The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

PUBLIC PETITIONS COMMITTEE

Tuesday 27 November 2012

Session 4

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PUBLIC PETITIONS COMMITTEE
17th Meeting 2012, Session 4

CONVENER

*David Stewart (Highlands and Islands) (Lab)

DEPUTY CONVENER

*Chic Brodie (South Scotland) (SNP)

COMMITTEE MEMBERS

*Jackson Carlaw (West Scotland) (Con)
*Adam Ingram (Carrick, Cumnock and Doon Valley) (SNP)
*Angus MacDonald (Falkirk East) (SNP)
*Anne McTaggart (Glasgow) (Lab)
*John Wilson (Central Scotland) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Elizabeth Corrigan (Scottish Care and Information on Miscarriage)
Nigel Don (Angus North and Mearns) (SNP)
Vicki Hendry (Somerville Foundation)
Nanette Milne (North East Scotland) (Con)
Dr Liza Morton
Maureen Sharkey (Scottish Care and Information on Miscarriage)

CLERK TO THE COMMITTEE

Anne Peat

LOCATION

Committee Room 1

Scottish Parliament

Public Petitions Committee

Tuesday 27 November 2012

[The Convener *opened the meeting at 10:04*]

New Petitions

Miscarriage (Causes) (PE1443)

The Convener (David Stewart): Good morning, ladies and gentlemen. I welcome you all to this meeting of the Public Petitions Committee. As always, I ask everyone who has a mobile phone or electronic device to switch it off now, please, as such devices interfere with our sound system.

I place on record our thanks to one of our assistant clerks, Alison Wilson, who is moving to the Rural Affairs, Climate Change and Environment Committee. The committee thanks her for her work over the past three years, and we wish her all the best in her new committee.

I welcome Andrew Howlett, who is replacing Alison. I thank him very much for joining the committee and hope that he enjoys his experience with us.

Agenda item 1 is consideration of new petitions. PE1443, by Maureen Sharkey, on behalf of Scottish Care and Information on Miscarriage, is on investigating the cause of miscarriages. Members have a note by the clerk, the Scottish Parliament information centre briefing and a copy of the petition.

I welcome Maureen Sharkey and Elizabeth Corrigan. Thank you for giving up your time to come along and speak to the committee.

I ask Maureen Sharkey to address the committee for around five minutes, after which I will kick off with a couple of questions. I will then ask all my colleagues whether they would like to ask additional questions.

Maureen Sharkey (Scottish Care and Information on Miscarriage): Thank you very much for inviting us to the meeting.

The petition is about women who can be helped by testing, not women who cannot. The current guidelines have no medical justification—it is an accountancy matter. Currently, women are required to suffer three consecutive losses before any relevant testing will be offered to them. We would like all women who have had a miscarriage to have access to investigation. We have argued for a change since 1994 but have found it very difficult to engage with the health service.

The latest statistics show that, from April 2009 to March 2010, there were 5,708 miscarriages in Scotland. The official definition of a miscarriage is

> “a spontaneous pregnancy loss up to 24 weeks”.

There are three trimesters in pregnancy, and miscarriage can happen in the first two. A spontaneous loss after 24 weeks is a stillbirth.

I would like to share with the committee the point of view of a woman who currently does not qualify for testing under the existing miscarriage policy. Last week, she said:

> “There were those feelings of complete failure as a woman that somehow they knew something that I wasn’t getting to know, that caused me to search within myself for a reason, that was very painful for me.”

Scottish Care and Information on Miscarriage is the only counselling organisation of its kind in Scotland. Over the past 18 years, I have heard and seen on a daily basis the physical and emotional effects of the policy on women. Those women generally feel like failures. They are unable to return to their work or they fail to function in the workplace. They suffer from depression, they isolate themselves, their relationships fail, and in some cases, they feel so helpless that they contemplate suicide.

The policy has a direct effect on friends and family members, too. Husbands often report how helpless they feel, as they are unable to help or make things better, and best friends are embarrassed by their on-going pregnancy. Miscarriage is hard to explain in the workplace when the medical response was a shrug of the shoulders and the words, “Come back if it happens again.”

Testing will help those who have a recognisable condition. The testing policy is not uniformly imposed across the country. Some are tested sooner, but I suspect that that is more to do with where the resources are and people having the confidence to stand up to the medical profession. Testing after miscarriage should not depend on an individual’s ability to argue for it; it should be part of the support that every woman and family gets from our health service.

The Convener: Thank you very much for your contribution.

I will kick off with a couple of questions. Do you think that the public understand the heartbreak, trauma and loss that families experience after a miscarriage? I suppose that that is the wider issue for me.

Maureen Sharkey: I think that that is an extremely difficult thing for people to understand, unless it has happened to them. From my personal experience—I have worked with women in a therapeutic counselling capacity for many years—I would say that one of the difficulties that the women raise time and again is the inability of other people to understand what has happened to them and the knock-on effect that that has on their lives.

The Convener: In a sense, it is a form of bereavement.

Maureen Sharkey: Absolutely.

The Convener: Do you feel that emotional or psychological support should be offered when families want it, not just to the woman involved but to the partner and any surviving children?

Maureen Sharkey: Yes. That is something that the organisation that both of us are with offers to all families in Scotland. We have done that for 18 years. We are open to calls from friends or relatives—a mother might phone us and ask us what she can do in support of her daughter. A husband or even an employer might make a similar request. The worst-case scenario is when women phone when they are in the midst of a miscarriage and do not know what to do. We might refer them to emergency services and talk them through that. That is an incredibly sad call to take.

John Wilson (Central Scotland) (SNP): Good morning. For me, the question is straightforward: why has it taken so long for such a petition to be lodged?

Maureen Sharkey: That is an extremely good point. There was always a hope that somewhere along the line we would be heard and the issue would be considered without our having to come here—although we are delighted to be here—but that has never happened.

John Wilson: Is that because you feel that the response that you have received from Government officials or health boards has not been satisfactory? It is clear that it has not been satisfactory—that is why we are discussing the petition. You said that, although there are guidelines that say that if someone suffers three miscarriages, they should get some support from the health board, some people get help sooner. Could you give some examples of good practice by health boards, as well as of health boards that do not carry out investigations and provide support in the way that you would like them to?

Maureen Sharkey: The first thing that we notice is that, following the bad news, women are just sent home or they might have an overnight stay in hospital, but they are not given any debriefing. It is all just a matter of course and then they are shown the door. In some cases there is a follow-up, but not always. That is what I meant when I said that there is no uniformity. Women are left to deal with things, to get their heads round what happened and to get themselves back to work. Unlike when other losses are experienced, there is no entitlement to time off. Women have to go straight back to the workplace. They are not given any debriefing before they leave the hospital.

John Wilson: That is all for the moment.

Angus MacDonald (Falkirk East) (SNP): Good morning, Maureen and Elizabeth. You mentioned in your preamble the variation in support across health board areas. We have a table that shows that there seems to be a significant variation by health board area in the total rate of miscarriages. For example, the rate in Grampian is about 10.2 per thousand women aged between 15 and 44, whereas the rate in Forth valley in my area is 4.6 per thousand women. Why do you think that the rate varies so much?

10:15

Maureen Sharkey: That is partly why testing needs to be done. If it is not done, we will never know why that is the case. At the moment, the rule is that a woman must have three consecutive losses. Some women could have two losses and then have a child but then have another loss, and they would not qualify for testing. Other women may have a stillbirth, a miscarriage, a couple of children and then another loss, and they would not qualify for testing either.

Chic Brodie (South Scotland) (SNP): Good morning. In reading the petition and the supporting documentation that we have received, I have become concerned about the lack of data. You say that 1 per cent of all miscarriages are recurrent miscarriages. How should NHS inform collect data to give pre-warning of that particular issue and how could data be gathered post-treatment? What discussions have you had with NHS inform or those who can collect data?

Maureen Sharkey: I am not entirely sure what you are asking.

Chic Brodie: You say that there is no data, and I am trying to scope it out. You say that the figure is 1 per cent but, according to the information that we have, data is not really being gathered.

Maureen Sharkey: No. The most recent statistics are for 2010. That is how far behind they are. I gathered those statistics last week, and they are two years behind.

Chic Brodie: I know of the actions that you have taken, but it seems to me that, once it is properly scoped and we have the data, that will provide a basis for pursuing any recourse to action.

Maureen Sharkey: Yes, but women have to shout quite loudly before that happens.

The Convener: I invite Elizabeth Corrigan to come in at any time. Are there any points that you wish to raise at this stage, Elizabeth?

Elizabeth Corrigan (Scottish Care and Information on Miscarriage): Only on the timespan, which I think is relevant, and my own personal experience. For the past 20 years, the policy has not changed that a woman must have three consecutive miscarriages before anything is done. I think that that is really awful.

Adam Ingram (Carrick, Cumnock and Doon Valley) (SNP): I would like to pick up on that point. The Scottish Government published "A Refreshed Framework for Maternity Care in Scotland" in January last year, the key aim of which was to improve health outcomes for both mother and child within maternity services by having services individualised according to women's needs.

In the case of miscarriage, every woman is different and the circumstances are different. My own wife had a miscarriage during her second pregnancy. I understand that a woman suffering a miscarriage during her first pregnancy would be significantly more alarmed or concerned about what that might imply for her future. In that case, there may be a strong case for having some sort of test. My wife had had a successful pregnancy before, and family support saw her through the miscarriage. Fortunately, we had three more healthy children afterwards.

Rather than taking a blanket approach to testing, is the idea of having an individualised service that would be sensitive to a woman's needs, as is set out in the Scottish Government's policy, not the way to go? Have you seen any difference in the approaches that are being taken across the country in response to that new Scottish Government policy in the area?

Maureen Sharkey: We are here today to ask that women who suffer one miscarriage are offered testing. I think that that is essential if it is to be understood from a scientific point of view what has happened, which is rarely answered in such cases. I think that that is the most difficult aspect for the women involved, who go away not knowing what happened or why. For every other kind of bereavement, people get an indication as to what happened and it is common for people to ask what happened and to get a response. However, in the case of miscarriages, women do not get that kind of response, which means that they start to search within themselves, which is a particularly painful process to watch. On most days, Elizabeth Corrigan and I hear women asking, "What did I do? What was it I didn't do?" Women get a bit anxious about those questions.

Adam Ingram: Have you seen any evidence of the new framework being put into practice up and down the country and maternity services taking an approach that focuses on the individual needs of particular women?

Maureen Sharkey: As I said earlier, some women are treated and responded to in a much better way than others. From one hospital to another and from one doctor to another, the situation is incredibly different. We know that from the work that we do, which can vary from speaking to someone in one phone call to working with someone for up to a year, which is how long some women take to recover from a miscarriage. In addition, there is always the fear of trying to become pregnant again for fear of a miscarriage happening again.

Anne McTaggart (Glasgow) (Lab): Good morning, Maureen and Elizabeth. I want to drill down a wee bit further into some of your points. What do you feel would assist these women in their communities and what needs to be put in place?

Maureen Sharkey: Testing. I think that it is absolutely necessary now that testing is done. If we could help 10 per cent, that would be 500 women, which is 10 women every week. That is why it is very important.

Anne McTaggart: Adam Ingram referred to the policy document "A Refreshed Framework for Maternity Care in Scotland". What are your views on that?

Maureen Sharkey: We have seen no change whatsoever—none.

Anne McTaggart: You said, though, that the situation was better in some areas than in others. Are those specific geographical areas or national health service areas?

Maureen Sharkey: It is a bit of both, but even then it is not uniform. It can depend on the consultant a woman sees or on the woman herself standing up in the middle of her grief and saying, "Look. I just need something done here." That is not really the ideal time for someone to be trying to argue their case.

John Wilson: I am sorry to come back in, Maureen and Elizabeth, but I want to go back to the figures that we have in front of us. In the written submission to support the petition, you referred to the same figures that we have before us. My difficulty is that the only figures that we have in front of us are about the number of miscarriages. Do you have any information about the number of recurring miscarriages within those figures? You referred to 1 per cent. It would be useful if the figures for recurring miscarriages were available and we could sit them alongside the 5,708 miscarriages in Scotland to see what proportion are recurring. We could measure that against the health boards to find out whether issues arise in that respect. As my colleague Angus MacDonald indicated, Grampian NHS Board has a miscarriage rate of 10.2 per 1,000 women aged between 15 and 44, while the figure for the islands health boards is 2.2. Clearly there is some variance there, but it would be useful if you were aware of how those figures relate to the number of subsequent miscarriages suffered by women in those areas.

Maureen Sharkey: I do not have those figures with me today. It is really important that all those figures are covered in a way that identifies all the issues. At the moment, we are two years behind with the figures. Nothing is up to date.

John Wilson: I agree. It would be useful for everyone concerned to be aware of the figures. It goes back to the point that you have raised on a couple of occasions, which is that we do not know whether what happens is that a good consultant, doctor or midwife decides to take on the issues at a local level and examine them further. It might also be down to pressures on services that are being delivered at the local level. We need to ensure that, when we take the issue forward, we do so in a way that results in a consistent service delivery throughout Scotland, and not just service delivery in one area while other areas are omitted.

Maureen Sharkey: We know from the care that we offer women following loss that, in planning a future pregnancy and during pregnancy, they are incredibly anxious. Our programme gives regular support to women and offers them referrals to various units and so on. We sit down and talk to them most weeks. We have a 74 per cent reduction in the incidence of miscarriage. However, we are extremely dependent on whether the hospital gives women information about our organisation. Despite the fact that we send information to the hospital, women often do not get it. It is distressing when women come through the door and say, “I specifically asked my doctor and the hospital for some counselling support and I wasn’t told about your organisation.” Those women have had to search for the information and are incredibly angry about it.

Jackson Carlaw (West Scotland) (Con): Good morning. I am slightly unpersuaded by what I have heard so far. It is good that there is an organisation from which people can obtain information, of which people can be made aware and to which people should have access and referral. It appears that only 1 per cent of women suffer recurrent miscarriage. I assume that, for most women, getting pregnant a second time and having a successful pregnancy is the best possible therapy for having lost the first child.

I am slightly concerned that if we start suggesting that there should be an automatic testing process, we create the very anxiety that you are trying to alleviate. If a woman suffers a miscarriage, she needs understanding and support. If she is told, “We’re sending you for tests”—and it seems that there would have to be a series of relevant tests—that creates an anxiety that there is something wrong when in fact women have suffered miscarriage throughout history.

My concern is that by initiating a statutory series of tests on an automatic basis, we create for women an anxiety that there is something wrong when in fact there may be nothing wrong at all and a second pregnancy will be completely successful. In my wife’s case, that was what happened.

I am concerned that some people might delay the process of considering having a second pregnancy because they are awaiting the outcome of tests. For as long as it took to get the information back—it might take even longer if we initiated thousands of these tests—we could create in women a completely unnecessary anxiety, which would compound the loss that they have suffered.

10:30

Maureen Sharkey: I totally disagree with you, I am afraid. I would say to you that women want to know what happened.

Jackson Carlaw: You say “women” in a general sense. How many of the 5,708 women have you spoken to?

Maureen Sharkey: We speak to thousands of women.

Jackson Carlaw: To how many of the 5,708 women who miscarried between April 2009 and March 2010 did you speak?

Maureen Sharkey: Last year, we offered 446 face-to-face appointments; 292 telephone sessions; and 303 fertility management sessions. On top of that, we offered email support, online support and other pieces of support.

Obviously, if someone did not want to know or did not want testing to take place, that would be their choice. I am suggesting that women should be offered that choice. At the moment, they are not.

Jackson Carlaw: If recurrent miscarriage affects only 1 per cent of women, the creation of a culture of the mandatory offering of testing might lead women who decline testing to think that it was wrong of them to decline it. Further, if the issue affects only 1 per cent of women, I wonder whether you might be unnecessarily creating an anxiety in women that something might be found by testing when, in fact, in 99 per cent of cases, the answer is that nothing will be found, and the most beneficial thing that they can do is get support and counselling to deal with the miscarriage and go on to have a successful second pregnancy, which is clearly what 99 per cent of them do.

Maureen Sharkey: Women do not always have a successful pregnancy following a loss. Some women suffer from recurrent loss. Recently, we saw a woman who had had two successive miscarriages but did not qualify for testing. She went into the private health system to figure out what might have happened and figured out that she needed to take low-dose aspirin. She asked what would have happened if she had taken the advice that she was given in the hospital just to try again and was told that, if she had become pregnant, she would have lost that baby, because she would not have been taking low-dose aspirin.

That is the kind of woman I am talking about. It does not take much to sort that out, and it does not cost much, either. The cost of the procedures for miscarriage is £501, and the cost of the emergency call-out—because the women have to be taken to hospital by the emergency services, as they are in an emergency situation—is £217. That adds up to a sum of £718. Blood tests cost between £53 and £72.

Jackson Carlaw: Yes, but that cost in relation to miscarriage would not be obviated, because the processes that you are advocating would come into play only after a miscarriage had been suffered.

Maureen Sharkey: Yes, but if someone is not tested, they could have further miscarriages. Very often, that is what happens.

Jackson Carlaw: Well, not very often—only 1 per cent of the time.

Maureen Sharkey: Again, I bring you back to the statistics, which state that, in 2010, 5,708 women suffered a miscarriage.

Jackson Carlaw: But not a second miscarriage. Nothing that you are suggesting would stop the first miscarriage. You are talking about a test in the event of a woman having suffered a miscarriage. Nothing that you are proposing by way of testing would have any impact on the number of primary miscarriages that women suffer.

Maureen Sharkey: But it would have an effect on subsequent pregnancies.

Jackson Carlaw: Yes, but that is not 5,708.

Maureen Sharkey: We can go back and forward with the figures—

Jackson Carlaw: It is 1 per cent.

Maureen Sharkey: What I am saying is—

Jackson Carlaw: It is five.

Maureen Sharkey: —if we do not test we will never know what the reasons for the miscarriage are. The whole point is the knock-on effect on women. I know from my own experience and my 18 years' experience of sitting down with women and offering them counselling the devastating effect on women.

Jackson Carlaw: On some women.

Maureen Sharkey: Yes. It has a devastating effect on some women.

The Convener: We are running a little bit short of time, so I will bring in Chic Brodie and then take a final point from Anne McTaggart.

Chic Brodie: I have a very quick question, convener. We know that there is no real data for recurrent miscarriages, but has Maureen Sharkey seen best practice from any of the health boards that she can share with us?

Maureen Sharkey: Well, there are the emergency services.

Chic Brodie: But is there any particular area?

Maureen Sharkey: It is very difficult to say.

Chic Brodie: So we cannot point to a particular health board that is doing well and translate that to other health boards.

Maureen Sharkey: As I have said, it is very difficult. Women might come in and say that a particular hospital was good, whereas others might report that the same hospital was not so good.

Anne McTaggart: With regard to Jackson Carlaw's point that a woman would need to have had a miscarriage before any testing could be carried out, do you think that the evidence from that testing could be used to ensure that other women did not reach even the first stage of miscarriage?

Maureen Sharkey: Absolutely.

Jackson Carlaw: But how?

Anne McTaggart: The evidence could be gathered and collated to prevent others from having a miscarriage.

Maureen Sharkey: You are absolutely right.

The Convener: We have run out of time, but I have a very quick question on a factual point. Does Scottish Care and Information on Miscarriage receive Scottish Government or any other funding?

Maureen Sharkey: Yes. We receive section 10 funding.

The Convener: Roughly how much do you get?

Maureen Sharkey: Not very much. It was cut by about 10 per cent or so. We get £7,000 a year.

The Convener: Is that your only source of funding?

Maureen Sharkey: No. We are also funded by Glasgow City Council. We received funding from North Lanarkshire Council, but its funding was cut this year. That was a pity because in the years that we worked there we saw an absolute drop in the number of miscarriages. Of course, we cannot say that that was entirely a result of what we were doing but it certainly had a lot to do with it.

The Convener: I presume that all your staff are volunteers.

Maureen Sharkey: Yes.

The Convener: After all, that is a very small amount of funding.

Maureen Sharkey: I know.

The Convener: You probably do not have this figure to hand, but have you estimated the costs to the Scottish Government if it decided to pursue the testing proposal in your petition?

Maureen Sharkey: As I have said, the testing costs between £53 and £72 per person.

The Convener: Do you have an estimate of the annual figure?

Maureen Sharkey: No.

The Convener: I appreciate that the question is very difficult to answer, but I expect that we, too, will be asked it if we refer the petition on.

Moving on to our next steps, I think that we should certainly continue this very interesting petition and ask the Scottish Government some of the questions that you have asked us. Our clerks have laid out some draft questions on, for example, the data collection issue that Chic Brodie raised, and seeking views on the petition from the Government, which will be the main player with regard to longer-term action. Do members wish to pursue any other points? I believe that it was suggested that we also ask the royal colleges, the professional associations, the Miscarriage Association and other such groups to take a more detailed look at the petition.

John Wilson: I suggest that as well writing to the royal colleges we also ask the British Medical Association Scotland about the guidance given to general practitioners on dealing with patients who have suffered a miscarriage.

The Convener: Okay. Do members have any other views?

Adam Ingram: I would like a detailed response from the Scottish Government on how the framework for maternity services is being rolled out and the feedback that has been received on it. Clearly practice differs across the country and we must establish the extent to which that has been addressed.

The Convener: We should also ask whether the effectiveness of the new framework has been studied. Is it also worth raising Angus MacDonald's point and asking about the different miscarriage rates in various health board areas?

Angus MacDonald: It would certainly be helpful to hear its response on the question why the figures vary so much.

The Convener: Do members have any other comments?

Jackson Carlaw: When we write to the royal colleges and others, can we ask why the current guidelines have been established?

The Convener: That is a good point.

As the petitioners will have heard, we will continue the petition and pursue a number of organisations for answers to certain questions that it raises. Obviously we will keep you up to date on progress. Finally, I thank both of you for your evidence. I realise that giving evidence is not an easy job.

At this point, I suspend the meeting for two minutes to allow our witnesses to leave and new witnesses to be seated.

10:41

Meeting suspended.

10:42

On resuming—

Congenital Heart Disease Patients (Care) (PE1446)

The Convener: The second new petition is PE1446, by Dr Liza Morton, on behalf of Scottish adult congenital heart patients, on Scottish standards for the care of adult congenital heart patients. Members will have received a note from the clerk, the SPICe briefing and the petition.

I welcome to the meeting our two witnesses and invite Dr Morton to make a short presentation of around five minutes. After the presentation, I will kick off with a couple of questions and, as the witnesses will have observed from the previous evidence session, my colleagues will then come in with other questions.

Dr Liza Morton: Thank you for inviting us to today's meeting.

Congenital heart disease describes any heart condition present from birth. It is the most common complex birth defect, affecting 1 in 125 live births, and has no cure. Each year 450 to 600 children in Scotland are born with the condition and an estimated 15,600 adults in Scotland are living with it.

Adult congenital heart disease is the success story of modern medicine. About 90 per cent of infants born with the condition are now reaching adulthood, whereas, in the 1940s, only 20 per cent survived. There are now more adults than children living with the condition and the population is growing.

It is recognised internationally that ACHD patients require specialist lifelong care. I am from the first generation of ACHD survivors; 16 years ago, when I moved from paediatric to adult care, there was no specialist service to transit to and many of us with the condition were discharged and then lost to the system. Although the recent designation of the Scottish adult congenital cardiac service—a specialist national centre based at the Golden Jubilee hospital in Clydebank—is welcome news, it is under-resourced with regard to the growing population it is required to care for. Around 3,000 patients need regular contact with the service and a further 7,000 to 8,000 require review. In England and Wales, the specialist advisory committee has recommended one consultant per 1,500 patients; SACCS has only three, one of whom is very new.

The latest SACCS annual report highlights risk across a number of areas in which care is potentially compromised. The budget is approximately £2 million, which does not provide comparable funding per patient to that which is provided for the treatment of other life-threatening conditions. The service does not include a funded out-patient service for the checking of pacemakers, it does not include accident and emergency services or on-call provision to support local accident and emergency care, and it does not have adequate psychological support, social work input, support from physiotherapy or any other holistic care.

10:45

Personally, I have experienced life-threatening problems at A and E with a non-specialist cardiologist misdiagnosing me as having a virus and discharging me when, in fact, the pacemaker on which I depend to live had a fault. I was discharged on a Friday night and was unable to access help until the following Tuesday, when I had to turn up at a clinic unannounced and demand that my pacemaker was checked. I was unable to access specialist advice and care during pregnancy and I have experienced a lack of understanding from and difficulties with GPs, non-specialist cardiologists and other health professionals. I also had difficulty in being informed about and referred to SACCS. Unfortunately, I am far from being the only patient who has reported such difficulties.

In 2006, England and Wales adopted “Adult Congenital Heart Disease: A commissioning guide for services for young people and Grown Ups with Congenital Heart Disease (GUCH)”, which was published by the Department of Health. Six years later, that guide has still not been adopted by NHS Scotland. Further, the NHS in England is in the process of agreeing standards for patients with representatives of the professional associations for surgeons, consultants and nurses. The draft standards have been out for public engagement and they are going out to consultation.

There is no justification for NHS Scotland to continue to delay developing and adopting such standards. The difficulties that result from the lack of standards include the fact that atrial septal defects—holes in the heart—are being closed in non-specialist centres, which puts patients at risk in the event of complications and is against the advice of the advisory committee.

The Scottish Parliament information centre briefing notes that the 2009 Scottish Government action plan stated that the national services division and SACCS were required to develop outreach clinics, referral pathways and a shared care model, and to implement the Department of Health commissioning guide. None of that has happened. Further, the SPICe briefing states that the NSD and SACCS are working with the Bravehearts patient group to design patient pathways, yet Gill Mitan, the chair of Bravehearts, reports that that has not been taken forward since 2010.

At a recent national patient conference that was held by the Somerville Foundation, Dr Hamish Walker, the director and lead clinician for SACCS, stated that, without access to 24/7 care, patients’ lives could be at risk.

Scottish patients deserve the same treatment as patients in England and Wales. We, the first generation of ACHD survivors, understand that the care that we receive is pioneering. We are willing to work with our cardiac teams and service providers to find the right answers in the hope of improving quality of life for the next generation. However, it is deeply frustrating and disappointing when we face unnecessary challenges. We have navigated the challenges of a childhood lived with heart disease, and as adults we are asking the Scottish Government to continue to support us on this difficult journey.

Living with a heart condition from birth is difficult enough without our having to fight our way through the medical system. We need standards for our care to ensure our safety, equity of access and quality of life, and we need an adequately funded national specialist centre. We have needed that for many years. We need to be treated respectfully and with understanding about what it means to live with a serious lifelong medical condition. We need to be heard. I urge the Scottish Government to listen and to take appropriate action as a matter of urgency.

The Convener: Thank you very much for your contribution, Dr Morton. I know that it is painful for you, but you gave us a good understanding of your petition. I say to Vicki Hendry that she should feel free to come in at any time if she wishes to answer any of our questions or make a contribution.

I begin with an obvious but pertinent question. Will you say fairly briefly why you are so concerned about services for adults with CHD?

Dr Morton: It is because, as things stand, our lives are at risk, particularly with regard to out-of-hours access. When we present at A and E or to our GPs, because there are no protocols or standards and there is no guidance, they just do not know what to do with us. In some cases, they catastrophise. For example, I turned up at A and E and the nurse I saw told me that I was in heart failure, which I was not. I know what my heart does and I knew that my pacemaker was broken, but that was alarming. I went on to see a cardiologist who told me that I had a virus and discharged me even though my heart rate was dropping repeatedly.

There are numerous examples of such things happening. Without guidance, GPs do not know what to do, so they do not listen to us or make the correct referrals. SACCS has 8,000 patients, but it is estimated that there are 16,000 congenital heart disease patients in Scotland, so where are the other patients?

The Convener: I suppose that that leads to what you are calling for. You feel that national mandatory standards are required in Scotland and that there is a particular gap in accident and emergency services.

Dr Morton: Absolutely—and there should be protocols for GPs and allied health professionals, so that they know what to do.

Another concern about A and E services is that the absence of standards means that non-specialist cardiologists will sometimes try to work outwith their competencies, which is extremely dangerous.

The Convener: Where do the missing patients go? Your figures are quite stark.

Dr Morton: That is a big problem. At the national conference, Dr Hamish Walker, who is the lead consultant for SACCS, presented a very worrying graph that showed that in other western countries many more adult CHD patients are known to the system. The concern is: where are the other Scottish patients? Do they exist? Have they not been referred? Are they still alive?

Vicki Hendry (Somerville Foundation): A lot of patients were discharged as children from paediatric services who would never be discharged now. They may be under the care of general cardiologists, but adults with congenital heart defects need specialist care, because a normal cardiologist does not understand the complexities of the condition.

The Convener: So, in Scotland, we have thousands of missing ACHD patients.

Vicki Hendry: We do.

The Convener: That is very worrying.

Dr Morton: It is worrying.

The other difficulty is that although some people with CHD may be being seen, some may not be being seen at all. We know of patients who have presented to their GP with heart failure in their 30s, 40s or 50s and the GP has not recognised or understood that that was due to a congenital condition. That is a result of people being discharged erroneously. When we were younger, the study of CHD was very new and there was a misunderstanding that the condition could be cured, so a lot of people were discharged. What was viewed as pioneering treatment—open-heart surgery—would be done and people would be discharged. It is now recognised internationally that there is no cure for such complex heart problems and that lifelong monitoring is necessary. You are right that the missing patients are a big worry.

The Convener: Thank you for that.

We will move on to questions from my colleagues.

Chic Brodie: What you have told us is slightly disconcerting. Dr Morton, returning to your experience of going to A and E, are you saying that the medical records do not follow the patient? Are there no means by which an A and E department can access someone’s records remotely?

Dr Morton: There are two different issues. The first issue is that the medical records do not follow the patient. I now have a copy of my records to take with me but, because there are no standards, patients will come up against doctors who will work outwith their competencies. I cannot say, “You have to phone SACCS—don’t treat me,” because the absence of guidance and protocols means that I have no rights as a patient. I met a cardiologist who decided that he knew better—he said that I had a virus and confidently discharged me. I could not make any demands, because there are no standards. That happens repeatedly.

It is extremely important for us to have standards, guidance and protocols because, as patients, we have no voice and no rights. Very often, because we have lived with the condition from birth, we know more than the medical professionals whom we meet, yet we cannot voice that.

Chic Brodie: You are obviously highly skilled and knowledgeable, but there are people with CHD who are not.

Dr Morton: Yes—that is the concern.

Chic Brodie: They will not know to ask the right questions. Are there no protocols or guidelines at all?

Dr Morton: There is nothing.

Vicki Hendry: I will give an example. One evening a fortnight ago, a patient phoned me from A and E in a district general hospital. The people at the hospital said that she had had a heart attack and they wanted to give her aspirin. She said that she had not had a heart attack, but that her electrocardiogram made it look as if she had. She could not take aspirin and wanted to know what to do. Someone looked at the case and thought that it looked like a heart attack, so they decided to treat the woman as a heart attack patient. The lack of 24-hour access to a specialist service means that people in hospitals cannot phone one of the CHD cardiologists to get advice. There are no protocols in place that say that, if a patient with CHD turns up at A and E, advice must be sought from a specialist cardiologist.

Chic Brodie: We have all these cards for people with particular illnesses, but people with CHD do not carry anything. Has the idea been promoted that people with CHD should carry a card?

Vicki Hendry: The Somerville Foundation issues passports, which are comparable. It is up to patients whether they carry those, but that still would not give cardiologists or out-of-hours services any information about what they should do if someone turned up—

Chic Brodie: No, I understand that. However, at least it would pinpoint what the patient has suffered from or is suffering from.

Vicki Hendry: Yes, it would.

Chic Brodie: I take your point about the role of the surgeon or consultant.

Vicki Hendry: At the moment, it is up to patients to be educated about their own conditions.

John Wilson: Good morning and thank you for your presentation, Dr Morton. It is enlightening to get first-hand experience of the issues that you have raised.

I am concerned about the standards, guidance and protocols that are in place. You read out a list of those who are engaged in developing standards south of the border, but one of the groups that you missed out is patients. Some of the experts on the conditions that you mentioned in your presentation are sitting in this room. Patients are vital in drawing up any standards and in ensuring that we have patient-centred support and care, rather than what consultants, nurses or doctors think. You have given some examples of people going to A and E departments where consultants or doctors feel that they know better than the patients.

You indicate in your petition that SACCS is currently not adequately resourced. You have referred to the three SACCS consultants who are currently employed. What would make the service adequately resourced? What would you like to be put in place?

Dr Morton: The main thing that we need is 24-hour access. Obviously, it is not feasible to have a specialist consultant at every A and E department in the country, but it is important that the specialist service is available through the appropriate pathways and that those at A and E know to phone the specialists for telephone consultation. That is one of the most important things, and its lack is one of the biggest dangers.

Another issue is about the provision of more holistic support. Congenital heart disease is a life-threatening illness that people live with from birth to death, and I do not know why there is currently no psychological support for people with the illness. I do not know whether the situation has improved—I hope that it has improved in paediatrics—but there certainly was no such support for me or my family when I was growing up. One of the biggest issues for me, as a psychologist, is that there is no psychological or holistic support.

Vicki Hendry: Another issue is the absence of a regional service. The national service was designated in 2007, I think. There was a regional service at the Western general hospital, but the whole service moved out to the Golden Jubilee hospital. That means that there is no regional service in the west of Scotland and that the national service sees patients who could be seen at regional level. As you will imagine, Glasgow has the largest number of patients, but it has no regional service to support patients with less complex conditions.

All the patients with complex conditions should be seen at national level and the patients with less complex conditions should be seen at regional level but with access to the national service as required. For example, pregnant women or people who require simple procedures such as gall bladder operations may have to go to the national service to have their operations carried out, because specialist anaesthesia cover is needed. The fact that there is currently no regional service in the west of Scotland needs to be addressed urgently, because it is putting a huge strain on the national service.

John Wilson: As you have correctly pointed out, the national service is based at the Golden Jubilee hospital. What happens to people who have the condition in the north-east or south-west of Scotland?

Vicki Hendry: There are regional services in Inverness, Aberdeen and Edinburgh.

Now that we have the new consultant at SACCS, the consultants are hoping to go back out and support the regional services, so a consultant might go out once a month to support the consultants who are out in the regional service. That spreads expertise and gives some advice. However, all that will depend on the doctors at the regional service being educated and knowing when to refer patients back to the national service.

11:00

Dr Morton: When Dr Walker set up the system, one of the intentions was to do events in the outreach clinics and to educate staff in local accident and emergency units, as well as educating GPs. However, there has just not been enough capacity to do that, because the service is so overwhelmed with the work that it has to do just now.

John Wilson: Another issue that has been raised is the number of patients who have been identified. SACCS claims that it covers 7,000 to 8,000 patients. However, as Dr Morton indicated, the figure could be double that. We do not have detailed analysis, research or case notes. How can we get an accurate figure of the number of patients who have a CHD condition so that we can develop services to cover their requirements or demands?

Dr Morton: One thing that was discussed at the Somerville Foundation conference was how to find the missing patients. I found out about SACCS by writing to Nicola Sturgeon. I got a letter back from her saying that there is a specialist service. I then had to ask for a referral. Not everyone will do that, and they should not have to.

One way of getting round that would be to raise awareness of the condition. Levels of awareness are very poor. CHD is the most common birth defect, but social support and awareness are incredibly poor. People do not know about it at all. The other idea is to educate GPs. If someone is born with a heart murmur or has some kind of congenital heart problem, that should be in their records. We need to educate GPs so that, if someone presents with breathlessness or fluid, their GP thinks to ask whether there is a congenital heart defect. At the moment, GPs are not doing that, and people are getting to the point of heart failure before that is queried.

Vicki Hendry: We should be able to find people using the GP coding system. Everything is allocated a code so, in theory, finding people should be simple. Of course, that depends on people being coded properly.

John Wilson: That brings me to my final question. Are adequate records kept by hospitals and passed on to GPs? I would like GPs to be knowledgeable about the situation. I would also like that to apply to practice nurses, because they are now being called on to deliver care. Is adequate information passed on to GPs when CHD is identified at birth?

Vicki Hendry: I cannot really answer that, although I can tell you my personal experience. There is one page of A4 detailing the surgery that I had almost 40 years ago, but I do not have any childhood records, because they are obviously long gone. There is a bit of a guessing game about the procedures that people have had.

John Wilson: I raised the question because I deal with constituents who claim that doctors or hospitals lose their medical records. There might be people out there who do not know that they have the condition, and if they are unaware of it, their GPs will be unaware of it.

Vicki Hendry: I agree. Going back 20 to 30 years, people were just discharged from the service. They were told that they were cured and that they could go off and live their lives, when some of them had complex, life-limiting conditions that needed lifelong follow-up.

Jackson Carlaw: Dr Morton, do you mind if I ask what you are a doctor of?

Dr Morton: Psychology.

Jackson Carlaw: Thank you.

I was intrigued by a particular point. Would you agree that one reason why 90 per cent survive today whereas only 20 per cent did so in the 1940s is probably because we are now far better at identifying the condition in the first instance? For example, I have personal experience of a child who had a stenosis that, in the 1940s, would probably not have been detected, because it was minor. Part of the reason why many more children with the condition survive into adulthood will be advances in medicine, but it will also be because we can now identify conditions in many children that were not identified before and which children previously perhaps lived with without even knowing that they had them.

Vicki Hendry: Well—

Jackson Carlaw: You are shaking your head to say no. What I said was what I was told for my personal situation.

Vicki Hendry: Can you clarify that what you are saying is that people with minor conditions live with them without knowing that they have them?

Jackson Carlaw: Yes, some do.

Vicki Hendry: Undoubtedly, that is the case, but it would be a small number of people.

Jackson Carlaw: So, what do you put the increased survival rate down to?

Vicki Hendry: It is down to advances in surgical and medical technology, and in anaesthetic technology.

Jackson Carlaw: Both the figures will obviously be a percentage of the number of people identified in the first place. I am just assuming that, in the 1940s, the people who were identified probably had a more serious initial condition, so the number who survived at that stage was probably lower because of that.

Vicki Hendry: Yes, because the surgery was not available to operate on them.

Jackson Carlaw: My own experience of a child with stenosis was quite good, but I am concerned about the path that you identified in relation to adult care. I am familiar with the teenage-transition offering that is available through Yorkhill hospital, which I thought was sympathetic, helpful and informative. However, it is clear from what you say that a considerable number of people in adult care do not receive the level of attention that they should or, by implication from your petition, the level of service that they would now receive in England and Wales.

Your petition raises a number of important issues that we need to pursue. You specifically referred to letters that you received from Nicola Sturgeon and from the Scottish Government in response to your representations and those of Michael Moore. It would be helpful to know what the character of those responses was.

Dr Morton: I have those responses, and I have responses dating back to 2004. Basically, the recent responses say that the NSD is dealing with the issue. However, when we go to the NSD, it says that it is awaiting the outcome of the English review of standards. We do not think that that response is acceptable. The NSD awaited the commissioning guide, which was six years ago, but no action was taken after that. It said that it would try to meet the commissioning guide, but nothing was written in stone. That does not help us, because I cannot go to my GP and say that they are meant to follow the guide. We have just had put-off statements such as, “We’ll wait and see what happens in England.” That is basically what we get.

Jackson Carlaw: From whom was that response most recently received?

Dr Morton: I got one from Alex Neil. My local MSP wrote to him, and I think that I got a reply last week.

Jackson Carlaw: Right. So that continues to be the position.

Dr Morton: Yes—that has been the standard response.

Jackson Carlaw: That has been the standard response for a number of years.

Dr Morton: Yes. I have a letter that I wrote in, I think, 2003, to which I got a response from Malcolm Chisholm in 2004. Obviously, things were nowhere near as developed in England and Wales at that point, but he said that the Government had raised my issues.

Jackson Carlaw: So despite the fact that matters have moved on considerably in England and Wales, the response is still that what has happened in England and Wales is being looked at.

Dr Morton: Yes.

Jackson Carlaw: Okay. Thank you.

Anne McTaggart: Just carrying on from that point, do you have a date for when the review that you mentioned will be concluded?

Dr Morton: Do you mean in England and Wales?

Anne McTaggart: Yes.

Vicki Hendry: It is expected to be implemented in 2014.

Anne McTaggart: Obviously, you have been studying the situation carefully. Have you seen any evidence that the system is working down in England and Wales?

Vicki Hendry: I speak to a lot of patients and, with that system, they feel more confident about their care, which is the most important thing. People feel confident that, when they go to their local accident and emergency unit, staff will be able to contact their unit and the specialist service for advice and that they will be transferred. Obviously, that already happens in Scotland 9 to 5, Monday to Friday, but not outwith those hours and, from talking to patients, I know that they feel very unsafe.

Dr Morton: The main issue is feeling unsafe. I have a pacemaker, on which I am and have always been completely dependent. At Yorkhill, if there were any issues, we could just phone. I would go right in and the issues would be dealt with there and then. I am completely dependent on an artificial machine. I do not think about it day to day, but when it breaks it is terrifying to think that I do not know where to go or who is going to fix it and I do not know who owns the issue. My experience last year was terrifying. The transition services are a lot better now, but we did not have that at all. I went from a really good service at Yorkhill, with a paediatric consultant who was like a member of the family, to a service at Stobhill that was basically for geriatrics, on a ward with people in their 70s and 80s. The service basically involved pacemaker checks, rather than any consideration of the congenital aspects of the condition.

Thankfully, things have moved forward and it is now recognised that we need specialist care. Without those standards, though, we do not have the back-up to give us confidence. As I am sure members can imagine, when you are not well, you do not really feel best placed to start making demands. You want the people who look after you to know what they are doing; you do not want them to debate among themselves and say, “I don’t really know what’s wrong with you. Your heart shouldn’t be doing this. This is a bit odd.”

It is about confidence, not just when things go wrong but in daily life. If I could go about my everyday life knowing that the service is there for me when I need it, psychologically, I would feel safer. It is about feeling safe.

Angus MacDonald: You are certainly opening our eyes this morning with regard to the difficulties that you have been experiencing. As you mentioned earlier, the organisation Bravehearts has been working with the Scottish Government to design patient pathways. I was concerned to hear that, according to Bravehearts, the issue has not been taken forward since 2010. Have you had any further contact with Bravehearts? Has any explanation been given for the lack of progress?

Dr Morton: We have Bravehearts here: Gill Mitan, the chairperson, is here and Vicky Hendry was also involved.

Vicki Hendry: I was involved in those discussions as part of the Somerville Foundation, when it was called the Grown Up Congenital Heart Patients Association. A patient pathway was written up, but basically just ground to a halt. There has been no explanation why that happened. As you can imagine, the clinicians are under a lot of pressure. Their first priority is patient care and they see a lot of patients in clinics and outwith clinics, and they run obstetric clinics and teenage transition clinics. Their time is valuable. From a patient perspective, you want them to be seeing patients; you do not want them to be sitting writing protocols and pushing paper.

I do not know why the work has stalled. We have had no explanation. NSD says that it is waiting for the English standards to come through.

Angus MacDonald: So the response that you get all the time is that people are waiting for the English standards.

Do you intend to approach the Scottish Government or ask Bravehearts why that work has ground to a halt?

Vicki Hendry: Bravehearts has no explanation.

Adam Ingram: You talk about your frustration at things not moving here in Scotland and at waiting for developments down south to be implemented up here. Would it not make sense to wait and see what standards the English NHS comes up for the service? Why is it a drawback that we in Scotland are waiting for those standards to be formulated?

11:15

Dr Morton: People’s lives are at risk in the meantime. We have already waited for six years from the publication of the commissioning guide. The standards have been developed and, ironically, some of the people who have developed them are Scottish surgeons. Our experts are going down to England and writing standards for England and Wales that we are not benefiting from.

Adam Ingram: Are those standards being implemented in England just now?

Vicki Hendry: The patients are being consulted on the standards, which have been written and are now being tweaked. It is important to recognise that the standards apply to regional areas in England. In Scotland, we are a national service and our geography means that some things will be slightly different.

Adam Ingram: I understand perfectly the issue with regard to the resourcing of the service, which you think must be addressed urgently. However, how is England operating differently from the NHS in Scotland in applying national standards, protocols and the like? Does that require the same urgency as the resource question that you have highlighted this morning?

Dr Morton: Yes.

Adam Ingram: Or do you just need an assurance that, as soon as things have been developed in England, they will be applied in Scotland? Where is the urgency in that regard?

Dr Morton: It is an urgent issue because, as I said, those standards give patients a voice and ensure that when they turn up at A and E they can get the consultant to phone SACCS. Even if the 24-hour provision existed and was resourced, we would still face an obstacle in getting GPs, consultants and midwives to listen to us.

When I was in labour with my son, the midwife would not believe that I had a heart condition. I was in labour for 10 hours and I was horrified that, when I tried to implement the protocol that had been established in many meetings beforehand, she asked, “Do you have a heart condition?” Such experiences are terrifying. I am articulate and can argue my case, but many people cannot. Without standards, and without informing GPs and other allied health professionals that they should work only within their competencies, and telling them what the referral pathways are, people’s lives are at risk.

The standards that have been developed are now out to consultation, so we are at a point at which Scotland can examine, develop and implement them quickly. They should not be vastly different, because they were developed by professional bodies of surgeons and medics. Those are the same people—some of them are Scottish representatives. There are different geographical issues, but it should not take that much work. We are now asking, “What are we waiting on?”

Vicki Hendry: We do not want to be sitting here in another six years saying that England has those standards and we still do not have them.

Adam Ingram: I am interested to know what stage we are at in implementing those standards. Is England ahead of us?

Vicki Hendry: NSD told me specifically this year that there is no point in Scotland having standards because we would not be able to meet them. That is scary, and it should not be the case. NSD said that the Cystic Fibrosis Trust introduced standards and that there was no point as they could not be met, and that there is no point in us doing that in Scotland. That shows you what we are up against. It is very frustrating: every time we speak to someone they say that NSD is dealing with it, but it is not doing so. That is why we are here today.

Dr Morton: Our fear is that NSD will continue to put it off. First, there was the consultation on the commissioning guide, and it said, “We’ll wait until England and Wales have got standards.” Six years down the line, it said, “Oh, we’ll wait until they’re implemented.” Then it said, “Oh, we’ll wait a few years and then we’ll review it.” Next, it might say, “We’ll wait until that review is finished.” NSD could just keep putting it off like that, and patients could be dying in the meantime, or having an impoverished quality of life.

Vicki Hendry: You must remember that congenital heart defects are life-limiting conditions. The vast majority of these patients have life-limiting conditions. The issue is important.

John Wilson: In the written submission that we received in support of the petition, Dr Morton notes that, in 2006, the Department of Health in England and Wales produced a commissioning guide for services for young people and grown-ups with congenital heart disease. Have any parts of that guide been introduced in Scotland in any way, shape or form? Ms Hendry has indicated that, in her opinion, the NSD does not want to introduce such guidance or standards in Scotland as that would be setting up the system to fail. That is a worrying issue. If the NSD is saying that we in Scotland will never meet those standards, that raises a series of other issues outwith the scope of the petition.

Vicki Hendry: Some elements of the Department of Health’s guide are being adopted, but only because clinicians are allowing them to happen or making them happen. We have world-class clinicians in Scotland. For example, Dr Hamish Walker is happy for patients to self-refer to the service.

John Wilson: That is not happening because of guides that have been released by NHS Scotland or anyone else; it is happening simply because clinicians are applying the lessons that they have learned from what is happening in England and Wales.

Vicki Hendry: Yes.

John Wilson: They are doing that off their own backs. There is no guidance from NHS Scotland at the moment on how to deal with patients with those conditions.

Vicki Hendry: That is correct.

The Convener: I have let the debate run on for a little longer than I would otherwise have done because I sensed that members were interested in the petition.

Members have been educated by the presentation and the points that have been made. I am sure that we need to write to the Scottish Government, at least. The clerks have outlined a number of other agencies that we should contact, and I endorse those recommendations.

Do members agree to follow the suggested action?

Members *indicated agreement.*

The Convener: Are there any other agencies that we should write to?

John Wilson: I suggest that we write to the NHS in England and Wales to ask when it expects its guidance to be fully implemented. If we had that date, that might put greater pressure on the Scottish Government to come up with answers.

I would like us to ask the Scottish Government why it has not introduced some of the guidance that was issued in England and Wales in 2006, which is currently being reviewed.

The Convener: That is a good point. The issue of the gap between the number of patients that SACCS deals with and the actual number of patients is worrying. We need to identify some data on that. Obviously, the concern is that people are suffering in their households and are not getting access to the services that they need. That is a vital point.

This is an interesting petition. We will pursue the issues and keep the petitioners actively informed about what is going on.

Thank you for coming along and giving such excellent evidence.

I suspend the meeting to allow the petitioners to leave.

11:25

Meeting suspended.

11:26

On resuming—

Smoking Ban (Review) (PE1451)

The Convener: The third new petition is PE1451, by Belinda Cunnison, on behalf of Freedom to Choose Scotland, on a review of the smoking ban. Members have a note by the clerk, which is paper 3, a SPICe briefing—both were late papers—and a copy of the petition. I invite members to make recommendations on how we should deal with the petition.

John Wilson: I have read the paperwork that the petitioner provided, the SPICe report and the clerk’s briefing. A number of issues to do with the built-up environment arise. The petitioner claims that, given changes in European legislation, there could be the possibility of reintroducing smoking in limited facilities.

Given the nature of the petition and the legislation that is in place, I suggest that we pass the petition to the Health and Sport Committee for its consideration. I know that other discussions are taking place on the possibility of extending the smoking ban, but I am minded to pass the petition to that committee for its consideration.

The Convener: Do members agree to that suggestion?

Members *indicated agreement.*

The Convener: We will refer the petition under rule 15.6.2 of the standing orders to the Health and Sport Committee as part of its remit.

Court Records (Access) (PE1455)

The Convener: The fourth and final new petition is PE1455, by James Macfarlane, on public access to court records. Members have a note by the clerk, a SPICe briefing and a copy of the petition. I invite members to consider the petition and agree what action to take.

John Wilson: From my initial reading of the petition I think that the petitioner has raised a number of interesting points. I know from the examination of online sheriff court papers that we can get details of who will appear in front of sheriffs and when they will do so, but there is nothing that follows that up and says what the sheriff’s decision was in individual cases. Therefore, there may be concerns about the information that is available.

I accept that the press and interested members of the public can sit in the gallery of a court and hear the judgment or decision in a court case, but it might be worth while submitting the petition to the Scottish Government for its consideration, to the Scottish Court Service, and to the Scottish Human Rights Commission in particular. I suggest that we also write to the Law Society of Scotland to ask for its views on the petition and about the practical implications of making such information available.

Information is available in certain cases, but it is not available across the board. We should therefore ask why the court service makes decisions to release information only in particular cases and not for all its judgments.

11:30

The Convener: I understand that, when the initial human rights and freedom of information legislation was going through when Labour was in power in 1997, restrictions were put on court proceedings. It would be useful to get an up-to-date position, as things may well have changed since then.

John Wilson: I am aware that there will be particular cases in which the court service would not want to release information about those who participated and gave evidence or the findings of the court, particularly if the person is underage. However, it would be worth while to check out the position.

The Convener: I certainly know from discussions with Victim Support Scotland that there would be real concerns about some information going out that is pertinent to very vulnerable victims, which is something that I think that we would all understand.

John Wilson: I suggest that we write to Victim Support Scotland.

The Convener: Yes. Do members agree to continue the petition, to seek further information as outlined in paragraph 17(1) of the clerk’s note, and also to write to Victim Support Scotland and the Law Society of Scotland to get their views?

Members *indicated agreement.*

Current Petitions

School Bus Safety (PE1098 and PE1223)

11:31

The Convener: Agenda item 3 is consideration of current petitions. Petitions PE1098, by Lynn Merrifield, on behalf of Kingseat community council, and PE1223, by Ron Beaty, on school bus safety, are linked.

Members have a note by the clerk, in which we are invited to note the submissions that we have received. We are looking to hold an event on this issue in the Parliament in May next year, which will be an interesting development. That will involve people across the board who have an interest in safety and all committee members. It should be a useful discussion.

John Wilson: The letter that we have received from the minister refers to the action that he is taking on tendering and the consultation, which I assume is on the provision of seat belts on school buses. It is anticipated that the results of that consultation will be before us in April 2013, which is quite timely given that we hope to have a debate in the chamber in May. It would be useful to write to the minister indicating our intention to seek a debate and to say that the consultation responses would be gratefully received as part of that debate.

The Convener: To clarify, the event will be in the Parliament and we will be involved with others who have an interest in this particular area, such as local authorities and safety campaigners. Nevertheless, John Wilson’s point is well made—we need to ensure that the minister knows what we are doing in May. Do members agree with that approach?

Members *indicated agreement.*

A90/A937 (Safety Improvements) (PE1236)

The Convener: The next current petition is PE1236, by Jill Campbell, on the A90 and A937 safety improvements. Members have a note by the clerk.

There are two members present who have a long-standing interest in the petition, both of whom are honorary committee members: Nigel Don and Nanette Milne. I thank them for giving us detailed maps, which we will look at. I ask Nigel Don to briefly address the committee first, and then Nanette Milne.

Nigel Don (Angus North and Mearns) (SNP): Thank you very much, convener. I am grateful to be counted as an honorary committee member. Nanette Milne and I are, of course, ex-committee members, too and we recognise some of the work that you have just been dealing with.

I have given members a map—I am grateful to the convener for distributing it—simply because one of the issues that has arisen in connection with the petition is the suggestion from Transport Scotland that it would be entirely appropriate for heavy vehicles leaving Montrose to go either via Brechin or up the coast via the Inverbervie route to get to the A90 if they were going north.

Superficially that might seem sensible, but if we look at the map we can see that nobody who is looking at a tachograph or worrying about their petrol consumption will be in a hurry to do that more than occasionally. It is entirely obvious that the A937 up through Marykirk to Laurencekirk is the sensible route and the suggestion that anyone might go any other way is—I will have to be very charitable this morning—not very wise. I will have to try to remember to be charitable, because it will be very difficult.

I am grateful that members are well aware of the issues here and I draw their attention to a couple of points in the response from Transport Scotland. It repeatedly takes the view that the junction is not presently dangerous or overloaded, but it accepts that there is a 50mph limit—the only 50mph on our trunk routes. Why is that limit there, ladies and gentlemen? It is there because the junction is overloaded and dangerous.

The second point is slightly more worrying, because it is a sleight of hand. Transport Scotland seems to keep suggesting that a single flyover at Laurencekirk will be developer led. That ignores the fact that once there is further development at Laurencekirk, there will need to be two flyovers—one at the north junction and one at the south junction. For those who are not familiar with Laurencekirk, its high street could best be described as a series of chicanes. It is virtually impossible to get down it without having to stop to let somebody past. The parallel road, on the other side of the railway line, literally is not wide enough for two heavy vehicles to pass each other. The idea that a development that will primarily occur in the north will somehow or other come up with the £25 million that, from previous comments from Transport Scotland, we know will be needed to provide the flyovers is—again, to be charitable—mistaken. The suggestion that somehow or other section 75 money will give us the south junction, which we need anyway and which is a pre-existing problem, is—even being charitable—nonsense.

I get the impression that we are getting nowhere with Transport Scotland. The petitioner and one of the other correspondents are in the public gallery and I am sure that they are nodding vigorously. We seem to be bashing our heads against a brick wall. I am not sure what the committee can do further, although you have been wonderfully supportive and I am very grateful. I suggest that we might want to see the petition go to the Infrastructure and Capital Investment Committee, because I think that it has a remit to worry about roads and transport. We might be able to make a rather more comprehensive presentation to it than we can possibly do in this context. We might be able to get ministers involved and demonstrate why this simply needs to be done and why it makes no sense to defer it.

The Convener: That seems a sensible suggestion. I will bring in Nanette Milne.

Nanette Milne (North East Scotland) (Con): I will be extremely brief, convener. I was lucky to be able to get along today because my committee is not meeting this morning, unusually.

I fully endorse what Nigel Don said. I do not know how long this petition has been going, but we really have been beating our heads against a brick wall, as far as Transport Scotland is concerned. I suspect that the only way that this can be progressed is to refer the petition to another committee, and the Infrastructure and Capital Investment Committee appears to be the obvious one.

Over many months and years, the Public Petitions Committee has made all sorts of moves to try to get something done about this junction. It is a very serious issue. Perhaps there have not been any serious accidents recently, but it is worrying to even drive past the junction on the main road, let alone get across the main road from some of the side roads. Something needs to be done.

The Convener: Thank you both again for coming along. You have been very helpful with keeping the committee up to date with local circumstances. Although this has been a long-running petition—I think that it has been going for five years now—it is clearly a huge local issue. I know that you have been very frustrated with Transport Scotland when trying to get some action and your suggestion about the Infrastructure and Capital Investment Committee seems very sensible. Do members agree?

Chic Brodie: I agree. Clearly the major impact is on the economic development of the north-east. The Aberdeen western peripheral route and all the associated developments will draw more and more traffic to the area, and the petition should be referred to the Infrastructure and Capital Investment Committee to try to crystallise decisions instead of simply promulgating the discussion about predictions of future traffic levels. Any such considerations should cover economic development in the north-east and come up with something better than a simple statement that the numbers have been underestimated. I am sure that they have been. Anyone who has driven on that road—as I have, many a time and oft—will support the petition and I endorse your suggestion that we write to the Infrastructure and Capital Investment Committee.

Angus MacDonald: I saw at first hand the issue with this junction just two weeks ago on a fact-finding visit to the north-east by Rural Affairs, Climate Change and Environment Committee members. We had to cross the junction on the way to Montrose, and it would be fair to say that the experience was hair-raising. Of course, I had been aware of the issues prior to that, having travelled to Aberdeen airport on occasion. There is a serious issue to address and given that, as Nigel Don has pointed out, we are getting nowhere with Transport Scotland, I feel that it is imperative that the petition be referred to the Infrastructure and Capital Investment Committee so that it can, I hope, be progressed.

John Wilson: I commend Nigel Don and Nanette Milne for their perseverance with this petition. Like me, Nigel Don was a member of the committee in the previous session when it dealt with the issue; indeed, Nanette Milne, too, was a committee member until just recently.

I also commend the petitioner Jill Campbell for her perseverance in this matter. Although we have at times been frustrated by the responses that we have received from Transport Scotland, we have nevertheless managed to get enough information from it to vindicate our decision to pass the petition to the Infrastructure and Capital Investment Committee. When we first dealt with the petition, Transport Scotland said that there was no issue to answer either with regard to the need for a grade-separated junction or about transport in the area; however, as members have made clear, anyone who has travelled on the main route will realise that there must be difficulties with the junction if they are being asked to reduce their speed to 50mph while passing it.

I put on record my thanks to the petitioner, who has been campaigning on this matter for eight years and longer. I hope that we can get the Infrastructure and Capital Investment Committee to take forward the petition in a way that gives some satisfaction both to the petitioner and to the residents in the area, and ensures that they get some solution to their current traffic problems.

The Convener: Are members agreed?

Members *indicated agreement.*

Chic Brodie: On the impact of heavy goods vehicles, I should also note that, for example, the opening of the Victoria and Albert museum at the Dundee end of the route might mean that we will have tourists—who, after all, might well fly into Aberdeen as much as they will fly into Edinburgh—using the road without knowing anything about it, and it is critical that we minimise the risk to them.

The Convener: I, too, endorse John Wilson’s comments about the petitioners, who have done a valiant job, and our guests Nigel Don and Nanette Milne.

I think that the committee is unanimous in its agreement to refer the petition under rule 15.6.2 to the Infrastructure and Capital Investment Committee for further consideration, and I thank our guests for coming along today.

Lesser-taught Languages and Cultures (University Teaching Funding) (PE1395)

11:45

The Convener: Our fourth current petition is PE1395, by Jan Čulík, on targeted funding for lesser-taught languages and cultures at Scottish universities. Members have a note from the clerk and the submissions. As members may recall, we heard a very good presentation from Jan Čulík and his colleagues from the University of Glasgow last year, and we have considered the petition on a number of occasions since.

One issue that it might be useful to drill down into further would be to ask the Scottish Further and Higher Education Funding Council how it gathers information on unmet demand for courses that are not currently being offered. There has been some coming and going on the issue, but the petition deals with what is an important, although not very easy, subject. I think that we have done as much as we can, but there is probably one little element that we have not quite covered. Are members agreed?

Members *indicated agreement.*

The Convener: We will write to the Scottish funding council to ask how it gathers information on unmet demand for courses that are not being offered.

Wild Animals in Circuses (Ban) (PE1400)

The Convener: The fifth current petition is PE1400, by Libby Anderson, on behalf of OneKind, on a ban on the use of wild animals in circuses. Members should have received a note from the clerk and a late letter from Libby Anderson. I throw the discussion open to members.

Chic Brodie: I am sure that we sympathise with the objective, but on the basis that the letter that we have just received indicates that there are no travelling circuses using wild animals that visit

Scotland or have their headquarters in Scotland, I am not sure how profound or expansive the petition is. I wonder whether it is worth while taking it forward.

The Convener: If I remember rightly, we heard evidence from Libby Anderson and her colleagues. You are right to say that no such travelling circuses visit Scotland, but I think that she is basically saying that she wants a commitment from the Scottish Government to deter any such travelling circus that might be likely to come to Scotland. Sending a fairly straightforward one-line letter, to which we would expect a one-line response, would clarify the issue for the petitioner. Do members agree to do that?

Members *indicated agreement.*

Marriage (PE1413)

The Convener: The sixth current petition is PE1413, by Amy King, on preserving marriage. Members have a note by the clerk and the submissions. Again, I invite contributions from members. I will give members a second to find the correct paperwork.

John Wilson had the misfortune to look up at the wrong time.

John Wilson: That may be because I read my papers prior to the meeting.

I suggest that we remit the petition to the Equal Opportunities Committee, which I believe will deal with the legislation that the Scottish Government proposes to introduce. I suggest that we pass the paperwork and responses that we have received so far to that committee, which can consider the petition as part of its discussions and deliberations on the forthcoming equal marriage legislation.

The Convener: Clearly, that will be a major piece of legislation, in which the Equal Opportunities Committee will probably play a major role. When there is major legislation coming before the Parliament, it probably makes sense to refer the petition to the relevant committee. Do members agree to do that?

Members *indicated agreement.*

The Convener: We will refer the petition to the Equal Opportunities Committee on the basis that that committee will be responsible for stage 1 scrutiny of the bill.

Public Sector Staff (Talents) (PE1423)

The Convener: The seventh current petition is PE1423, by Gordon Hall, on behalf of the Unreasonable Learners, on harnessing the undoubted talent of public sector staff. Following our very useful round-table discussion, it was agreed that members would consider a paper from the clerk on the next steps. Members now have a note from the clerk. Do members have any views?

The clerk's recommendation is that we refer the petition to the Local Government and Regeneration Committee, which is currently undertaking an inquiry into public service reform. I understand that there will be a meeting on Thursday 6 December for which the various participants have suggested that they will produce further work. Is it agreed to refer the petition to the Local Government and Regeneration Committee?

Members *indicated agreement.*

Ambulance Services (Remote and Rural Areas) (PE1432)

The Convener: The eighth and final current petition is PE1432, by Joseph Duncalf and Anthony Duncalf, on improving emergency ambulance provision in remote and rural areas. Members have a note by the clerk—paper 11—and all the submissions. I invite comments from members.

As members will see from the recommendations, there is a strong argument that we should now close the petition on the basis that the Scottish Ambulance Service has made improvements in performance and has taken steps to improve its data gathering, which the petitioners suggested. The Scottish Ambulance Service has, therefore, taken the steps that the petitioners wanted it to take.

John Wilson: I seek advice on whether the petitioners have responded to the latest correspondence that we have received from the health and social care integration directorate. There are a couple of comments in the letter that we received on 23 October relating to the response times. The letter states:

> "It is important to recognise that good progress has been made in relation to the Category A response time target; at an all mainland Scotland level performance has improved from 62% in 2007/08 to 73% in 2011/12. For the Dumfries and Galloway area, the equivalent figures are 58% in 2007/08 to 66.9% in 2011/12."

I am not sure whether the petitioners would want to respond to the letter. Rather than close the petition, should we give the petitioners the opportunity to respond if they wish before we finally close it?

The Convener: I understand that we have given them that opportunity but have not had a letter back from them yet.

John Wilson: The timing of any response depends on when they were contacted.

The Convener: Would you rather that we received some comments from the petitioners before we closed the petition?

John Wilson: I am not sure when the petitioners were given sight of the letter that we have received. I would rather not close the petition now in case the petitioners come back and said that they would like us to examine further some of the figures that have been presented in the correspondence that has been received by the committee. I would hate us to close the petition only for the petitioners to come along and say—

The Convener: That is not a problem. We can easily write to the petitioners, get their views and bring the petition back to a future committee meeting.

John Wilson: They might not have any views, but I would like to give them that opportunity.

The Convener: I think that it is tidier for us to do that. Is that agreed?

Jackson Carlaw: I would like to test the assertion that engagement is taking place with the local community. The final paragraph of the letter in which that is referred to is slightly more vague than I would have liked an assurance to be.

Chic Brodie: I am not sure that this is pertinent, but I have attended several NHS Dumfries and Galloway board meetings and the issue has not surfaced among the critical items. I am not diminishing the suggestion in any way but I think that, once we have agreed a course of action, we should put the thing to bed.

The Convener: Okay. We will write to the petitioners and consider the petition at a future meeting. Is that agreed?

Members *indicated agreement.*

The Convener: That was the last item on the agenda. I ask members to stay behind for a brief discussion in private.

Meeting closed at 11:53.

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