The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

PUBLIC PETITIONS COMMITTEE

Tuesday 1 November 2011

Session 4

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CONTENTS

PUBLIC PETITIONS COMMITTEE

6th Meeting 2011, Session 4

CONVENER

*David Stewart (Highlands and Islands) (Lab)

DEPUTY CONVENER

*Sandra White (Glasgow Kelvin) (SNP)

COMMITTEE MEMBERS

*Neil Bibby (West Scotland) (Lab)
*Mark McDonald (North East Scotland) (SNP)
*Nanette Milne (North East Scotland) (Con)
*Bill Walker (Dunfermline) (SNP)
*John Wilson (Central Scotland) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Dorothy Farquharson
Stephen Fyfe (Diabetes UK Scotland)
Jane-Claire Judson (Diabetes UK Scotland)

CLERK TO THE COMMITTEE

Anne Peat

LOCATION

Committee Room 2

Scottish Parliament

Public Petitions Committee

Tuesday 1 November 2011

[The Convener *opened the meeting at 14:00*]

New Petition

Access to Insulin Pump Therapy (PE1404)

The Convener (David Stewart): Good afternoon, ladies and gentlemen. I welcome you all to the Public Petitions Committee's sixth meeting in 2011. No apologies have been received. I remind everyone to switch off mobile phones and all electronic devices.

Item 1 is consideration of a new petition; PE1404, which is on access to insulin pump therapy. Members have a copy of the note by the clerk, the Scottish Parliament information centre briefing and the petition.

Just for the record, I make it clear that I am a co-convener of the cross-party group on diabetes.

I welcome our witnesses. We are joined by Stephen Fyfe, Jane-Claire Judson and Dorothy Farquharson. You are very welcome and I thank you for coming along. I invite Ms Judson to make a short presentation of around five minutes, after which we will move to questions. We have a little more time than usual.

Jane-Claire Judson (Diabetes UK Scotland): Thank you for having us along to speak to our petition.

I am sure that the committee knows the background to the petition, which deals with a matter that is very close to our heart, as a charity, and to the hearts of many people with diabetes across Scotland, who will be watching the meeting online and checking what we say.

On Friday 21 October, at the Scottish National Party conference in Inverness, the Cabinet Secretary for Health, Wellbeing and Cities Strategy made a welcome announcement about targets for provision of insulin pumps. It was a joyous moment for many people with diabetes across the country. Given that it is quite a short time since then—11 days—you would think that there would still be a feeling of positivity in the diabetes community, but within a matter of hours of the announcement some pessimism and bleakness had set in.

As the announcement was made, people said online that it was "awesome", "brilliant" and "amazing", and that they were "very pleased". People were crying at their computers as they watched the speech come online, but within hours people on our Facebook pages and on Twitter were questioning how the commitment would be implemented and whether the 14 health boards would act on it and ensure that people get the pumps that had been promised. By the end of our fringe event that evening, we knew that people were worried.

You might ask why there was such pessimism within a matter of hours. The fact is that people have been fighting for provision of insulin pumps for 30 years. For many years—since we started to collect data through the Scottish diabetes survey, and since there have been diabetes action plans in Scotland—people have been promised that positive measures would be taken. We are very concerned that the provision of pumps will not be introduced across Scotland, despite Nicola Sturgeon's announcement, because of a lack of health board accountability. Similar policy announcements have been made in the past. There are Scottish intercollegiate guidelines network guidelines on the issue and there is an action plan, but there is a marked inequity across Scotland.

A week ago, someone asked me what advice I would give them about getting a pump. In a flippant moment, I said that they should move to Tayside or Lothian, but when I thought about what I had said, it was crushing to realise that, despite the cabinet secretary's announcement, that might be the best way to get a pump. We are extremely concerned that, while some health boards carry the target on the provision of pumps in Scotland, others seem to be able to ignore pronouncements, guidelines and other information on what is right for patients in their areas. We are worried that they will continue to do that and that the inequality gap might widen rather than close, with the result that more people in some areas might not get pumps.

There is no rationale for that. The evidence exists, as do the commitment from healthcare professionals and patients and—certainly since Friday 21 October—the political will, but we are extremely concerned that there is a stratum of health boards in the system that are not being held accountable and which will not deliver pumps for people with diabetes.

I will give an example of how that issue affects people. A boy in Glasgow—I will call him Gavin—received a pump not long ago. His mum described the effect as "getting my little boy back"—the little boy that she knew before he was diagnosed with diabetes, which has had such an impact on his life. However, she said that she is a bit worried and nervous about telling people that he has a pump, because she knows that it is a knife in the heart for parents who cannot get a pump for their child. She feels that she cannot share what should have been good news—something that affects her child's life positively—with other parents with whom she had campaigned for pumps. That is a sad indictment of our health service.

Pumps are the specific issue for us, but on health board accountability, I attended an event just a week ago that was hosted by the Long Term Conditions Alliance Scotland. The issue of pumps came up, along with the question of how to get decisions made in the health service. Everybody agreed that the problem is not the political statements that are made at national level or what is happening on the ground, but the decisions that are made at health-board level and whether boards can be held to account for those.

The patients who have been campaigning for pumps have done everything in their power to make their case heard. They have learned about their condition—they are probably among the most experienced and knowledgeable people in Scotland on diabetes. They have followed the procedures: they have gone to their managed clinical network, they have written to members of the Scottish Parliament—who have been incredibly supportive—and they have formed voluntary groups to campaign on the issue. They have done everything that one would expect in order to engage with the NHS.

However, throughout Scotland, even the best health boards that are trying to deliver pumps are still only reaching a provision level of 3 or 4 per cent. That is just not good enough for the people of Scotland, and particularly for the people who are living with type 1 diabetes.

I will show the committee the petition that we have been running for the past four weeks, which has garnered more than 1,000 signatures. Although we were not able to use the Parliament's petitions website, we set up one of our own to ensure that we captured what people are saying throughout Scotland.

We received comments from people, such as:

> "I got my pump 18 months ago and it made a huge difference in my life—I now have a life. I spent the two years pre-pump in hospital every three to four weeks with diabetic ketoacidosis. I think a pump should be offered to everyone no matter where they stay."

Joanna said:

> "I have waited five years for the pump and I just got it a month ago. I feel it would help a lot of other people in Scotland. The blood glucose control you achieve with the pump is amazing. Please, please give us more support."

People with diabetes should not have their care decided on the basis of where they live instead of whether they meet agreed medical criteria. The petition is not asking for something new, for a treatment that is untested or for health guidance to be changed. It is simply asking for the care that people with diabetes have been told they can receive to be delivered fairly. I ask the committee to investigate health board accountability and inequity in access to insulin pumps.

The Convener: I thank you for your presentation, which was clear and interesting. As you will know, I have taken a particular interest in the issue. It is perhaps a cliché in Scotland to talk about postcode lotteries, but I am concerned about the huge variance in the figures.

You mention that provision in NHS Ayrshire and Arran stands at 0.4 per cent, and there are severe problems in NHS Greater Glasgow and Clyde. I am also concerned about rural areas, such as my own area of the Highlands and Islands. Provision in NHS Highland is running at around 1 per cent, while the NHS Western Isles figure stands at 0.6 per cent. If we look at the bigger picture, we see that provision in England is around 5 per cent, in Europe it is 15 per cent, and in the United States it stands at 40 per cent. We are very much in the relegation zone as far as insulin pumps are concerned.

As you said, we are not talking about some ad hoc suggestion for medical treatment. The National Institute for Health and Clinical Excellence recommends the pump, as do the SIGN guidelines. I will ask a couple of questions before I bring in Bill Walker.

Do you have real concerns that there is almost a breakdown between the recommendations that have come—in fairness—from people such as Nicola Sturgeon that the boards should get their act together and try to reach 5 per cent, and what is happening in health boards on the ground?

Jane-Claire Judson: Yes. To add to the figures that you have just mentioned, the take-up of insulin pumps in Slovenia is 65 per cent, so the gap throughout Europe is huge. We certainly think that there are cultural barriers to use of insulin pumps in Scotland, in addition to the rationale that is used by health boards for not implementing use of the pumps.

In Scotland we use evidence-based medicine; we take into account the research that is currently available, the patient voice and, of course, clinical practice on the ground. We feel strongly that people are cherry picking the evidence that they wish to look at and that clinical practice and the patient voice are not being heard. "Postcode lottery" might seem to be an overused phrase, but I cannot think of a better way to describe a situation in which your outcome will depend on which hospital you attend, and which clinic in which health board. We want to look at why some health boards have managed to make progress while others have not. We are supposed to have a reputation for sharing good practice within the community in Scotland, so it seems to be strange that it has not happened with insulin pump services.

The Convener: It is probably difficult for you to answer this question, but is the breakdown in communication from health board bureaucracy, such as chief executives, or is it from consultants or diabetes nurses? Where is the problem? I ask because there is clearly huge variance across Scotland.

Jane-Claire Judson: In some ways, you are hitting the nail on the head. We are not entirely sure where that line is being drawn. Certainly we know that in NHS Greater Glasgow and Clyde business cases were put forward, discussed and agreed on. Every health board, in fact, has done that and published its plans within the diabetes action plan, but implementation does not seem to be happening. For example, NHS Ayrshire and Arran was given money for pumps, but we know that the money for structured education was not planned for, which stopped the pumps being delivered in Ayrshire and Arran, so something is evidently going wrong at the planning and strategic level. We have not been able to pin that down and we think that it is down to levels of transparency and accountability within health boards. To find out who has made the ultimate decision on insulin pumps within a health board is incredibly difficult and patients find it very hard to make their voices heard within health boards because that is not clear.

The Convener: I have a final question before I bring in Bill Walker. My other concern is that young people are being deprived of a service. In NHS Highland no-one under 16 has an insulin pump, but the recommendations from SIGN are quite clear about young people and insulin pumps. What have you picked up from other health boards and are you equally concerned about young people being deprived of insulin pumps?

Jane-Claire Judson: Absolutely. We are particularly concerned about children, because quite often they will not necessarily have as loud a voice as adults within a system. To give NHS Greater Glasgow and Clyde its due, it did deliver insulin pumps for children, but we know there are issues in NHS Highland, in NHS Ayrshire and Arran and in several other areas.

To illustrate, a young girl called Daisy received a pump and for the first time was able to eat a slice of birthday cake on her birthday. It is interesting that organisations such as Save the Children say that not being able to celebrate your birthday is a sign of child poverty. If you are not able to do that because you are not able to manage your blood glucose levels, when a pump would enable you to do that, it is not just about a medical device, it is about quality of life—whether the child is able to access education, health and a family life.

Bill Walker (Dunfermline) (SNP): I do not like the phrase “postcode lottery”, because it gives postcodes and lotteries a bad name. I do not know what the alternative is; it seems to be part of the culture now.

I would like to pursue what our visitors have discussed and give them a little more opportunity. Clearly there is variation in provision. I have had dealings with the health service a lot as a supplier in a previous life. Is it just a question of people not regarding provision of pumps as a priority or is it internal rationing of money? Does it come down to whether we could throw money at this—not just money for the kit, but for training people and so on—as so many things that we deal with in Parliament do?

Jane-Claire Judson: Obviously we have to be careful around NHS budgets; we understand that they must be managed and must be balanced. The cost effectiveness of pumps has been proven and the cost of pumps has been set out within SIGN and certainly within the technology assessment that was carried out by Professor Norman Waugh, who is based in Scotland. The cost works out at roughly £5 million over five years—about £1 million a year. If you look at the health service budget, that is a drop in the ocean. There is also the problem that pumps are perceived as being some kind of special treatment when they are not. They have been around for 30 years and should be mainstream—they are just a part of insulin therapy that people with type 1 diabetes require to live their lives fully.

14:15

There are always issues around ring fencing money or deciding how to spend it. On savings, our argument is that given that Parliament has a stated intention to support preventative spend, we would hope that people would front-load that money. In the great scheme of things, £5 million is quite a small amount. We are concerned about the fact that insulin pumps cannot be prioritised, given the impact that they can have on diabetes.

Bill Walker: I want to pick up on something that you said. The preventative spend argument is a very good one. I am hearing an argument for something that is genuinely about preventative spend, as opposed to its being for something that is dressed up as preventative spend, so I encourage you to continue making it in your campaigning.

Sandra White (Glasgow Kelvin) (SNP): Good afternoon. Like you, I was delighted when Nicola Sturgeon, the Cabinet Secretary for Health, Wellbeing and Cities Strategy, made her announcement regarding insulin pumps at the Scottish National Party conference. She went on to say that by 2013, 25 per cent of all type 1 diabetes sufferers under the age of 18 will have access to insulin pumps. As the petition states, provision in NHS Greater Glasgow and Clyde is only 0.9 per cent. Other MSPs from Glasgow and I have been dealing with the issue and we thought, “Great! Somebody’s listening to us at last.” We, too, were joyous. I have no doubt that the cabinet secretary will push the matter and will keep the promise that she made at conference, but it comes back to the situation in health boards: we have to ask why particular health boards are not keeping that promise.

Is the way forward for us to tell health boards that they have to provide pumps, or is it to make the money for pumps available to health boards and ring fence it? I want your ideas about how we should pursue this to help the young boy from Glasgow whom you mentioned and other people from Glasgow who say that they cannot get insulin pumps.

Jane-Claire Judson: There are two parts to the answer to that. The first is about delivery of insulin pumps. Ring fencing is very attractive, because it often works. On the other hand, it could perpetuate the idea that insulin pumps are somehow special. We want them to be mainstreamed; we want them to be seen as just part of the insulin therapy that is available.

It would help to be more directive to health boards and to find a way to make them more accountable, on a year-by-year basis, on the delivery of pumps. Nicola Sturgeon has announced targets, but this is about how those targets are delivered by health boards and how the boards are held to account through the Scottish diabetes group.

The other side of the matter is the mechanisms for making health boards accountable. We have looked through the legislation for health boards and the paths that could be taken. If a health board is not performing—several have not been—what do you do? I am not saying that there will be an answer to that today, but we think that this committee could look at that. We have an amazing commitment from the cabinet secretary, but how do we take it forward and ensure that health boards deliver on it?

Sandra White: I have a follow-up question on that. Your idea regarding monitoring is very good, but there have to be checks and balances by Government to ensure that if the money is there, provision is delivered. You are quite right to talk about insulin pumps being mainstreamed.

The problem that I always found when I approached the health board on behalf of a constituent was that it said that training was needed and that that sometimes caused difficulty. I am not an expert, so will you elaborate on what was meant by training? People are denied insulin pumps and I have been told that there are difficulties with some aspects. What difficulties are there and who are they perceived to exist for?

Jane-Claire Judson: There have been difficulties in health boards around staff training. Some staff have been nervous about putting patients on insulin pumps because they do not understand the technology or are not able to educate the patient. We question why health boards have not tackled that, given that it has been well known for a long time, and why they have not progressed it in anticipation of delivering on pumps. It comes back to strategy and planning within health boards. If they are saying that that is the barrier to their delivering on pumps, why are they not removing it? That question has to be put to them.

It would be interesting to find out whether health boards that have sorted the problem with delivery of pumps have some trigger that the other boards do not. Is the difference cultural or financial or is something else going on? We think that an answer to that interesting question would unlock provision of insulin pumps for a lot of people.

Mark McDonald (North East Scotland) (SNP): This issue is quite close to me because my best man has type 1 diabetes. I realise that, in politics these days, it is a bit dodgy to talk about your best man, but I stress that that is our only connection. I think I am on safe enough ground.

Are the people who use standard insulin pens and consumables, and who ought to be on pumps, in the system? Are you basically contending that the treatment that they are getting is probably not the most suitable for them?

Jane-Claire Judson: Yes. The diabetes guidelines say that patients should be on the insulin regime that is best for them. We accept that pumps are not for everyone; indeed, even people with diabetes accept that not everyone should have a pump and that pumps are not a panacea.

However, we—and healthcare professionals—know that certain people in the system could benefit from pumps. It is almost the elephant in the room. We know that the treatment could help, but it is not being delivered. People are meeting the criteria that have been set by NICE and SIGN, they have done everything that has been asked of them to control their diabetes and often have been through structured education or have spent many years managing their condition. It is not their fault that that has not worked. We need to be careful about simply assuming that there must be something wrong with the person dealing with their diabetes and deciding as a result that they should not be put on a pump.

I ask Dorothy Farquharson to tell the committee the difference that the pump has made to her life.

Dorothy Farquharson: I have had a pump for six years. Before that, I was having problems with gallstones, but I was in a catch-22 situation: I was very ill but the doctors could not operate because my blood sugars had been so high for three years. After a lot of wrangling and approaches to the health board, I eventually got a pump and in five weeks my HbA1c was brought down from about 9.4 to 7.7. As you can imagine, any digestive problem, upset or problem with food absorption that did not coincide with administering of insulin would give me enormous problems and make me quite ill. As a result, the pump saved my life. If I had not had it, my life would have got only worse.

Diabetes affects everything in one’s body. Children are being diagnosed with it younger and younger and are having to go through their whole school life with it. It affects their ability to achieve their potential and they end up not getting jobs that are appropriate to their intelligence. It is impossible to achieve perfect control through injections, but the pump can improve control to the extent that people can achieve their potential and live their lives. I cannot really describe the difference that a pump can make, even for someone who got it when she was 60.

The longer you have diabetes, the more damage it does. If you give children a pump when they are young and they manage to achieve perfect control and good HbA1c, they can go on to achieve things and have longer working lives, which is good for the country’s economy. It is nonsensical that pumps are not available. I believe that the health boards that are turning their backs on such a move simply do not want to go there. They say that it is elitist, that it is only for certain people and that it is too expensive, but they are just making excuses. They simply do not have the structures in place and are just backing off and digging their heels in—

The Convener: I am sorry for interrupting—I will allow Mark McDonald in shortly—but should we as politicians name and shame the health boards that are clearly not performing in this regard?

Dorothy Farquharson: You should. Nobody likes a postcode lottery, but that is what we have in relation to NHS Greater Glasgow and Clyde, NHS Lanarkshire and NHS Ayrshire and Arran.

The Convener: I will bring Mark MacDonald back in as I think that I interrupted him.

Mark McDonald: Given what my colleague Bill Walker said earlier, I will avoid his wrath by referring to the geographical disparity in practice according to health board areas.

Where is the blockage in the system that prevents the national aspiration from being delivered? Is it at the clinical end or the health board end, or is it at middle-management level?

Jane-Claire Judson: The blockage seems to be in a particular stratum in health boards. We know that there are clinicians who want the best for their patients. We find it difficult sometimes as a charity because we have healthcare professional members who tell us things anecdotally, but we cannot disclose who they are or put them on the record. However, I know from speaking to healthcare professionals that many of them are under a lot of pressure not to deliver on pumps and not to tell their patients about pumps. I do not understand that. It must be very stressful for the healthcare professional to know that there is a treatment that could help their patient but they are being steered away from it from within their health board.

That is not to say that there are not some healthcare professionals who do not particularly agree with pumps. We think that that is a cultural issue, because some clinicians will have experienced pumps 30 years ago when they were not so technologically advanced, who were very caring then of their patients who were affected by pumps, so there will be a residual cultural issue there. We understand and accept that. However, we also think that, against the odds, a number of healthcare professionals are delivering on pumps.

On the convener’s reference to naming and shaming, we know who is and who is not doing well on insulin pumps. However, within health boards, clinicians are frightened about what would happen if they just started putting people on pumps.

Mark McDonald: My colleague Bill Walker spoke about preventative expenditure. Obviously, the Government is very much focused on trying to shift the mindset towards preventative spend. There is obviously a cost disparity between a pump and an insulin pen—I think that it is around £1,200. If you could demonstrate to policy makers and health boards the lifetime savings that could be achieved from a person being on a pump as opposed to an insulin pen, you would make the preventative spend argument. I am interested to know whether you have such statistics or whether you could get them in order to reinforce your argument.

Jane-Claire Judson: Absolutely. On the reduction of complications from diabetes, among people on insulin pumps the risk of eye disease is reduced by 76 per cent. The cost of laser treatment for an eye is about £1,000, so there would be a cost saving from not having to do that. Similarly, the risk of kidney disease is reduced by 54 per cent and that of serious kidney disease is reduced by 39 per cent. Dialysis is hugely expensive to the NHS, so preventing the need for that is obviously really important.

Severe diabetic incidents have significant costs for the NHS. If somebody experiences such an episode and perhaps needs community-based intervention by a diabetes specialist nurse, that comes out at around £300 and more significant intervention would cost about £900. We reckon that the cost difference between multiple daily injections and the pump is about £900 a year, so the person having only one fewer hypoglycaemic event a year would cover the cost. That does not take into account the fact that the more hypoglycaemic episodes somebody has, the more likely they are to develop complications. Dorothy Farquharson can explain about her retinopathy.

Dorothy Farquharson: When I got the pump I had maculopathy damage in both eyes. The left eye was not as bad as the right, but it is now totally clear and the right eye has improved to the extent that I have never needed laser treatment, although the ophthalmologist told me that he had been thinking about it, when I asked him to give me a breakdown of how my eyes had improved over the past few years since having the pump.

14:30

Nanette Milne (North East Scotland) (Con): I should say for the record that I am co-convener of the cross-party group on diabetes. During the previous session of the Parliament I hosted a breakfast event on insulin pumps, and what Dorothy Farquharson said very much corroborates what the patients I met at the event said. There is no doubt about the benefits of pumps to people’s lives—let alone the good prognosis for people who are on pumps.

The situation is difficult. We talk about preventative spend but we tend to operate in the short term when we plan finances. Health boards look at their budgets from year to year, and when budgets are constrained boards will not splash out on treatments that they do not think are essential.

In England, the rate of patients who are on pumps is roughly twice the rate in Scotland. Why is there such a difference? Do the better health board areas have clinical champions, who are beating the drum? Often the people who shout loudest get results. I suppose your information must be anecdotal, because I do not think that there is research evidence on the difference between England and Scotland. I have worked in hospital medicine and I know that some clinicians bang the drum harder than others do.

We operate in a world in which we must set priorities. I often think that I could almost use the same speech in many members’ business debates about clinical conditions—and the phrase “postcode lottery” can be used in just about all of them. It can be difficult for health boards to prioritise investment. Do you have general comments on that? We must try to push forward on the issue.

Jane-Claire Judson: Strong clinical leadership is key in the provision of insulin pumps and we have such leadership in pockets of Scotland. If the committee takes the issue forward we can pass you the names of clinical leaders in that regard.

It is always painful to realise that another part of the United Kingdom is doing better than we are doing. I talk to colleagues throughout the UK and I have realised that when the introduction of insulin pumps has been considered in England, more international evidence has been gathered.

When the SIGN guidelines were being drawn up, there were discussions about the extent to which international evidence should be considered and there was a focus on evidence from Scotland. Our nation has a fantastic health service, but I thought that the focus was narrow. Given the number of patients in Scotland who are on pumps, it is difficult to get the evidence that we need without looking outwith our area.

Good practice has been collated, and the health technology assessment centre put together a how-to, why-to guide. People can work through the guide if they want to put the business case for an insulin pump service and to set up and deliver such a service. The information is there; we just do not know why the approach is not being implemented.

The border is not very far away and I am sure that we could bring people together to share experience and knowledge. The information would help everyone, whether they are entirely for or still a little against insulin pumps.

Our key frustration is that we in Scotland know how to deliver an insulin pump service—it is not an unknown. We are not proposing something that is completely new or that is risky or dangerous. The stumbling block is the barrier to implementation, which we must try to get over. I do not know how long we can go on saying to patients, “It will happen some day.” We have been saying that for 30 years and the phrase has become slightly hollow. I feel very strongly about that.

I accept the point that we can make similar arguments on many health issues. However, some people have been waiting all their lives for an insulin pump.

John Wilson (Central Scotland) (SNP): Will you clarify something in your petition? On page 2, you said that provision is patchy,

> "ranging from 4.6 and 4.4 per cent in Tayside and Fife Health Boards respectively to a mere ... 0.9 per cent in Greater Glasgow and Clyde."

However, in the table under that paragraph the rate of insulin pump use is given as 5.7 per cent in NHS Tayside, 5.9 per cent in NHS Fife and 1.1 per cent in NHS Greater Glasgow and Clyde. What is the distinction between what you put in your written submission and the Scottish diabetes survey findings? Are some insulin pumps being used by other groups who have diabetes? I want to understand how the figures relate to each other.

Jane-Claire Judson: Part of the issue with the figures on pumps is to do with where the information comes from. There can be differences if the information comes from the individual health boards, the Scottish diabetes survey or other bits of work. Stephen Fyfe might want to comment on the differences, but I know that tables 25 and 26 in the Scottish diabetes survey use slightly different ranges. So the figure for people with type 1 diabetes who are on continuous subcutaneous insulin infusion is a percentage of all people with type 1 diabetes, whereas other tables break that down into adults and children. Some health boards break the figure down differently in relation to transition. That is why there are disparities in the figures. We face challenges as a result of that, because patients often tell us that they have been told that a certain number of people have pumps, but we show them another piece of information that does not tally with that.

Even at the NHS Greater Glasgow and Clyde annual review, there was a discussion about what a waiting list is, how many people are on it and how many people have pumps. So even within health boards, the figures are not always completely nailed down. It would be beneficial for everybody if we had accurate information.

Stephen Fyfe (Diabetes UK Scotland): The criteria for getting an insulin pump are distinct and different for adults and children. Previously, answers to parliamentary questions have given that breakdown, which enabled us to identify where the good services were, but that information is no longer available. We understand that the Scottish Government, through the Scottish diabetes group, will try to produce that data, but at the moment we have a set of data that includes adults and children even though there are different criteria for them. From what we understand, that data also includes private patients. That situation makes it difficult to pin down exactly what is happening in each health board, although we certainly can see big differences between health boards.

John Wilson: I wanted to clarify that issue, because the percentages that are in the written part are different from those in the table. For one health board, the figure in the written part is half the figure in the table, which is frightening given what we are trying to achieve.

Have we improved the situation? Jane-Claire Judson mentioned that the issue has been around for 30 years and Dorothy Farquharson gave a good example from six years ago of the difference that a pump can make to someone's life. Has the number of insulin pumps that are available to patients increased over the past five or 10 years and, if so, what changes have there been in that timeframe?

Jane-Claire Judson: It can be argued that there has been an improvement, although that depends on what we term an improvement. More people go on to pumps every year, but we are starting from such a low baseline and the numbers are so small that I would not call that an improvement. In essence, people who end up with an insulin pump do so against the odds and not because of a driven policy across the 14 health boards. About 696 people in Scotland are currently on insulin pumps. The data that has been collected over the past three years through the Scottish diabetes survey shows a year-on-year increase in the figure, but that is nothing if we are to reach the target that has been set out by SIGN and NICE. If anything, it is a step backwards, because we will not meet the targets for another 20, 30 or possibly 40 years. Further, that takes into account only the number of people who could be on a pump now and does not include people in the future.

It sounds brilliant when the data shows, for example, that the number of people who are on pumps has tripled in the past three or four years, but when we examine the figures, we find that only 2 or 3 per cent of people with type 1 diabetes are on pumps, which is nowhere near the 12 to 15 per cent that it should be.

John Wilson: Earlier, you said that health boards make decisions about who should receive a pump. Are you any clearer about the criteria that the health boards and clinicians use when determining who should get an insulin pump and who should not? I fully take on board your point that there are too few pumps and that we are not meeting any standards—whether they be SIGN guideline standards or standards in Europe and elsewhere—in terms of the number of insulin pumps that are available. Is there any indication from health boards about what criteria are being used and how they are selecting candidates for the use of insulin pumps?

Jane-Claire Judson: We would like health boards to answer that question. The criteria that they should be using have been published, but they are evidently not using them, or else we would have much higher numbers.

I am sorry to bring the discussion back to NHS Greater Glasgow and Clyde, but it provides a good example of this point. Patients there were told that they were on a waiting list, then they were told that there was no waiting list, then a waiting list was mysteriously opened up again. Just over a week ago, the health board was asked about insulin pumps and said that it still had to define what a waiting list is. To us, that is the crux of the problem. People can read the SIGN guidelines or an action plan or a leaflet on insulin pumps, but the health board is not being transparent about what criteria are being used. The situation across Scotland is not fair. Some health boards will be trying to use that guidance as openly and transparently as possible but come up against barriers involving money or training. In other areas, health boards might claim that those are the barriers, but we know that different criteria are being used.

I know that the patients who have been campaigning on this issue are conscious of the fact that whoever shouts the loudest gets what they want. There have been concerns that parents who are campaigning on the issue might just go off into the sunset once their child has a pump. I have to say, however, that that has not happened. Anyone who has received a pump has remained in the campaign and in the diabetes community and has continued to try to ensure that other people get the same treatment. I would like that equality of approach to be taken by the health boards themselves.

Dorothy Farquharson: I am a member of the Glasgow managed clinical network on diabetes and was on the pump strategy group two or three years ago. We decided that we would try to come up with a strategy that would increase the supply of pumps to 100 a year. We put that to NHS Greater Glasgow and Clyde in September. By the end of the tax year, however, the proposal had disappeared. We had been turned down, but the health board did not even have the courtesy to tell us—at least, not me—what the reasons for that decision were.

Neil Bibby (West Scotland) (Lab): I would like to follow up on Mark McDonald’s question about preventative spend. Diabetes can cause amputations, which have a devastating impact on people’s lives. You mentioned a number of conditions that insulin pumps can prevent. What impact would having an insulin pump have on someone’s likelihood of having an amputation?

Jane-Claire Judson: Essentially, any complication to do with diabetes that you could name would be positively affected by better control. If better control can be achieved with an insulin pump, there will be a reduction in amputations.

Amputations are one of the most expensive procedures that someone can have in the NHS. Most surgeons would prefer to carry out procedures that they feel are necessary. They want to use their skills on people for whom that procedure really is the end of the road, as it were. I know that surgeons do not like to take off limbs if that can be prevented. That is not where they want to be in terms of how they deliver care.

The insulin pump is the closest thing that we have in mainstream therapy to how the body would naturally produce and manage insulin. Anything that mimics that closely will help with amputations. There are around 85 diabetes-related amputations a week in the UK, so I imagine that the number in Scotland is fairly high.

Amputation has an impact on the patient’s quality of life and longevity. A horrific piece of evidence is that a person has a lifespan of roughly five years after an amputation, no matter how good their control is or what happens. That is what people face when that situation has happened to them. Good control of diabetes prevents amputations and prevents people from finding themselves in that situation.

I am not a clinician who must make a decision in a health board, but an insulin pump could stop people from entering the NHS by another channel because of an amputation, retinopathy or kidney disease. Somebody once explained to me that a general practitioner’s job is to keep people out of the NHS—that is the ultimate idea. In some ways, the insulin pump is like that—it can keep people out of the healthcare system for as long as possible.

14:45

The Convener: I am afraid that we are running out of time. I thank the witnesses for their evidence and members for their questions.

I do not have enough time to ask my two additional questions, but I will place on the record the other two issues that concern me. One is the news that people who have two hypos in a year will be given a driving ban—perhaps I will communicate about that in writing. I am also concerned about the procurement of insulin pumps. As you know, I have previously raised the issue of consultants buying more expensive insulin pumps than those recommended by procurement Scotland. It is unfortunate that I do not have time to ask about those issues, which I would have liked to raise.

I ask the witnesses to bear with us while I ask committee members for their views on the next steps, which the clerk's paper covers.

Sandra White: We should continue the petition. I know that the cabinet secretary has made a commitment and I am sure that that was done in good faith. The issue is more that health boards are not coming up with the goods. I suggest that we ask the cabinet secretary and the Government for their views on the petition and whether they will undertake a review, as the petitioner requests. I would also like us to write to ask health boards how many clinicians have been trained in insulin pumps. The clerk's paper says that the cabinet secretary was to write to health boards that had made less progress, which were to report back at the end of September. If that report is available, could we see it?

John Wilson: Sandra White's second point was about writing to health boards. Rather than write to all health boards, I suggest that we write to NHS Fife, NHS Tayside, NHS Greater Glasgow and Clyde and NHS Ayrshire and Arran along the lines that Sandra White suggested and to ask about their criteria for allocating insulin pumps. I have selected two health board areas in which the figures are above 4.5 per cent and two in which the figures are below 1 per cent. We should find out what criteria health boards are using and try to tease out issues from health boards and clinicians.

The Convener: I agree with John Wilson. I suggest writing to other rural health boards, too. I presume that in very small health boards such as NHS Western Isles and NHS Shetland decisions would come down to one or two consultants, who would be important. It is important to have their views.

Nanette Milne: In answering my questions, Jane-Claire Judson said that she could give us the names of clinicians who had particularly supported insulin pumps for their patients. I am interested in finding out one or two such names and in writing to them for their views on the best way to go about getting insulin pumps from health boards.

Bill Walker: The petition should certainly be continued. The aim is to get to the bottom of the situation. If the issue is a lack of resources—I mean money—we should know. If some health boards are spending money on measures other than insulin pumps, we should know that. More research is required. We must get more evidence.

The Convener: Are members happy to continue the petition in the way that the clerk's paper suggests and to raise the additional points that Sandra White, John Wilson, Bill Walker and Nanette Milne have made?

Members *indicated agreement.*

The Convener: That is agreed unanimously.

I thank our three witnesses—Stephen Fyfe, Jane-Claire Judson and Dorothy Farquharson—for coming along to give evidence. The session was excellent. Thank you for giving up your time and helping the committee to understand this difficult problem.

I suspend the meeting to allow our witnesses to leave.

14:49

Meeting suspended.

14:50

On resuming—

Current Petitions

Transport Strategies (PE1115)

The Convener: There are seven current petitions for consideration today. The first is PE1115, on national and regional transport strategies. Members have received a note from the clerk. I invite comments on the petition.

John Wilson: As the committee will be aware, we have considered the petition at a number of meetings. Given that, in the light of Transport Scotland's response, we have taken the petition as far as we can, I propose that we take up the petitioner's suggestion and refer it to the Infrastructure and Capital Investment Committee to allow that committee to look at it in the light of the wider rail network investment strategies that Transport Scotland and the Scottish Government are developing.

Sandra White: I was not on the committee in 2008 when the petition first came to it but, looking at the amount of work that has been done on the petition, I do not particularly agree with John Wilson. However, perhaps he can explain his position more fully. I am minded to close the petition, because Transport Scotland has said that its preferred option is to enhance existing stations rather than to reopen other stations. It has also offered to work with stakeholders, including the petitioner, in developing its plans. From 2008 to 2011, we have taken lots of evidence on the petition. Transport Scotland will certainly not move in the direction of reopening Blackford station and I would not like to give the petitioner false hope by sending the petition to another committee. I recommend that we close the petition but, obviously, the committee will make the decision.

Mark McDonald: I would like us to proceed as John Wilson has suggested. In doing so, we would not necessarily be giving false hope; we would be allowing the Infrastructure and Capital Investment Committee to be aware of the issue when it considers the overall rail utilisation strategy. For those of us in areas where there are campaigns to bring old railway stations back into use or people are lobbying for new railway stations, such issues need to be looked at when the Infrastructure and Capital Investment Committee considers the overall strategy. It might come to nothing, but it is important that we at least pass the petition on to that committee and allow it to consider the issue within the overall rail utilisation strategy. I therefore support the approach that John Wilson suggests.

Nanette Milne: I agree with Mark McDonald and John Wilson. A lot of work has gone into the petition and this is our last shot at it. The petition should be kept open long enough for the Infrastructure and Capital Investment Committee to look at it.

Bill Walker: I agree, too. I understand that this committee has to call it a day on certain petitions, but this one should be passed on. I am a great fan of reopening stations and I would like the Infrastructure and Capital Investment Committee to look at the matter.

Sandra White: I am happy to go along with the majority. I hope that the matter goes further on the Infrastructure and Capital Investment Committee. I do not want to give the petitioner false hope, but I am happy to drop my suggestion that we close the petition.

The Convener: It seems that consensus has broken out. We will refer the petition to the Infrastructure and Capital Investment Committee under rule 15.6.2.

Nature Conservation (Scotland) Act 2004 (Snares) (PE1124)

The Convener: PE1124 is on banning the manufacture, sale, possession and use of snares. Members have received a note from the clerk. I remind the committee that, in an additional paper that has been circulated, the petitioner has set out another proposal.

Nanette Milne: Although the petition has come before the committee a number of times and although a lot of work has been done on it, the petitioner has made two fairly valid points. Given that, for some time now, we have been awaiting the results of research commissioned by the Department for Environment, Food and Rural Affairs, we should keep the petition open until we hear about that. Moreover, I could not find out when the snaring provisions in the Wildlife and Natural Environment (Scotland) Act 2011 come into force, and it would be helpful if the Government could tell us when that is going to happen.

The Convener: In summary, do members agree to keep the petition open until we get the results of the DEFRA research and to write to the Scottish Government about the snaring provisions in the 2011 act?

John Wilson: I agree with asking the Scottish Government when the provisions in the 2011 act will come into force. However, I have difficulty with the proposal to wait for the DEFRA report, which we were advised would be available in 2011. I suggest that we ask DEFRA when the report is likely to be published, because my fear is that, if we continue the petition simply because we are awaiting a report from DEFRA, we will have a long wait. After all, we have been waiting for the report for 18 months now. Once we get a response from DEFRA, we can decide whether to keep the petition open.

The Convener: The clerk has been in touch with DEFRA, which has confirmed that it is actively working on completing the report. Nevertheless, we are happy to write to it again for confirmation.

Do members agree to continue the petition along the lines suggested by Nanette Milne?

Members *indicated agreement.*

Clostridium Difficile (Public Inquiry) (PE1225)

The Convener: PE1225 relates to the outbreak of clostridium difficile. Members will have the clerk's note and I understand that the petitioner has advised that she is content for the petition to be closed. Do members agree with the petitioner?

Members *indicated agreement.*

Wallace Safe Conduct (PE1350)

The Convener: PE1350 is on the return of the Wallace safe conduct. Again, members will have the clerk's note. I invite members' comments, but the committee should note that the petitioner has advised that he is content that the petition be closed.

Sandra White: I should declare an interest as a member of the Society of William Wallace—indeed, many years ago, I was its press officer. I have to say that I am very pleased for Nick Brand and the others, who have sent the committee a very nice letter of congratulation.

The Convener: Such letters are always gladly accepted by the committee.

John Wilson: I endorse Sandra White's comments and, for those who might go and check my entry in the register of interests, put on record my membership of the society.

The Convener: I am happy to endorse your safe conduct out of the meeting.

Do members agree to close the petition?

Members *indicated agreement.*

Access to Justice (Environment) (PE1372)

The Convener: PE1372 is on access to justice in environment matters. The convener of the Equal Opportunities Committee has contacted me individually to say that she is enthusiastic for the petition to be referred to that committee. I stress, though, that the proposal has not been put to the whole committee.

Sandra White: I am happy to take the convener's advice and look forward to referring the petition to the Equal Opportunities Committee.

The Convener: Is that agreed?

Members *indicated agreement.*

Education (Qualified Teachers' Contact Hours) (PE1391)

15:00

The Convener: PE1391 is on protecting children's right to be taught by qualified teachers for 25 hours a week. Again, members will have the clerk's note. The committee will also recall that we took oral evidence on the petition some months ago and therefore have direct experience of it. I invite members' comments.

Neil Bibby: I declare an interest as a Renfrewshire councillor and as someone who knows members of the Renfrewshire parent council forum.

As the committee will be aware, the petition was submitted by parents in Renfrewshire who were extremely angry at council proposals to take teachers out of the classroom and cut 60 teaching posts. Since we last discussed the issue, we have received feedback from the General Teaching Council for Scotland, which appears to fully support the parents; the Educational Institute of Scotland, which broadly supports the petition but has made a couple of suggestions about the wording that I believe the parent council has agreed in its submission; and the Scottish Government, whose rather non-committal response says simply that the McCrone review is on-going. I think that we should ask the Scottish Government how that review will impact on the proposal.

The Convener: Mr Bibby, did you mean the McCormac review?

Neil Bibby: I apologise—I am getting my teacher employment reviews mixed up. I meant the McCormac review.

John Wilson: It tends to become confusing when you have McCrone, McCormac and the crossover in what are called McCrone hours, which is the period of time that teachers have to be in the classroom.

Given that the petition raises a number of issues, including the impact that the proposal might have on primary education, I wonder whether it might be more useful to refer it to the

Education and Culture Committee, which is debating the McCormac review.

Sandra White: I agree. I noted down a number of recommendations that could be made and actions that could be taken. Given that legislation will be needed to clarify the situation, any proposal to change legislation or introduce a bill would have to go before a committee. I also draw members' attention to the recommendation in the McCormac review that the use of external experts be facilitated, which is an issue that should also be raised with the Education and Culture Committee.

Bill Walker: I agree with the previous two speakers. Having been exposed to teaching and tutoring in schools and colleges, I want other people to be able to help in teaching. Many valuable people act as instructors and trainers, particularly in vocational areas. I do not want to cut teachers out, but we have to sort out some approach that involves other professionals. As a result, I think that it would be good to refer it to the Education and Culture Committee.

Neil Bibby: As the Education and Culture Committee will be looking at the McCormac review over the next period, I do not think that there is any danger of the petition being dropped, which would have been my worry about referring it. In the circumstances, I am happy to go with that suggestion.

I also note that, when the parents gave evidence, they quite rightly pointed out that they were not against additional enrichment in the programme. Instead, they were expressing concern about the proposal to replace teachers in classrooms with non-teaching staff. That is a big difference and we should all reflect on it.

The Convener: Are members content to refer the petition to the Education and Culture Committee under rule 15.6.2?

Members *indicated agreement.*

City Status (Ancient Prescriptive Usage) (PE1392)

The Convener: PE1392 is on city status by right of ancient prescriptive usage. Members will have the clerk's note and I invite comments.

Sandra White: Bill, did you want to comment on this?

Bill Walker: No.

Sandra White: Basically, we should close the petition and not give false hope to people. After all, the Scottish Government has made it clear that it is not going to take the matter any further.

Bill Walker: Actually, I will make a comment. I should declare an interest in that I know Robert McEwan. With regret, I agree with Sandra White that we should close the petition because it has probably—and unfortunately, as far as I am concerned—gone as far as it can. It is probably best to close it now.

The Convener: Do members agree to close the petition under rule 15.7 on the basis that, for a number of years now, the petitioners and others have made direct and unsuccessful representations to the UK Government? There are other reasons in the clerk's note that we can highlight.

Members *indicated agreement.*

Meeting closed at 15:05.

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