Chisholm announced the ex gratia payment, I got a phone call at 7 o'clock that night from the same doctor, asking, "How does my cousin get this money?" No one had ever worked this out. His cousin could probably have spent £20,000 in one night at the casino, but with the ex gratia payment, no differentiation was made between rich and poor. There was just a recognition in terms of that payment.

The biggest issue is the gulf between stage 1 and stage 2. It would be good if we could find some way of getting away from stage 1 and stage 2 and having some other system for people to get financial aid. I am sure that a lot of people in stage 2 recognise the difficulties being experienced by those who, by chance, have not had a doctor come and say to them, "You are now in stage 2." They will be having all the effects that Petra Wright has talked about; they will be suffering from a whole range of illnesses probably associated with having hepatitis, but they will just not have developed cirrhosis to a certain level.

Bill Wright: We have members in stage 1, stage 2 and what is called stage zero, which is where people have applied to the Skipton Fund for £20,000 but have been refused because their

medical records—in other words, any record of their ever having received a blood transfusion—have been lost. We have members who have had blood transfusions, too.

I want to come back to my earlier comment about our being where we are as a result of what we inherited. We considered the Canadian system, which has six stages; my colleague Dan Farthing-Sykes, our chief executive, and I had some informal discussions with Government officials about having a stage 1A—or whatever it might be called—to bridge the gulf. Our concern is that, if we start to rewrite the review group's proposals, we will be a year on and no further forward. There will be further deaths. There will be people who will not have received £30,000—although they might well do before the election. We do not know when we are going to get that £30,000 to people. We think that it is far better to get the money in and give people access to the new support and grant fund, which will take some time to establish.

Petra Wright has said that further work has to be done. This is by no means the end of the story, but there are some recommendations in the review group's report that can be acted upon immediately. That is my concern; I want to get some money into people's bank accounts, and we have an opportunity here to do that.

It is very important to put all that into the context of the wider UK situation. As you might be aware, the UK Government has announced that a further £100 million will be dedicated to the matter for the rest of the UK. We have had a brief look at what is being proposed under the consultation, and we understand that the funding will include the cost of treatment with the new drugs, which amounts to £60,000 per person. That takes out a very large chunk of the £100 million.

On 25 March last year, the day when the Penrose report came out, the Prime Minister announced a further £25 million. On the face of it, that appeared to be a pretty generous interim payment, but when I wrote to him, asking him how it was to be distributed and how the Government had reached the £25 million figure, I never received a response.

I say that to provide some context, because on 25 March last year Jackson Carlaw, the spokesman for the Conservatives, said that he was personally rather proud of how Scotland had dealt with the issue, given that we had set up a group of people who worked with Government. We had arguments, and the discussions at times were tense—they were tense between all of us at some points—but we still came up with the report. I commend that report to the committee, but we need to move ahead and enact as many of the recommendations as we possibly can.

The report acknowledges that further work has to be done on the issues with regard to stage 1, and we do not shy away from that. As I have said, we have members in stage 1; indeed, I have spent time with a stage 1 widow, so we have seen how unjust the situation has been. However, there are hits that we can make at an early date, and I impress on the committee the need to get ahead and take what action we can. We need to engage the medical profession and academics in exploring issues around fatigue and mental health problems that have arisen as a consequence. I am sure that Petra Wright can comment on that.

Petra Wright: Yes. I was going to bring the discussion to a good conclusion by saying that, as recommended by Penrose, we need to find the people who still have to be found. The Hepatitis C Trust is on the short-life working group looking at that aspect.

However, although we are happy enough, we are getting a bit impatient about it all. For instance, it is estimated that only 200 people in Scotland who acquired hepatitis C through a blood transfusion pre-1991 are still to be found. I would dispute that number and think it extremely low, especially when I think back through recent history. There was an infection in Edinburgh royal infirmary's accident and emergency department; an in-patient was infected in Lanarkshire a couple of years ago; and there was a rogue dentist in Ayrshire. There have been many opportunities in the past for people to have picked up infections through NHS treatment other than through direct blood transfusion.

It would help a lot if we had a degree of screening across the country, such as the birth cohort screening in America in which everyone in a certain age group is requested to go and have a hepatitis C test. We do not think that spending a lot of time trying to figure out how to find only 200 people will prove to be cost effective in finding the people whom we need to find. We need to look at the whole community—I hope that the guys sitting beside me do not mind me saying this—of people out there who have hepatitis C and do not know it.

Philip Dolan: Just to add to that, I am also on the working group that was set up under Professor Goldberg. Interestingly, it has met only once, and I keep trying to find out when it is going to meet again. I understand that the difficulty has been that some of the people who are required to be on the working group, such as doctors from the blood transfusion service, are never available. Although the group members were appointed at the same time as the review group, we are now a year on, and we are no further forward.

When I come to meetings such as this one, I carry various documents with me. I have a letter dating back to the 1980s from the senior people in

blood transfusion and the Scottish Office, saying that it was necessary to look back. However, we seem not to have got anywhere in the 30-odd years since that letter—which you can see if you want—was sent. I am just going back to what Petra Wright said in that respect.

The Convener: Petra, you mentioned the figure of 200 people who have still not been identified. Are you aware of how that number was identified? Why is it 200? Where did a nice round number like that come from?

10:45

Petra Wright: I have no idea where it comes from. It seems to be a ridiculous number.

The Convener: Have you collectively done any work to estimate what the number is more likely to be?

Petra Wright: No, not in particular. A lot of people who applied to the Skipton Fund were refused because they did not have enough evidence, and a lot of people are recorded by Health Protection Scotland as "Don't know" under the criteria for transmission route. We can sometimes be too narrow in our search criteria and it would be more cost effective to cast a wider net in the hope of helping more people.

I always relate the issue to watching "Casualty" or "Holby City", which always amuses some people. People are brought into accident and emergency and they are given UFDs, LFTs and whatever else. Why not just tag on hepatitis? Why make it different? Testing for it can be made a normal part of healthcare.

The majority of people—particularly women who have had babies—will say, "I can't have that because I've been tested for it." However, they have not. They will automatically be tested for HIV and hepatitis B, but they will not be tested for hepatitis C unless they are a known drug addict or come from a high-risk area, such as Pakistan. There are many missed opportunities to find those people. Do we want to find them?

The Convener: That question is left hanging.

Rhoda Grant (Highlands and Islands) (Lab): I do not think that the witnesses are poles apart in what they want us to see.

The subject of tissue samples for research has been brought up. Currently, tissue samples are held, but the people whose tissue samples they are are not aware that they are being held and, indeed, whether they are being used for medical research. I want to know your thoughts on that and on how easy it would be to identify the people whose samples are being held. Given the evidence that we have received, it seems to me that it might be easy if they could be identified from research. That seems to be one of the concerns. How would people go about getting permission to use samples and informing people that they are held?

Philip Dolan: That is an interesting question. For 12 years, I was the vice-chairman of a research ethics committee for the primary care trust in Glasgow, and I have also dealt with haemophilia at various times. I stick to the Helsinki agreement. When a sample is taken from a person for research, it is for that specific and particular topic at that time. Someone has to go back to the person to seek their permission if they want to use a sample for another reason.

Way back when various pieces of research were being done in the red-light district in Glasgow, street workers were tested anonymously. The question cropped up that, if those who were tested made an insurance claim later without mentioning that they had been tested—they might have married a millionaire and wanted some money—they might find that they would not get anything because insurance companies will, sure as fate, find out a reason for not paying.

If I give a specimen for something, I give it for that particular thing and I do not want it to be used for anything else unless I am asked for permission. I might well be quite happy to give permission, but the regional approach to ethics was that a person should give agreement and sign for a particular test or survey. I would have reservations. That is a personal viewpoint but it was the view that was held when I was involved with the ethics committee.

Bill Wright: I am a wee bit reluctant to enter into that because the way that the samples are administered is beyond my technical expertise. Will you enlarge on an example a wee bit, Ms Grant?

Rhoda Grant: My understanding is that samples that could be used for research are anonymised so the excuse given is that it is not possible to track them back to the people to whom they belong. There are concerns that samples from people who are living may be held and used for research. Those people need to know whether that is the case and give their informed consent if it is.

Bill Wright: Yes. I can think of instances in which that might be a concern, such as CJD. Unfortunately, as well as having been a victim of hepatitis C and HIV, the haemophilia community was informed in the 1990s that there was the possibility of exposure to CJD for a very discrete period over a couple of years. Previously, CJD had only been thought to be passed through beef but it appeared that, because of the concentrates,

it might also have been passed through blood products.

There is a big ethical question about that because, in Scotland, as in any developed country, research is needed. We need to get the medical ethics right and we have to consider the detail. Haemophilia Scotland says that, as a general rule, anybody who gives a blood sample that is to be used for research purposes should be made well aware of what the research purposes might be and decide whether they want to be informed of the outcome. I must confess that I do not know what the exact written ethical rules on that are.

Dennis Robertson: The Scottish Government has agreed to fund the Scottish Infected Blood Forum and Haemophilia Scotland for the next three years. Do you have a common purpose for what you will do over the next three years and do you expect that there will be recurring funding after that?

Philip Dolan: Although the money was announced several months ago, it is just coming into our bank. It might be in our bank this weekend but it has not reached us yet. We have been soldiering on on my superannuation and various other people's donations. I have a list of receipts to which the funding might go.

The main purpose of the Scottish Infected Blood Forum has been for people to discuss the matter. People who have been infected through blood transfusion in particular have never had an opportunity to talk to somebody else who has hepatitis C and it is amazing to have the opportunity to meet, discuss, share with and support one another through the forum. You will find that a number of the people who told their stories in the document that I gave the committee and will speak about them in the film that will be shown at our event tomorrow night have said what an advantage it has been to be able to go to the forum.

At the moment, we publish documents and support people. My phone rings regularly. We hope to put in place a part-time worker who will work in the same way as Dan Farthing-Sykes does for Haemophilia Scotland.

Did you ask something else?

Dennis Robertson: You said that the Scottish Infected Blood Forum provides support, which is excellent, and I dare say that you provide appropriate information and advice. Do the two organisations have a common cause and a common aim to maintain awareness of the issue and call for appropriate outcomes?

Philip Dolan: The answer is yes. Obviously, we are here today because we have been campaigning for financial and other help and support for people. For instance, we have been campaigning for counselling—there is a suggestion from the review group that counselling could become available.

There is also an opportunity to improve treatment. There are new treatments around, but again, whether they are made available to someone depends on where the person is. I am one of those reluctant people who are wary about going on to new treatments, having lived through getting snake venom away back in my early days, being given cryoprecipitate and factor VIII, which gave me hepatitis C, and getting letters that said, "We note you've received blood products from someone who has since died of variant CJD." When I talk about that in my household, the best thing is to get the dictionary out. All the dictionaries in my house have a bookmark at S, where I can find "sympathy".

The whole purpose of what we do is to try to improve treatment. I hope that one of these days someone will find a cure. In the film, you might see a doctor saying, "With new treatment you'll be cured." However, as I said, you can never guarantee that the disease is absolutely cured, because it can lie dormant somewhere else in the body.

We are working to improve the lives of our members and give support to families.

Petra Wright: The Hepatitis C Trust has a patient helpline, and anyone with hepatitis C can use our services. We run a counselling service for victims of contaminated blood, which is funded by England and Wales—I cannot remember whether it is through the Caxton Foundation, the Skipton Fund or something else like that. We have a good understanding of people's needs.

We run a couple of health days, to encourage people to have treatment, at which we explain the advances that have been made over the years in relation to hepatitis C.

Bill Wright: We have a set of objectives, which are set out with the Office of the Scottish Charity Regulator and overlap a great deal with those of the Scottish Infected Blood Forum. We do not specifically name HIV or hepatitis C in the objectives, but for obvious reasons a considerable section of our membership and the population that we seek to support were infected. In the work that we do, there is considerable overlap with the Scottish Infected Blood Forum and the Hepatitis C Trust. We have learned a great deal from those organisations, as well as from other organisations, such as Waverley Care, which deals with HIV.

I think that the implication of Dennis Robertson's question was about how to get the best bang for your buck when spending public money. To a

certain extent, we are potentially drawing on the same pot. We can see advantages in the Scottish Infected Blood Forum having a part-time officer, because the person would be in daily contact with our office in Edinburgh, as well as with Petra Wright, who administers the Hepatitis C Trust in Scotland.

11:00

From our perspective, it is very useful to have secured some public funding to have people working for us. However, we are looking to the future and trying to be more independent. Ultimately, as a charity, we do not want to be dependent on Government because at some stage in the future we may well wish to be critical of it. There is a balance to be achieved there regarding the funding of all health charities.

The Convener: We have had a wee discussion about public funding—how much is the public funding of the various bodies? Do we know?

Petra Wright: The Hepatitis C Trust does not get anything at all in Scotland.

Philip Dolan: The funding that we have been given is £25,000 for this year.

The Convener: Do you not get anything, Mr Wright? Are you not expecting a cheque in the post this weekend like Mr Dolan?

Bill Wright: We already have it.

The Convener: It is in the bank; it is not in the post. But you are not telling us what it was.

Bill Wright: We have an arrangement. We have had £75,000 this year.

The Convener: Okay. I asked about that just to complete the picture—not for any other reason.

Dennis Robertson: Is the £75,000 for three years?

Bill Wright: No. It is for this financial year, until 31 March next year.

The Convener: I presume that you welcome the three-year funding.

Bill Wright: Yes.

The Convener: Committee members have no more questions. Mr Dolan is indicating that he wants to speak again. Of course you can have the last word, Mr Dolan. Indeed, if any of the witnesses wants to add anything, they are welcome to do so. We have all your written evidence, which is extensive, but if you have any other issues that you expected to be asked about and wish to place on the record, please do so.

Philip Dolan: In our submission, we mentioned the fact that on 4 March 1998, there was an adjournment debate about factor VIII in the Westminster Parliament. It was to do with getting proper blood products. The debate was introduced by Roseanna Cunningham and supported by John Swinney and John McAllion. It pointed out the case of a young person in Scotland who had been refused the correct treatment.

For your benefit, if you want to read it, you will see the story of that young person on page 20 of "Living Well with Infected Blood: case studies on experiences of contracting and living with a virus". He was the youngest-ever person in Britain at that time to be put on a treatment for hepatitis C, which did not work. He was aged eight. I just want to draw attention to the stories of the people in the case studies booklet. There is another story in there about a person who got hepatitis C as a result of it being sexually transmitted by his wife, who had had a blood transfusion.

Such cases are seen as rare but they exist. For many people, not just the people in the studies, there are difficulties in getting benefits. They can get no benefits for months and months until they go through various tribunals and so on.

You will also remember the stigma at school. When people heard that a pupil had haemophilia that was fine, but when HIV came around, they wanted that same pupil to be removed. Suddenly the situation arose where a headteacher's niece or someone like that would happen to be in the same class as them, so the pupil would be moved away in order not to be close to them. Such stories cropped up time and time again. As we have said, the impact was to increase the stigma associated with people.

That is a reminder of some of the main issues that arise because a person has hepatitis C and the assumptions about what that means. The impact of tiredness has been mentioned many times. I mentioned the length of time that it sometimes took for a person to be told that they have hepatitis C. In 1991, I asked a consultant whether I had hepatitis C. I was told that there was nothing to be bothered about. I went back and got my medical records, which I gave to the doctor. The doctor said, "Oh—I see that in 1978 we knew you had non-A, non-B." That is the forerunner of hepatitis C.

Ethics have been mentioned. Ethically, in order for someone to test someone else, they should ask for permission. They should also inform that person afterwards about the results, because a person must make decisions about the condition as, for example, it can be passed on to their partners.

Others have complained that it was very difficult to get an appointment with a hepatologist, even though one had been requested. As has been

mentioned, people have been regarded as a junkie or a leper. Such stories come out in the case studies booklet.

In some cases, there has been a lack of professional understanding. Without reading the case records, a nurse would hand over a box of needles and say, "You know what to do with them." Of course, the person did not know what do, because they had not been told that they had hepatitis C.

The booklet will tell you a number of stories in which people's marriages have broken up, or they have lost their homes because of financial problems. Those are the practical impacts that the condition has had.

The Convener: You are finishing on a significant note, as I am sure that the committee would agree. The issue is not about medical titles or formulas for compensation, but about people. The committee genuinely understands that.

Many of us have been involved in the journey that you have described, although not in the same way that you were. I and others—Malcolm Chisholm has been mentioned—were on the original Health and Community Care Committee. Indeed, the cabinet secretary, who is waiting outside the door, was on that committee when we first started this long journey.

It is on that note—that the issue is about people—that we will conclude this session. We know that from our casework as well as our committee work. We have dealt with many constituents who have found themselves in a frightening situation. We have been in a position to help where we could.

I will allow the briefest of comments by Mr Wright and, of course, I will not deny Petra Wright a final quick word, if she wants one. The cabinet secretary is with us now, and we need to proceed.

Petra Wright: We are running out of time. We have spent 30 years waiting. I hope that the Scottish Government will accept our recommendations from the financial review group and at least let us make some forward movement towards finishing this.

Bill Wright: I thank the convener and the members for having us here today. I am aware that some of you, after a long period in Parliament and after sitting on the various health committees, are retiring. Others may or may not return. I hope that those of you who are here today, having heard this story, will return, because there is a job to be done in future sessions of Parliament in order to ensure that what has been recommended is seen through.

I understand that you will be going into private session to discuss both this evidence and that of the cabinet secretary. I very much hope that you are able to support the recommendations and that we can move forward. You talked about closure. Supporting the recommendations would be a big step towards that.

Philip Dolan: Could I—

The Convener: No. I am sorry, Mr Dolan.

We are not going into private session. We will take evidence now from the cabinet secretary and her colleagues. The witnesses are welcome to stay for that and to watch from the public gallery.

I thank you all for your attendance, the time that you have given, the written evidence and, indeed, the oral evidence that you have presented this morning.

I suspend the meeting to allow a changeover of witnesses.

11:10

Meeting suspended.

11:15

On resuming—

The Convener: I welcome the cabinet secretary and her officials for the second evidence session this morning. Shona Robison is the Cabinet Secretary for Health, Wellbeing and Sport, Gareth Brown is acting head of the health protection division in the Scottish Government, and Professor David Goldberg is from Health Protection Scotland.

I give the cabinet secretary this opportunity to make some opening remarks.

The Cabinet Secretary for Health, Wellbeing and Sport (Shona Robison): Thank you for the opportunity to speak to the committee today about the Penrose inquiry report. The Penrose inquiry scrutinised tragic past events in detail, but since publication of the report, our focus has been on the future and on trying to support better those who have been affected.

I have met many of those who have been directly affected over the years, and I continue to meet the key campaigners regularly. It is clear that they have faced a multitude of physical, mental and social impacts that continue to this day and will, in many cases, endure for the rest of their lives. For all the people who have been infected and for their families there are clearly complex and interacting impacts on overall health, life expectancy, quality of life, mental and emotional wellbeing and the ability to work.

Following publication of the Penrose inquiry report, I and the First Minister apologised on

behalf of the Government of Scotland and the NHS in Scotland to everyone who has had to deal with the devastating impacts, and I reiterate that apology here today. Expressions of sympathy and regret obviously go only so far, and there is an on-going need for direct support systems, financial and otherwise. There is a need to make available intensive support, including mental health support if appropriate, for those who have been most severely affected.

Lord Penrose's single recommendation was that the Scottish Government should take all reasonable steps to offer a hepatitis C test to anybody who might have been infected before 1991 by a blood transfusion and who has not already been diagnosed. We accepted that recommendation and have considered carefully how to take it forward in the context of a previous look-back exercise in 1995 and awareness-raising campaigns that took place as late as 2008. We established a short-life working group, chaired by Professor David Goldberg, to consider the recommendation further. That group, which includes patients' representatives, is modelling the number of people who might be infected and undiagnosed, and will consider what further action should be taken.

Beyond the work of that group, Scotland has invested significantly in tackling hepatitis C since 2008: we are recognised internationally for what we have done. Anyone can ask to be tested by their general practitioner and the chief medical officer wrote to GPs specifically to encourage testing following publication of the inquiry report.

The other major piece of work is our review of the financial support schemes. We established an independent group that included a majority of patient representatives and an independent chair to provide us with recommendations on how patients in Scotland should be supported in the future. Although there was debate and some disagreement among the members of the group, the group concluded its work late last year and provided me with a report and recommendations. I am now considering that report and will make an announcement before the end of the parliamentary session.

I am also pleased that we have provided funding to Haemophilia Scotland and the Scottish Infected Blood Forum to support their advice, advocacy and peer-support services. We also funded the Scottish Infected Blood Forum to carry out a scoping exercise to investigate the support needs of people who have been affected; that work contributed to the review. We have also funded a pilot of additional psychological support for haemophilia patients in Edinburgh that included adults and children.

I confirm that a national managed clinical network has been established for inherited bleeding disorders that includes patients in service decisions and in driving best practice and quality improvement. We continue to ensure access to hepatitis C therapies in Scotland, despite the high costs of the most effective therapies, and we support NHS boards with around £28 million per year for sexual health and blood-borne virus services.

In all those ways we have shown our commitment to supporting the people who have been affected by the tragedy. In considering how we respond to the recommendations from our review group, I am optimistic that I will be able to show that we want to maintain and improve that support in the future.

I look forward to answering questions.

The Convener: Thank you, cabinet secretary. We will move directly to questions—the first is from Dennis Robertson.

Dennis Robertson: Good morning, cabinet secretary. You have heard quite a lot of the evidence, and it will be no surprise to you that there is some frustration about the Penrose inquiry—the length of time that it took and its having made only one recommendation. I welcome the statement that you have made this morning and the support that you have provided—both financial support and advice to groups. Have you and the UK Government discussed the outcome of the inquiry? If so, can you share that with us?

Shona Robison: First of all, as I am sure you will have heard during the evidence session, Penrose was an independent inquiry. As I said at the time, I accept that the outcome of that inquiry did not meet the expectations of many of the people who have been affected; that is just a fact. However, the inquiry was independent and, if nothing else, it gave the opportunity for testimony to be given and for people's experiences to be recorded.

Clearly, the recommendation and what Penrose said in his report are as relevant to other parts of these islands and, potentially, internationally, as they are to Scotland. We expect all Governments to look at the Penrose inquiry and to take from it any lessons for their own systems.

In relation to what happened beyond Penrose, most of the discussions that we have had with the UK Government have been about the financial provisions. You will be aware that the UK has recently made an announcement about the review of its systems. The biggest priority for us is to get a better set of financial arrangements to get money into the hands of those who need it most, as quickly as possible.

There are some practical issues to address. The systems that deliver the current financial provisions are UK systems—in the main, the Skipton Fund and Caxton Foundation. The UK Government has signalled that it wants to change those systems anyway, and we want to get our own Scottish systems up and running. In the meantime, we will require a delivery mechanism for any enhanced financial arrangements. We have yet to announce the acceptance of the recommendations, but we need some interim arrangements in order to get the money into the hands of affected people as quickly as possible, while we set up our own arrangements. We have been having very good dialogue at ministerial and official levels.

One final point to make is that I was disappointed about the winter fuel payments. That could have been a quick way to put additional resources into the hands of people who feel the cold in winter because of their conditions. However, that required the agreement of all four nations, so I have expressed my disappointment very directly to the UK Government that we could not agree that.

Dennis Robertson: Thank you. In relation to the financial settlement and the discussions that the Deputy First Minister is having with the UK Government, do you anticipate that that will have any impact in the form of powers being devolved?

Shona Robison: There are a number of issues to consider. Any enhanced arrangements that we set up if we accept the recommendations would require to be funded here in Scotland. We do not have an issue with that, but the one area about which we are in discussion is support for people who were infected with HIV. Those schemes pre-date devolution and were set up and funded on a UK basis through the Treasury. We would be keen to bring all those arrangements into one system in Scotland, but we would want to ensure that the resources and some of the infrastructure costs are disaggregated and that we, along with Wales and Northern Ireland, get our fair share. There are quite a few issues to be resolved, but my main priority is to put something in place—even on an interim basis—to get the payments out to people as quickly as possible.

Dennis Robertson: That is welcome news; I am sure that those who have been affected will be pleased to hear that announcement.

We have heard about the impact on people's wellbeing of hep C and other blood-borne conditions. Have you made any representations to the Department for Work and Pensions on behalf of people with conditions such as hep C and haemophilia, given the welfare reforms that are currently taking place? Have you had any conversations with the DWP with regard to recognising the impact in terms of work and financial recompense?

Shona Robison: We have said clearly that, if we accept the recommendations and have an enhanced set of financial arrangements in Scotland—whether that involves a lump sum or additional annual payments—none of that should affect benefits to which people are already entitled or become entitled, and they should not be taxed, either. They are not taxed under the current arrangements, and we do not see why that should change for any enhanced arrangements here in Scotland. We are still in discussions with the UK Government and the DWP about that; Gareth Brown may want to say a bit more.

Gareth Brown (Scottish Government): The payments that recipients currently receive are not taxable, and there is no impact on benefits. During the financial review group process there was a clear message from people who receive payments that that should continue to be the case. As the cabinet secretary said, that is what we want. In the discussions that we will have with the UK Government about setting up new schemes in Scotland and putting in place an interim arrangement to cover the time that we will need to set up Scottish schemes, we will highlight that we want that practice to continue so that benefits are not affected by payments under those ex gratia schemes.

Dennis Robertson: Thank you. I am sure that that news is very welcome for all recipients.

Rhoda Grant: I welcome the fact that you are looking at the recommendations of the review group, but there have been some concerns. All our witnesses were keen that the recommendations be taken on board and put in place as soon as possible, but that should not be the final stage. There were concerns about Skipton 1, Skipton 2 and Skipton 0, which apply to people who could not prove that they had received contaminated blood products and therefore did not qualify for compensation. Will work on the issue continue? I have mentioned a constituent of mine who has hep C, and it is absolutely debilitating, but the person does not have chronic liver disease and therefore does not qualify for Skipton 2. There are many people in that category, and many others are in the category in which they cannot even start to apply. Will work continue to ensure that we pull in the greatest number of people who need compensation?

Shona Robison: Yes. I was struck by proposal 5 from the review group, which clearly states:

"The current thresholds for Stage 1 and Stage 2 of the Skipton Fund should be the subject of a specific, evidence-based review to create new criteria based on health impact, rather than focusing predominantly on liver damage."

That is absolutely right, but it will take a bit of time, which is why we are going through the process in stages.

First, the review group is clear in its recommendation that we should get money as quickly as possible to those who are most affected and most in need. In my view, if we accept the recommendations, that should happen. While we get that done, we should get on with the relationship between stages 1 and 2. There are international comparators: for example, Canada has six different stages—there are not simply two stages with big differences between them and no other stages in between. We recognise that there are various health needs within stage 1, and that the system does not really acknowledge that. The short answer to your question is yes—we see that as an important recommendation.

11:30

Rhoda Grant: What about people who do not qualify because their medical records are incomplete, or because proper records were not kept in the first place?

Gareth Brown: That issue was raised during the financial review. I have a couple of comments to make.

We understand that the current schemes do not require medical records; they adopt a low threshold of doubt. For example, they can rely on evidence such as a trained clinician thinking that a person was infected by the NHS—it is seen as reasonable in such cases to assume that it is so. There is not an absolute requirement for medical records; we know that some people have received payments without them.

However, there is clearly a sense in the community that some people are being refused without good reason. The core issue is about how the current schemes engage with the people to whom they make payments. There is a real sense that decisions have been made in a locked room and that the appeals mechanism is not very good because it does not communicate the reasons for appeal very well or give people an opportunity to state their case. In line with the recommendations, the cabinet secretary will reflect on the fact that we want the schemes that are set up in Scotland to be much more open and transparent than that. I am sure that there will always be decisions that people are not entirely happy with, but it is important that those decisions are communicated well, and that there is a clear appeals process in which a different set of people make that second decision. That is how we hope to set up the schemes.

The Convener: That is the direction of travel that that community would want, as we heard in evidence earlier. We need to get to that point of financial help for people, and we have heard from the cabinet secretary that there will be "enhanced arrangements" around that. Can you describe what "enhanced arrangements" means?

Shona Robison: Essentially, we have to decide whether to accept the recommendations of the review group. If we accept those recommendations, they will become the enhanced arrangements. Gareth Brown described the complexity in having a Scottish system. It will take some time to establish that Scottish system, and we do not want people to have to wait until it is up and running. Meanwhile, we are talking to folk south of the border about how we can, through the existing schemes, develop interim arrangements that will allow for payments to be made.

Before I announce what I am going to do, I want to be clearer about the delivery mechanism and about when we can deliver the system. You will appreciate that we are involved in some detailed discussions with the UK Government—and with those who run the schemes down south—to ensure that, rather than our just saying that we are going to do something, we actually have the delivery mechanism in place to do it, as well as a timeframe for getting money into people's hands. I want all that to be clear before we announce our decision. I will absolutely do that before purdah.

The Convener: Do you consider that a part-payment could be an interim measure?

Shona Robison: No. If we accept the levels of payment that were recommended by the review group, those payments would not reduce in any way. Those payments can be made, but the issue relates to how they are made—by what means and through which scheme. At the moment, it is most likely that they will have to be paid through the existing Skipton and Caxton schemes because we have not established a Scottish scheme, and it will take time to do that. The issue is the technical side of getting payments to people. Those schemes hold all the data on people; we do not hold it and it will take time for it to be passed to a Scottish scheme. I want to get the additional resources into people's hands as quickly as possible.

The Convener: So, would a Scottish set-up happen after the financial arrangements have been settled, and would it deal with further actions?

Shona Robison: I imagine that it would be a matter of setting up the Scottish system while the additional payments are being made through the existing schemes. The UK Government is currently reviewing the schemes—it already wants different schemes, so it will all change, and it will take time for us to get the Scottish end of that

sorted out. In the meantime, I want to use the existing schemes to get payments to people, if that is possible. We are in dialogue with the existing schemes about that.

That is the short answer.

The Convener: In Scotland, who would be entitled to an interim payment? Would they be entitled by the fact that they live here, or by the fact that they were contaminated here? What if the person now lives in Canada or England?

Shona Robison: The Skipton Fund and Caxton Foundation already pay recipients in Scotland. We pay into those schemes, to pay people—

The Convener: So you know them.

Shona Robison: Yes, we know who they are. The data are held by Skipton and Caxton, and we pay into the existing schemes so that Scottish recipients get the payments. Those people are already identified.

If new people were to be identified tomorrow, they would go on to the Skipton and Caxton schemes, but if we get new Scottish arrangements in place, new people will be able to go directly on to the new scheme, once it is established. Most people are already known about and are already receiving payments. The issue is that the payments are inadequate, which is why we set up the review group.

The Convener: If we know who the recipients are in Scotland, is the issue to do with getting money from the UK pot and an agreement to pay them? We know where the people are. What is preventing us from giving them an interim payment before the election?

Shona Robison: We already pay for Scottish recipients. Scotland pays into the Skipton and Caxton funds for Scottish recipients to get the money. However, the schemes are administered on a UK basis. All the information about who the recipients are is administered on a UK basis.

We are saying that, as an interim measure, we would enhance the payments that we make to the UK schemes, so that Scottish recipients would get a higher payment in line with the review group's recommendations. However, we want eventually to set up a Scottish scheme to pay people.

It is not about the UK Government paying anything; it is about our being able to use the existing schemes to pay more money to folk in Scotland.

The Convener: Do you not expect something from the announcement about UK funding?

Shona Robison: We already pay for people in Scotland to receive money, apart from money from the HIV scheme, which is Treasury funded. That is the only scheme that is paid on a different basis. We fund Scottish recipients of the other schemes.

The Convener: Yes, but I am talking about the enhancement and whether the payment goes from £20,000 or £30,000 to £50,000, if that is a good way of putting it. Will none of that be funded by the UK Government, given its announcement?

Shona Robison: If we accept the review group's recommendations, we will pay those resources in Scotland—

The Convener: Do we not get anything from the UK Government?

Shona Robison: If the schemes are disaggregated, there might be a sharing of infrastructure costs and administrative costs between Wales, Northern Ireland, Scotland and England. The HIV scheme is different. It is Treasury funded, so it would be treated differently and we would expect a share of it.

The Department of Health review makes it clear that it is talking about an England-only scheme for English recipients. The DOH is talking about taking things in a different direction from the one that we are taking. It is entitled to do that, and it is consulting on its proposed arrangements. In Scotland, we are trying to come up with the best set of arrangements to meet the needs of people in Scotland. The review group has given us an indication of what the priorities should be and it will be for us to pay for them.

The Convener: When the earlier panel talked about the announcement about finance and enhancements, which they support, they said that the new scheme would include treatment costs, which concerned them, because they thought that it would impact on payments.

Shona Robison: The UK Government Department of Health announced more money for treatment for people in England. England has been a bit slower than Scotland to roll out the new drug therapies for hepatitis C. In Scotland, we got the new hep C drug therapies out there earlier. The review in England, for England only, focused more attention on hepatitis C therapies to help people to clear the virus.

We are talking about two different things. One concerns the review for England only, which is mainly focused on hepatitis C numbers, with a look at some of the other arrangements, and it is for those south of the border to decide what they do around that; the other is our review group's recommendations, which are different.

As I said in my opening remarks, we already invest £28 million a year in the system for hepatitis C drug treatment, and new drugs are coming online all the time. This year, we expect more still. We have a different set of issues to deal with.

England is slightly behind the curve in terms of the number of people who have not had access to those drugs. To some degree, they are catching up, which is why the focus of their attention has been more on that.

Malcolm Chisholm: That answer dealt with my initial question. I experienced a bit of déjà vu because, as you will remember cabinet secretary, we previously had to sort out the powers to issue a payment and address whether it would affect social security. I assume that the latter issue is not an issue any more because, if it was all right before, it will be all right now.

Shona Robison: Exactly; that is our assumption. However, just to make sure, we are getting it nailed down.

Malcolm Chisholm: It sounds as though you are dealing only with issues around the practical administration. Over and above the issues that you have addressed exhaustively in the past 10 minutes, do you have to resolve any other issues around the recommendations of the financial report, or are you simply working out the practicalities with the UK Government?

Shona Robison: First, we have to say whether we accept the recommendations. I hope that I have given you a flavour of our view on the subject, which is that we are sympathetic to those recommendations. I know that they have been long debated and thought through by the review group. You are right to say that we are engaged in the practical arrangements around the mechanism of getting that money into people's hands. We also want to ensure that we have nailed down the issues around any payment being tax-free and having no impact on benefits; we want to be absolutely sure of that.

Malcolm Chisholm: Is it your intention to pull out completely so that you have a completely separate Scottish scheme, or will the scheme still sit within the existing arrangements?

Shona Robison: The people who are involved in the review group and others to whom I have spoken outwith the review group say that their preference would be for a Scottish system, not only for the purposes of administering money—that concerns technical issues, which we can deal with anyway—but because of other issues, such as those that Gareth Brown set out that are to do with the approach of the schemes. Quite a few people have said that they have had to jump through hoops and have had quite negative experiences in accessing some of the existing UK schemes. We want Scottish arrangements so that we can come at the issue from a slightly different perspective and ensure that the schemes can maximise the support that is given to folk.

Obviously, systems will still need to be in place, but I think that we can make the tenor of them better than is the case with the existing Skipton and Caxton schemes.

Malcolm Chisholm: A lot of what we heard this morning dealt with the Penrose inquiry and you know the concerns that have been expressed about that. Is the Government considering the issue of the conduct of enquiries in the light of the Penrose inquiry, or is that issue not really on your radar?

Shona Robison: There is no formal review of the Inquiries Act 2005, if that is what you mean. However, with regard to a few inquiries over the years, there have been concerns about time and cost, and we would want to learn lessons from any inquiry that is carried out. However, we cannot get away from the fact that, under the Inquiries Act 2005, inquiries are independent and we cannot interfere with their timeframes and costs. Of course, we can give guidance and, on a number of cases, we have written to the chair of the inquiry to say that we hope that they will keep to the timescale as laid out. Ultimately, however, for good reasons, we are limited in what we can do, because of the independence of the inquiry. There is a fine line. We want inquiries to get to the root of the matter in a timely fashion and for a reasonable cost. Ultimately, however, because of the independent nature of inquiries, it is sometimes difficult to deliver those things.

11:45

Malcolm Chisholm: I might be treading on someone else's toes here, but we would like to hear about the recommendation and its implementation.

Shona Robison: I will bring Professor David Goldberg in on that.

Professor David Goldberg (Health Protection Scotland): Thank you for inviting me to give evidence. We were asked to identify the extent of the challenge that has been presented by the inquiry recommendations and to decide what more can be done. It is an important consideration, because it is in the context of Scotland probably having done more than any other country in the world to tackle hepatitis C through raising awareness, prevention, diagnosis, treatment and care. One has to consider all that has happened in the past, particularly during the past seven or eight years, and then ask whether more can be done.

Another dimension was that we also had to look at the impact of the publication of the Penrose inquiry, because it generated an enormous amount of publicity. You could not buy that sort of publicity: it was front-page headlines, the cabinet secretary talked about it in Parliament and it was

also raised in the UK Parliament. That was an enormous amount of awareness raising. We took it on ourselves to examine the impact of that publicity on hepatitis C virus testing and it was serious. Several hundred people, perhaps even as many as a thousand, came forward in the few weeks following the publication of the inquiry, particularly in the first week. We also had reports of general practices being inundated with phone calls. There was some concern in primary care about that, but it settled down.

A short-life working group was established, which I chair. The group is multidisciplinary and has representation from several agencies, including Public Health England and the UK Hepatitis C Trust, because we wanted to bring in some external views. We met in October; we could not meet any earlier because we were waiting for the HCV testing data that would indicate the impact that publication had had. We had a very good meeting. Philip Dolan was at that meeting and made some fine contributions to the debate.

Out of that meeting we were given the task of generating more information about the estimated number of people who are infected and remain undiagnosed from the pre-1991 period and the number of people who are at risk. If we were going to do anything, we would focus our attention on that latter group. Since October, the Scottish National Blood Transfusion Service has done some excellent work to estimate the size of the at-risk population, which is people who were transfused pre-1991 and are still alive today. We are talking about nearly 100,000 individuals. I was quite surprised at the size of the population.

We do not think that many of those individuals are affected. The number of 200 was mentioned earlier and in some of the notes. We think that approximately 200 individuals who were infected are alive, the great majority of whom have been diagnosed. That leaves us with maybe 20 to 40 people who are undiagnosed. It is not an exact science and we are doing our best to estimate the size of the infected population but, if the figure is 20 to 40, that would mean that probably about one in 2,500 to one in 5,000 of the 100,000 who are at risk are infected. That tells you what the challenge is.

It is very difficult to tell what proportion of the 100,000 or so have already been tested because we just do not know. I think that the majority probably have not had a test. That said, we think that the great majority of the 200 who are infected and alive have probably been diagnosed because 25 or 30 years or more have elapsed between the time of their infection and today. There have been loads of opportunities for them to come through the health system. People get blood tests taken and liver function tests done and, if they have raised enzymes, they will generally get tested for various viruses, including hepatitis C. Some will have developed symptoms, which will have promoted testing and diagnosis. For those reasons, there is a skew towards the diagnosis of those who were infected but, generally speaking, those who received a blood transfusion and are at risk and are still alive will not have been tested.

That is where we are. A report is being prepared that will include an option appraisal on what more we can do. That report will be completed in draft form by the end of the month and circulated to the short-life working group for comment. We meet again in late March or early April and I hope that that will be the final meeting. I hope that just a few amendments will be made to the draft report and that it will then be submitted to the Scottish Government for its consideration.

Malcolm Chisholm: What is the figure of 200?

Professor Goldberg: That figure is the estimated number of people who were infected through a blood transfusion pre-1991 and who are alive.

Malcolm Chisholm: What is the figure based on?

Professor Goldberg: It is based on a range of modelling work.

Malcolm Chisholm: Do the results from the people who came forward for testing after the report match up with that figure?

Professor Goldberg: The data show that about 300 or 400 individuals came forward whose case notes indicated that they did so because they had had a blood transfusion or because of Penrose. Others came forward for whom there was no indication in the case notes. One of the 400 turned out to be positive, but we do not know whether that individual actually acquired his or her infection through blood transfusion.

Scotland is in a very good position—probably better than most other countries—in relation to data and trying to estimate the size of the infected and uninfected populations, but there is still a bit of uncertainty around some of the estimates.

Nanette Milne (North East Scotland) (Con): The question that I was going to ask has just been covered. I was going to ask about the 200 figure.

The Convener: As Fiona McLeod does not want to follow up either, Richard Lyle has the next question.

Richard Lyle: This disaster happened 30 years ago. We have been talking about it for 17 years and we are finally getting to an end result. I personally thank the cabinet secretary for the work that you have done in the last number of months. I

also thank the First Minister and you for making a public apology to the people who have suffered.

I welcome your announcement this morning that it will be a Scottish settlement and that you will ensure that any payout or funding—I do not want to know figures at the moment—will be announced before the end of the parliamentary session. Bill Wright commented that he was concerned that it would spill over into the next parliamentary session and he wanted the system to be set up.

In answer to a question that I put to you a few weeks ago during the budget process, you commented that payments would be made from the Scottish Government and not come out of local health boards' funding. Will you confirm that again?

I know that you have made the commitment and answered quite a few questions, but can we ensure that, by the middle of next month, we will have financial closure or a financial system for people who have suffered for the past 30 years? Last night, on social media, many people were discussing that that was what they wanted, and I promised that I would ask the question.

Shona Robison: I recognise your involvement in the issue and your campaigning over the years. However, the people who should receive the most thanks are the campaigners outside the Parliament. I remember sitting around the table at the Health and Community Care Committee in the first session of the Parliament. Hepatitis C was one of the first issues that the committee dealt with. The campaigning of a group of people, many of whom had severe health needs, got the Parliament's attention and ensured that the issue was given such focus and attention that it led to the Penrose inquiry. No matter what people think about the outcome of the inquiry, had it not been for the campaigners' tenacity, an inquiry would not have come about. Therefore, I say a big thank you to them all.

We will make an announcement before purdah because people want to know. You will appreciate that we are trying to dot the i's and cross the t's on some of the mechanisms. The new financial arrangements will be funded through the Scottish Government. The hep C drug therapies will continue to be funded through the health boards, which have targets for how many people should be treated each year.

We want to get the financial systems up and running as quickly as possible, but that requires us to sort out some of the practicalities. That is the focus of the discussions that Gareth Brown and his team have been having with folk down in the Department of Health and the people who are in charge of the existing schemes.

Richard Lyle: Professor Goldberg, you mentioned 200 undiagnosed people and said that more than 100,000 people who were transfused prior to 1991 might be at risk. If I had been in a car accident in that period, had been in a coma and did not know that I had received a blood transfusion, how would I know that I had hep C? I take the point that, if I got into discussion with a doctor, they might be able to tell me. I have had a blood test and blood pressure tests, for example—my wife gets very annoyed when I tell her that I have one of the best blood pressures that people have come across, or so I am told. If I were to go into hospital today—to accident and emergency, say—would I be tested for hep C? By the way, I have not been in a car crash and I have never received a blood transfusion.

Penrose recommended that, in Scotland, we should check whether there are more people out there who require our help. With the greatest respect to you, professor, how can we say that we suspect that there are only 200 people? We honestly do not know.

12:00

Professor Goldberg: It is an estimate. I am not saying that only 200 people acquired HCV through blood transfusion; it was many more than that. What I am saying is that we think that the great majority of those who were infected have died and that 200 are still living. All of the estimates are based on a range of data available to us. Assumptions are made and we do our best to provide an estimate. There are confidence intervals around that estimate. That is a central estimate; there is also a low figure and a high figure.

Your point about whether an individual knows that he or she has had a blood transfusion is a good one. It is an important point, because not everybody would know. It is a really tricky area and all the things that you are alluding to will be considered in the option appraisal. We will consider what more we can do in the context of the "reasonable steps" that Penrose talked about. We will do the option appraisal and come up with a favoured option, which will be submitted to the Government.

One of our challenges is that, although we think that the numbers are small, those numbers are important. In addition, we must consider that there are probably in the region of 14,500 people in total with hepatitis C in Scotland who remain undiagnosed. Even though Scotland has one of the best case-finding records of any country in the world, 35 to 40 per cent of the total infected population remain undiagnosed. As Philip Dolan alluded to earlier, we cannot look at the group who acquired hepatitis C through blood transfusion in

isolation. Although the Penrose inquiry was about that group, we should also think about the undiagnosed context—the 14,000. The very great majority of those are people who have injected drugs in the past, although most of them probably no longer do so. We need to do as much as possible to try to identify them, because there are new effective therapies, and those individuals can benefit from those therapies.

It is a challenge. That said, Scotland has done a really good job on that front and will continue to do so.

Richard Lyle: Professor Goldberg has just reminded me of one more question that I wanted to ask the cabinet secretary. There will be an announcement next month. What retrospective provision will we make for the families who no longer have their loved one? I do not know what the findings will be, so I am asking you whether you can give us that information. If you cannot, I am happy to wait until next month.

Shona Robison: Obviously, that is a difficult area. We certainly recognise the needs of widows and widowers. The review group also recognised that and it was important to the group to ensure that widows and widowers receive support. One of the recommendations was that a proportion of the support that is given to the person concerned should continue after their death. Obviously, that is going forward, rather than retrospectively.

Gareth Brown: In the current schemes, there is discretionary funding that is available to widows and families. Patient groups have told us that it is quite often difficult to access that funding.

Another recommendation of the financial review is that, when the primary recipient dies, those future widows—if I can put it that way—should receive an on-going 75 per cent. The review group also recommended that widows of people who died in the past should be eligible for 75 per cent of what their partner would have received. That does not exist at the moment, and we will have to work out how we can make that work.

Some of those people will not be in contact with the schemes any more, as a person may have died 10 years ago. It is about trying to track those people down. I know that the review group in particular was concerned that there may be widows out there who have moved on or who are not in contact with the schemes any more but who would be eligible for funding under a new Scottish scheme if the recommendations were accepted. There is absolutely something in there for the future bereaved and people who have been bereaved in the past.

The Convener: I have a couple of wee supplementary questions about what Professor Goldberg said about the at-risk group of 14,500 people. Does the Scottish Government have a view on extending tests to people who were drug users in the 1970s, 1980s and 1990s?

Shona Robison: In the current system, anybody who presents and who may have been at a high risk would be encouraged to have a test. Obviously, the decision is ultimately for the person, but given that we want as many people as possible to get access to the new therapies, which can clear the virus in the vast majority of cases, the emphasis is on trying to identify who those people are, no matter the circumstances of their infection, and to get them on to the new drug therapies. That is the whole thrust of the strategy.

More drugs are being developed and, as I said, new drugs are coming on stream this year. Those drugs are very effective and very different from the therapies of the past. That is an important message. There are fewer side effects, so people who may have decided not to have the previous treatment are opting to have the new treatment.

The Convener: Is there regular testing or a programme to test those who were drug users in the 1970s, 1980s and 1990s? Is that group being caught? Would it be considered reasonable to extend active testing to that group of people? Alternatively, have I been misled from our briefing and the evidence?

Professor Goldberg: There is a huge range of initiatives to promote testing among not only people who currently inject drugs but those who have injected in the past. The people who have injected in the past—in the 1970s and 1980s—are an important group, as they may well have more advanced liver disease.

We have done surveys of general practitioners throughout the country, and they have reported high rates of offering tests for hepatitis C to individuals whom they believe have injected drugs in the past. That said, there is still work to be done, as 14,500 is still a large number of individuals.

We have to put it in context. Before the action plan, under 40 per cent of infected people were diagnosed. Now, over 60 per cent have been diagnosed and every year, an additional 2,000 individuals are being diagnosed, so a lot of really good work is being done.

We have been scratching our heads and asking whether there is anything more that can and should be done. It is not an easy question to answer, but I think that a recommendation will come out of our option appraisal that focuses not just on those who acquired the infection through blood transfusion but on those who got the infection in other ways.

The Convener: Is there a historical issue relating to the impact on people and the community? Will that be considered?

Shona Robison: If people are not in contact with services any more, they are obviously harder to find but, as David Goldberg laid out, GPs are proactive in having that conversation with people about previous drug-taking and may encourage them to have a test, for example. Those are obviously difficult discussions that take place between clinicians and patients.

David Goldberg mentioned the work that his group is doing around how to do more to find those who are currently undiagnosed, no matter how they were infected. That work will benefit not just those who were infected through a blood transfusion but that wider group of people. We will receive the conclusions of that work in due course from David's group.

The Convener: We had extensive written and oral evidence from the first panel of witnesses today. The point was made that we should focus not just on the liver, to put it in layman's terms, but on the wider impact on an individual's body and outcomes. Petra Wright raised the point that extrahepatic conditions should be a key component in the eligibility criteria for financial support. Do you have a view on that?

Shona Robison: The further work proposals that the review group came up with capture that issue. The group said that people at stage 1 have a wide variety of health issues. Some people have cleared the virus and may have very few health impacts, although I am not underplaying the psychological and emotional impacts of having been infected—those impacts are definitely recognised. However, within stage 1, there will be people who have significant health needs—there is a wide variety of needs within stage 1. The review group recognised that and said that we should look at whether we need to have various bands rather than just stages 1 and 2.

Also, the research is beginning to show that a whole range of conditions may be linked to hepatitis C infection. It is taking time to understand those conditions a bit more. We need to keep on top of the evidence and what it is telling us. It is not just about focusing on liver damage. Part of my response will be the further work that the review group has recommended, not just on the financial elements but on other elements, including the issues that you have outlined, convener.

The Convener: Does the Canadian six-stage model take into consideration those wider health issues?

Shona Robison: Yes. We have looked at that model—Gareth Brown looked at it in some detail. There are international models that we may want to look at when we establish our Scottish system, as we want it to be a bit more responsive to people's needs than the current system.

Rhoda Grant: I have a quick supplementary before I get to my substantive question.

We heard in the first evidence session this morning that the short-life working group that Professor Goldberg is chairing has met only once. If that is the case, how can it report? Has other work been done between the first meeting and what will be the last meeting, when the report is drawn up?

12:15

Professor Goldberg: One of the actions decided on by the group, which met in October, was to generate estimates of the size of the at-risk population. The blood transfusion service was asked to do that work and it has now deliberated. One or two other smaller pieces of work needed to be done, so the group is going to meet this month—we have struggled a bit with dates, but we are going to meet—and we will meet again, hopefully for the final time, in March or early April.

Rhoda Grant: That means that the working group will have met only twice when it reports.

Professor Goldberg: We will just have to wait and see—it is a short-life working group. I am hoping that the group will come to a conclusion. The draft report will be sent in advance to the group members so that they will have it before the meeting. I do not anticipate too much in the way of change following the meeting and I am hopeful that we can send a final report to the Government shortly after we meet. That is the position.

Shona Robison: It would not be unusual for a lot of work to be carried out between meetings by other people that the group has requested the work from. The group's job is to analyse that and to come up with conclusions. As Professor Goldberg has just outlined, other organisations were asked to provide pieces of work to the group.

Professor Goldberg: Indeed. There are a number of issues. We did not meet until October, but we were waiting for the results of the HCV test data in relation to the publication of the inquiry, as I mentioned earlier. It has taken a few months for the SNBTS work and a few other bits and pieces to be done. Now we are going to meet, and a report has to be written. In the context of the inquiry in general, that seems quite reasonable; I do not really have any concerns about that.

Rhoda Grant: My second question is about blood and tissue samples from sufferers, which may be held somewhere. There is concern that those are being held and used for research. What does the cabinet secretary plan to do to identify

whether that is the case and, if it is, to ensure that the people whose blood and tissue samples have been used in research are informed and that their consent is sought?

Shona Robison: Gareth Brown will answer that.

Gareth Brown: That issue has been raised. We are not aware that it is a big problem, but of course there may be historically-held samples and people may not know what they are to track that down.

The important thing is that the right sort of regulatory arrangements are in place to ensure that the right consents are gathered when it is possible to do that. I understand that there is a process. Healthcare Improvement Scotland is responsible for developing standards and assessing performance, and there is an accreditation scheme setting out the governance arrangements for repositories of tissues and samples. Arrangements are certainly in place; the challenge is trying to find historical samples.

Under the current arrangements, any samples that were identified would need to be dealt with under the governance arrangements that now exist, which are about fully informed consent and making sure that people have the opportunity to say what will happen to their samples.

There are not banks of tissue. We have gone through a number of issues in the past about retention of organs, and there has been human tissue legislation, which is in the same area. It may have been an issue in the past, because of how the NHS worked, but it certainly should not be an issue now. Clear governance arrangements exist and, if any samples or tissues emerge, they will be dealt with under those governance arrangements.

Shona Robison: We will, however, ensure that Healthcare Improvement Scotland is made aware of the evidence that has been presented to the committee on the matter, so that it can be looked at to reassure that body and us that arrangements are being followed as they should be and that, as Gareth Brown said, we are talking about historical samples rather than things not being carried out as they should be under the current legislation. That legislation is very detailed and the committee was very much involved in establishing it.

Rhoda Grant: Samples that were taken in the past would come under the new legislation and one would assume that, if they are being held, they should not be being held without permission.

Gareth Brown: That would come down to a determination of what the legislation says and I do not have a view on that—I would need to check. Certainly, the governance arrangements exist, although they are not necessarily about legislation; they include the accreditation scheme and the processes that bodies and research organisations should follow. I expect that any historical samples that come to light should be considered under that sort of process. I cannot tell you today what the legislation says, because I am not clear on it; I would need to check.

Shona Robison: We will check and get back to the committee on that specific point. We will also make Healthcare Improvement Scotland aware of the concerns that have been raised and ask it to reassure itself and us about those issues.

Nanette Milne: Quite a lot of frustration has been expressed to us about the small number of case studies that were examined during the Penrose evidence taking. Is there any intention of giving people their day in court, let us say, so that they can put across their experiences? Is there any intention of investigating the other people who were affected but who were not interviewed by Penrose?

Shona Robison: That is difficult, because it was for Lord Penrose and the inquiry to decide on the number of witnesses, which witnesses and what oral testimony to take. Obviously he had to satisfy the inquiry's terms of reference, but otherwise he had a great deal of flexibility. Normally, inquiries try to get a range of specific cases to highlight different circumstances, but the independence of the inquiry means that it is up to the inquiry to determine how many cases that should be. I would expect any inquiry to look at a range of circumstances.

I understand the frustration. I have spoken directly to people who felt that they should have been given the opportunity to be heard by the inquiry but, as I say, it is not for us as politicians to determine that. The inquiry had to determine that, but I understand people's frustrations.

Nanette Milne: I just thought that it was important to put that on the record.

The Convener: Thank you. As there are no other questions from the committee, I thank the cabinet secretary and her colleagues for being with us and for the evidence that they have provided.

Subordinate Legislation

Public Bodies (Joint Working) (Prescribed Health Board Functions) (Scotland) Amendment Regulations 2016 (SSI 2016/15)

12:22

The Convener: We have four negative instruments before us today.

On the Public Bodies (Joint Working) (Prescribed Health Board Functions) (Scotland) Amendment Regulations 2016 (SSI 2016/15), there has been no motion to annul and the Delegated Powers and Law Reform Committee has not made any comments on the regulations. As there are no comments from members, do we agree to make no recommendation?

Members *indicated agreement.*

National Assistance (Sums for Personal Requirements) (Scotland) Regulations 2016 (SSI 2016/23)

The Convener: Again, there has been no motion to annul and the Delegated Powers and Law Reform Committee has not made any comments on the regulations. As there are no comments from members, do we agree to make no recommendation?

Members *indicated agreement.*

Products Containing Meat etc (Scotland) Amendment Regulations 2016 (SSI 2016/24)

The Convener: There has been no motion to annul and the Delegated Powers and Law Reform Committee has not commented on the regulations. Do we agree to make no recommendations?

Members *indicated agreement.*

National Assistance (Assessment of Resources) Amendment (Scotland) Regulations 2016 (SSI 2016/25)

The Convener: There has been no motion to annul and the Delegated Powers and Law Reform Committee has not made any comments on the regulations. As there are no comments from members, do we agree to make no recommendation?

Members *indicated agreement.*

Petition

Co-location of General Medical Practices and Community Pharmacies (PE1492)

12:25

The Convener: Members will see the petition in their papers. I note that the petitioner has advised that he is happy for the petition to be closed at this point. Of course, it will remain open to the petitioner to lodge another petition on the issue if it transpires in the fullness of time that the work that is being done to address the issues does not improve services.

Does the committee agree to close the petition?

Members *indicated agreement.*

The Convener: As previously agreed, we now go into private.

12:26

Meeting continued in private until 12:45.

Published in Edinburgh by the Scottish Parliamentary Corporate Body

All documents are available on
the Scottish Parliament website at:

www.scottish.parliament.uk

Information on non-endorsed print suppliers
Is available here:

www.scottish.parliament.uk/documents

For information on the Scottish Parliament contact
Public Information on:

Telephone: 0131 348 5000
Textphone: 0800 092 7100
Email: sp.info@scottish.parliament.uk