

# **PUBLIC PETITIONS COMMITTEE**

Tuesday 17 November 2009

Session 3

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## CONTENTS

Tuesday 17 November 2009

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<b>INTERESTS</b> .....	2103
<b>CURRENT PETITIONS</b> .....	2104
Cancer Treatment (Cetuximab) (PE1108) .....	2104
<b>NEW PETITIONS</b> .....	2120
Schools (Health Promotion and Nutrition) Act 2007 (Fair Trade Products) (PE1292 and PE1290) .....	2120
Stillbirths and Neonatal Deaths (PE1291) .....	2130
Physical Disability (National Reports) (PE1279) .....	2142
Postcodes (PE1283) .....	2142
Medical Records (PE1287) .....	2147
Planning (Playing Fields and Open Spaces) (PE1293 and PE1250) .....	2148
<b>CURRENT PETITIONS</b> .....	2150
Criminal Memoirs (Publication for Profit) (PE504) .....	2150
Violence against Women (PE1103) .....	2151
Nature Conservation (Scotland) Act 2004 (Snares) (PE1124) .....	2154
Scottish Agricultural Wages Board (PE1139) .....	2155
Disabled Parking (PE1149) .....	2156
Further Education (Students with Complex Needs) (PE1180) .....	2156
Bone Marrow Services (PE1204) .....	2161
Clostridium Difficile (Public Inquiry) (PE1225) .....	2163
Biological Data (PE1229) .....	2163
Scottish Class Action Procedure (PE1234) .....	2164
HM Prison Kilmarnock Contract (Independent Review) (PE1241) .....	2164
Voluntary Sector Mental Health Services (Funding Framework) (PE1258) .....	2165
<b>NEW PETITIONS (NOTIFICATION)</b> .....	2166

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# **PUBLIC PETITIONS COMMITTEE**

## **16<sup>th</sup> Meeting 2009, Session 3**

### **CONVENER**

\*Mr Frank McAveety (Glasgow Shettleston) (Lab)

### **DEPUTY CONVENER**

\*John Farquhar Munro (Ross, Skye and Inverness West) (LD)

### **COMMITTEE MEMBERS**

\*Rhona Brankin (Midlothian) (Lab)

\*Bill Butler (Glasgow Anniesland) (Lab)

\*Nigel Don (North East Scotland) (SNP)

\*Robin Harper (Lothians) (Green)

\*Anne McLaughlin (Glasgow) (SNP)

\*Nanette Milne (North East Scotland) (Con)

\*John Wilson (Central Scotland) (SNP)

### **COMMITTEE SUBSTITUTES**

Claire Baker (Mid Scotland and Fife) (Lab)

Jamie McGrigor (Highlands and Islands) (Con)

Nicol Stephen (Aberdeen South) (LD)

Bill Wilson (West of Scotland) (SNP)

\*attended

### **THE FOLLOWING ALSO ATTENDED :**

Colin Brown (Scottish Government Healthcare Quality and Strategy Directorate)

Marion Currie (Stillbirth and Neonatal Death Society)

Alex Fergusson (Galloway and Upper Nithsdale)

Neal Long (Stillbirth and Neonatal Death Society)

Tina McGeever

Michael McMahon (Hamilton North and Bellshill) (Lab)

Ann McMurray (Stillbirth and Neonatal Death Society)

Peter Peacock (Highlands and Islands) (Lab)

Mary Scanlon (Highlands and Islands) (Con)

Julia Standing (Dyce Academy)

Laura Stebbings (Dyce Academy)

Nicola Sturgeon (Deputy First Minister and Cabinet Secretary for Health and Wellbeing)

Ruth Teehan (Dyce Academy)

Erin Young (Dyce Academy)

### **CLERK TO THE COMMITTEE**

Fergus Cochrane

### **ASSISTANT CLERKS**

Franck David

Alison Wilson

### **LOCATION**

Committee Room 2

## Scottish Parliament

### Public Petitions Committee

*Tuesday 17 November 2009*

[THE CONVENER *opened the meeting at 14:01*]

### Interests

**The Convener (Mr Frank McAveety):** Good afternoon, everyone, and welcome to the 16<sup>th</sup> meeting in 2009 of the Public Petitions Committee. All electronic devices should be switched off in case they interfere with the broadcasting mechanisms. We have a full agenda today, with a number of people speaking to the committee.

Agenda item 1 is a declaration of interests. I welcome Rhona Brankin, who is a new member of the committee. In accordance with section 3 of the “Code of Conduct for Members of the Scottish Parliament”, I invite her to declare any interests that are relevant to the committee’s remit.

**Rhona Brankin (Midlothian) (Lab):** I refer members to my Scottish Parliament declaration of interests.

**The Convener:** Thank you.

I put on record our appreciation of Marlyn Glen’s contribution to our work and wish her well in her continuing work with the Equal Opportunities Committee.

## Current Petitions

### Cancer Treatment (Cetuximab) (PE1108)

14:02

**The Convener:** Item 2 is consideration of a current petition with which we are familiar. PE1108, which was lodged by Tina McGeever on behalf of her late husband, Mike Gray, calls on the Scottish Parliament to urge the Scottish Government to consider the provision of cancer treatment drugs, in particular cetuximab, on the national health service to ensure equity across NHS boards in determining the appropriateness, effectiveness and availability of such treatments.

We have considered the petition in substantial detail. At our meeting on 6 October, we agreed to invite the Cabinet Secretary for Health and Wellbeing to attend a meeting to detail the progress that has been made, and today I welcome Nicola Sturgeon to the committee. We have provided her with information that relates to the petition, which will, I hope, facilitate discussion.

I also welcome the Scottish woman of the year, Tina McGeever, who was the major contributor to the petition. She should feel free to sit at the table if she wishes to do so—in quickly scanning around, I see that she has already done so. I congratulate her on her award and achievement, which I know she recognises as an achievement for compelling emotional reasons.

I invite the cabinet secretary to make some opening remarks.

**The Deputy First Minister and Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon):** Thank you very much, convener. I welcome the opportunity to update members on the progress that we have made so far in addressing the recommendations in your inquiry report.

There can be no doubt in anybody’s mind that consideration of the important issues that the petition raised identified necessary and significant improvements that had to be made to the availability of and access to innovative treatments for NHS patients. I am pleased to report that substantial progress has been made in a number of areas and that work is on-going in other areas. With the committee’s indulgence, I will take a few moments to run through some of that progress. I, too, welcome Tina McGeever to the meeting and pay tribute to her for lodging the petition and for driving some of the changes that we will discuss today.

From the outset, our intention has been to achieve a strategic approach to change and

improvement. We do not want to make changes only at the margin. Our intention has been to focus on clinical effectiveness, patient safety and person centredness.

The Government's responses under each of the headings of the committee's recommendations have been addressed in previous correspondence with the committee, most notably the response that was provided on 3 September 2008, and in the statement that I made to the Scottish Parliament on 25 March 2009.

In summary, each of the key themes of the committee's recommendations, which spanned clarity about roles, provision of guidance, gathering of data, the role of quality-adjusted life years and the availability of new medicines, including exceptional prescribing and funding arrangements, is being addressed in detail by several strands of work. Taken together, those strands, which we will no doubt discuss in more detail today, are intended to provide a strategic framework that for the first time in Scotland sets out the arrangements for the introduction and availability of new medicines, with the express aim of achieving greater clarity and consistency of approach across the country.

The strands of work were set out in my response of 3 September 2008, which addressed each of the recommendations. My statement in Parliament on 25 March 2009 set out a range of additional development areas, as well as other areas of progress, such as the publication of the revised guidance on arrangements for NHS patients receiving health care services through private health care arrangements.

I will give a brief update on progress on other points that I covered in the statement. The first related to the development of extensive new guidance for NHS boards on the introduction and availability of new medicines. Guidance has been developed and is intended to provide a framework to which NHS boards must align local policies on access to new medicines. The draft guidance contains specific advice on what we now term individual patient treatment requests, which were previously known as exceptional prescribing requests, and has been circulated to NHS boards and a wide range of stakeholders and patient groups for comment. I would be pleased to give the committee the opportunity to influence the guidance prior to publication.

Comments on the draft guidance are expected by 20 November, which is the end of this week. Work will continue thereafter, so that we can finalise and issue the guidance as soon as possible. The user-friendly patient information leaflet that is being developed by health rights information Scotland and is intended to describe the end-to-end process, from licensing through to

individual patient treatment requests, is currently being tested in a variety of groups involving health care professionals, patients and the wider public.

In my statement in March, I announced that the Scottish Medicines Consortium would shortly publish on its website modifiers to be used when appraising new medicines for which the cost per QALY is in excess of the normal parameters. Those modifiers have been published and have been on the SMC website for some time. They give the SMC increased flexibility that can be applied to any new medicine that it is appraising, not just cancer medicines and end-of-life medicines. I understand that so far the SMC has approved three new drugs under the new arrangements.

I also said in my statement that I had accepted the recommendation that a national framework for assessing proposed patient access schemes at national level be established as a way of potentially reducing the overall cost of new medicines. A patient access schemes assessment group has been established. It will function separately from the SMC and provide an independent and objective evaluation of access schemes across Scotland. The group is currently operating in a transitional phase, but to date three schemes have been appraised under the arrangements; that has resulted in the acceptance by the SMC of two cancer medicines as part of patient access schemes.

I hope that all the developments that I have described will improve access to new medicines in the NHS for patients throughout Scotland. The committee made recommendations on the need for national data gathering, which are being progressed via on-going work at national level to develop information technology and data analysis systems to provide information on medicines uptake and how medicines are being used. That is work in progress. I am happy to update the committee on it further today, but I am sure that the committee will request on-going updates. A key message in the draft guidance is that NHS boards need to identify and share good practice in planning and introducing new medicines.

That was a relatively brief update. Like the committee, I remain committed to ensuring that people have the best health care possible. In addressing the committee's recommendations—we have tried and continue to try to address them all, one by one—we are intent on improving access to new medicines. The issues are complex and at times difficult, but we are committed to continuing to work with the committee to do what we can to improve the systems that are in place. I am pleased to say that there is clear momentum throughout the NHS in Scotland to achieve greater access and greater consistency.

I am happy to answer questions.

**The Convener:** We have questions about data gathering and quality-adjusted life years that we will submit for written responses rather than ask today.

You have highlighted several issues. The committee has played a role—in partnership, I hope, with you—through the parliamentary debate and the subsequent responses in finding better ways of operating in the health service. We have made progress since the petition was lodged.

Members will explore with you the issues that you have identified.

**Bill Butler (Glasgow Annie'sland) (Lab):** Good afternoon, cabinet secretary and colleagues. You wrote to NHS boards on 29 January. Were their responses positive? Do they accept the need for change? What is the position on achieving a coherent picture throughout the country? You talked about clear momentum. How much more has to be done?

**Nicola Sturgeon:** We have done much, but there is more to do—this is work in progress. As you said, I wrote to all NHS boards on 29 January. We received responses from all 14 territorial NHS boards. Although the evidence is anecdotal and the proof of the pudding will be in the eating, I detect a strong momentum and a clear determination in the NHS to improve the arrangements that are in place.

The responses from all the NHS boards were fully assessed, distilled and fed into the preparation of the draft guidance that I mentioned in my introduction. The process was inevitably quite long, because it was important to get that right and to consult not just NHS boards but other stakeholders. That guidance is almost in its final form and is with NHS boards and other stakeholders, as I said. The deadline for comments is 20 November, which is this Friday. Thereafter, we will aim to finalise the guidance as quickly as possible. In the period between the deadline for comments and publication, I will give the committee the chance to see and comment on the guidance.

The process of formulating and finalising the guidance has been lengthy, but NHS boards have not been at a standstill while that has happened. The process of drawing up the guidance required us to consider best practice around the country, so that we could spread that best practice through the guidance. Boards have already examined their policies and processes and thought about what they need to do. I hope that, by the time the guidance is published, most if not all boards will be able to say that they have policies in place that comply with the guidance.

**Bill Butler:** The committee looks forward to having input into finalising the guidance. As part of

that necessarily complex process, have boards been encouraged to talk to one another?

14:15

**Nicola Sturgeon:** Yes. As I said in my opening remarks, the Government's intention has been to set the strategic framework. Part of that is about ensuring that existing best practice is shared among boards so that those that do not comply with best practice are pulled up to scratch. Where, frankly, things might be done better than was the case in any NHS board in the past, we want all boards to improve on their position. Therefore, a lot of discussion has been involved. I say again that, in my experience, boards have been very up for that. Certainly, that has been the tenor of the feedback from them.

Obviously, once the guidance has been operational for a reasonable period, the situation will be reviewed. All boards will be expected to demonstrate that their policies are aligned with the guidance and that the board is doing what is required of it, so the publication of the guidance will not be the end of the story. We will monitor the impact of the guidance to ensure that it is having the desired effect.

**Bill Butler:** Obviously, policies should be under constant review, especially for such serious matters.

I have one more question. When the cabinet secretary mentioned the new modifiers that the Scottish Medicines Consortium has published, she mentioned that three new drugs are now available. What are those drugs? Are there any other practical examples of how things are now better as a result of the publication of the SMC's new modifiers?

**Nicola Sturgeon:** I knew that I would be asked what the drugs are called, but they are all unpronounceable—

**Bill Butler:** I will not push it, then.

**Nicola Sturgeon:** The three drugs are sunitinib, romiplostim and mecasermin—

**The Convener:** That is exactly what we were thinking.

**Nicola Sturgeon:** I am sure that my pronunciation is way off mark, but we can provide further details about those drugs. Sorry, what was the second part of the question?

**Bill Butler:** Basically, are there any other practical examples of how things have improved because of the new modifiers that the SMC has published?

**Nicola Sturgeon:** It is important to see the modifiers almost as a stand-alone. They are

designed to give the SMC more flexibility than it had in situations where the standard QALY methodology—which I know all members are now well versed in—would not, in the normal course of events, lead to the approval of a drug. The modifiers apply to drugs that might, for example, deliver a significant extension to a patient's life, improve a patient's quality of life but not prolong that life or provide some other benefit for which no other therapies are available. Those are some examples of the modifiers. The three drugs that I mentioned are the only drugs that have been approved under the modified approach since that came into place in May this year. Therefore, it is reasonable to say that, in all likelihood, those three drugs would not have been approved but for the modifiers.

Separate from the SMC modifiers is the patient access scheme. I mentioned two cancer drugs that have been approved under the patient access scheme. That is another example of a practical difference that has been made. Over and above all that, as I said earlier, the process of preparing and consulting on the new guidance is already leading NHS boards to make improvements in their local processes. Obviously, that is a practical benefit of the committee's work.

**Bill Butler:** Absolutely. I will not ask the cabinet secretary to pronounce these if they are difficult, but could she perhaps have a go at telling us which two new cancer drugs have been approved under the patient access scheme? Is cetuximab one of those, or is it being considered?

**Nicola Sturgeon:** Cetuximab is not one of the two drugs that I mentioned, but cetuximab is due to be considered under a patient access scheme proposal in the fairly near future. The two drugs—I will not pronounce them, but I will say what they do—are for the treatment of multiple myeloma and for the treatment of gastrointestinal tumours.

**Nanette Milne (North East Scotland) (Con):** I understand that other drugs are currently available under the patient access scheme in England. What are those drugs? Will they become available to patients in Scotland and, if so, when will that happen?

**Nicola Sturgeon:** I can provide that information to the committee, but I do not have it with me today. The arrangement that we have put in place for the consideration at a national level of patient access requests involves an assessment group that will consider applications that are made for the approval of drugs. The assessment group examines patient access scheme proposals and, if it considers them worth going ahead with, the information goes to the SMC for it to make its recommendation in the light of that. Applications that are made under patient access schemes are considered in that way. I know that applications for

some of the drugs that are available in England have not yet been made in Scotland. However, that is in the hands of the drug companies and I dare say that the picture will be fast changing.

**Nanette Milne:** One of the issues that arose in our inquiry, which led to the progress that is being made, was regional variation in prescribing, which we are trying to overcome. Will the new guidance reduce the risk of postcode prescribing and ensure more consistency? I hope that it will. Will the decision-making process become more transparent?

**Nicola Sturgeon:** The answer to both those questions is yes, I hope so. National consistency is important. The patient access scheme system and SMC modifiers operate at the national level and ensure consistency at that level. The guidance to NHS boards on the processes and systems that they should have in place for the introduction of new drugs and for exceptional prescribing—or individual patient treatment requests, as we are now calling them—will ensure much greater consistency throughout the country. I expect that there will be greater transparency as well, as the guidance to boards includes guidance on the need to put their policies in writing, to have them on their websites, to have clear arrangements for communicating decisions to patients and to have patient involvement in some of the decisions. All those things will improve the transparency.

We are trying to establish systems that encourage and facilitate consistency throughout the country. I agree that that is very important. Nevertheless, some of the decisions—especially on individual patient treatment requests—will, of necessity, deal with individual patients' circumstances, so there will continue to be instances of an individual in one part of the country getting a decision on a particular drug that an individual in another part of the country might not get. That will not be a sign of inconsistency; in most cases, it will be a sign that there are different circumstances at play in the two cases. We must be open eyed about that.

We are determined to establish systems that facilitate the consistency that the committee has requested in the past.

**Nanette Milne:** Hopefully, the greater transparency of the system will make it obvious why certain patients do not get the decisions that they want.

My final question is on the status of SMC guidance and the account that clinicians must take of it. You have said before that NHS boards are expected to take SMC advice into account. When medicines have been approved by the SMC, will there be a timescale in which boards will have to



make those medicines available to patients? If a board decides not to add an approved medicine to its formulary, what will be the basis of the decision-making process? Will the guidance ensure that that process is robust and consistent?

**Nicola Sturgeon:** The guidance will lay out the steps that the boards must take through their area drug and therapeutic committees to implement the SMC's recommendations, and it will include timescales in which those decisions must be made.

I have made it clear before and I will continue to make it clear—not just to the committee, but to all NHS boards—that SMC recommendations are not optional. When the SMC recommends a drug, a board has an obligation to make that drug or its equivalent, if it is not a unique drug, available. There is no doubt about that. If, at any time, there is any evidence or suggestion that a board is not acting in that way, the issue will be taken up vigorously with the board in question.

**Nanette Milne:** Thank you for that. There is a feeling that barriers are sometimes put in the way of patients getting SMC-approved treatments.

**The Convener:** You referred to individual patient treatment requests. Is that the new name for them?

**Nicola Sturgeon:** Yes. It is the new name for exceptional prescribing.

**The Convener:** I thought so. I asked just for clarification.

**Anne McLaughlin (Glasgow) (SNP):** Poor communication was one of the issues that Tina McGeever's petition highlighted. In paragraph 85, our report suggests that health boards should appoint local liaison officers, whose role would be to encourage better liaison between the clinician, the health board and the patient. Will you ask health boards to appoint local liaison officers? If not, what practical steps should they take to address such problems?

**Nicola Sturgeon:** Yes. That was an important recommendation, and the guidance will direct NHS boards to put in place and to identify the staff members who have the responsibility of being liaison officers. As well as having to identify an appropriate person who is well placed to perform that role, they will have to signpost patients and the public to that person through their written policies and their website, so that it is well known who that person is and they can be easily identified by patients who require help and information.

**Anne McLaughlin:** Is local liaison better now than it was a year ago?

**Nicola Sturgeon:** Yes, I think that that is the

case. Is it where we want it to be in all NHS boards? Not necessarily. Many of the changes that will bring that about will follow from the guidance. As I said, boards are already working on bringing their policies and procedures into line with what they expect the guidance to say. I would not say that it is job done on that aspect or on any other aspect of the issue. We have made great progress, but some of this is work in progress, which we need to continue.

**Anne McLaughlin:** I welcome the input of health rights information Scotland to the guidance on exceptional prescribing, or individual patient treatment requests, as the issue is now referred to, but were any other bodies, such as patient bodies, involved in drawing up the guidance? We all welcome the fact that you said that you would seek comments from the committee on the draft guidance when it comes out. Will any of the patient bodies be asked to comment on the draft guidance?

**Nicola Sturgeon:** The draft guidance is currently with NHS boards and other stakeholders, including patient groups. The leaflet has been sent for comment to a total of 36 stakeholders, 22 of which are cancer-related organisations. They include Breakthrough Breast Cancer, the rarer cancers forum, Macmillan Cancer Support, Bowel Cancer UK and the Scottish cancer coalition. The Scottish long-term conditions alliance, which covers a range of long-term conditions, has also been consulted on the leaflet, because it is important that we get it right.

**The Convener:** Are there any other questions on the broad area of availability?

**Bill Butler:** You talked about the desire and the need to ensure uniformity of process for patients across boards. Will there be uniformity of process for patients who wish to appeal against the decision of a board not to fund a treatment?

**Nicola Sturgeon:** The guidance will make it clear to boards that they require to have in place clear and understandable arrangements for patients who want to appeal. The processes will not necessarily be identical in every part of the country, although because, as Nanette Milne said, all the policies and procedures in different board areas will be highly transparent, my view is that they will end up being very similar. The appeals system is an important part of the process, and it is just as important that that part of the process is understood as it is that earlier parts of the process are understood.

**Bill Butler:** That part of the process will be as transparent as other parts of the process.

**Nicola Sturgeon:** Yes.

**Bill Butler:** I am grateful for that.

**Nigel Don (North East Scotland) (SNP):** Good afternoon. In the context of leaflets or information generally, to what extent will boards be required to take on the fact that not everyone reads English? Not everyone's first language is English and some people simply cannot read for a variety of reasons.

**Nicola Sturgeon:** It is our normal practice to make leaflets available in a range of languages and formats. I am looking for a nod to tell me that that will be the case with the leaflet that we are discussing.

**Colin Brown (Scottish Government Health Care Quality and Strategy Directorate):** Absolutely.

**Nigel Don:** Thank you for that confirmation.

**Colin Brown:** One of the reasons for choosing to involve health rights information Scotland was to ensure that the equality proofing was done and that the information that was produced was as widely accessible as possible. Equally, with information that is made available through NHS boards, we expect existing arrangements for engaging the public to take account of the point that you make.

**Nigel Don:** I am just very glad that the issue has been taken on board at the beginning of the process, because too often it is done too late.

**The Convener:** Do members have any more questions about availability?

**Nanette Milne:** On the exceptional prescribing process—that process has a new name—does every board now give each patient and clinician the opportunity to attend its meetings together when individual cases are being discussed?

**Nicola Sturgeon:** Several boards already do that, but the guidance will make it clear that where that is appropriate and desirable from the patient's point of view—I will not go into all the circumstances in which it might not be appropriate or desirable—they should have the opportunity to be present.

14:30

**The Convener:** I want to ask about the swiftness of response, never mind the disappointment of it. I refer to the petitioner's experience. How quickly would you expect people at the health board level to respond under the new criteria and guidance?

**Nicola Sturgeon:** To exceptional prescribing requests?

**The Convener:** Yes.

**Nicola Sturgeon:** It is quite difficult to set absolute rules and guidance on that. The guidance that we will publish will say that the timescales that

are followed must be sensitive and responsive to the patient's clinical condition. I will not spell out different circumstances, but there will be many circumstances in which quick consideration of the request and a quick decision are essential. In other cases, things may not require to be as quick. We would always want speed to be balanced with proper and full consideration of the request in all cases.

Regardless of the speed that might be dictated by clinical circumstances, it is crucial that the patient or their family is kept fully informed at all steps of the process and that the process is fully explained to them. I have spoken to patients who have experience of the system, and I am sure that Tina McGeever can speak about it as well. Often, the problem is that people do not really understand the process that will lead to a monumental decision for them. To a large extent, the speed of the process will be dictated by clinical circumstances, but regardless of that speed the patient must be involved and the process must be explained to them every step of the way.

**The Convener:** We understand that. Obviously, we wanted the timescales to be a bit firmer, but we understand the complexities that are involved.

If you find that health boards do not respond in any real sense to the broad criteria, how can you deal with that? How would you deal with a situation in which there had clearly not been enough attention to detail, if one arose again?

**Nicola Sturgeon:** Any failure of a board in the area that we are discussing—or in any other for that matter—to comply with guidance and meet the standards that it is expected to meet would be taken up directly with it either by me or by my officials through the normal accountability and performance arrangements that are in place for boards. The guidance is not yet in place, but it will be shortly. We intend to give it a reasonable period of operation and then review its impact by asking boards to demonstrate what it has meant to their policies and patients' experiences.

**The Convener:** Next, we want to explore funding, which is always the more challenging area for us all. We want to explore how individuals can economically deal with demands for access to drugs.

**Rhona Brankin:** I have just joined the committee, but I understand from my reading that revised guidelines on co-funding have been issued to NHS boards. I want to ask about those guidelines, as co-funding is obviously a major issue. What response has there been to them? Are you monitoring whether they are being applied uniformly throughout Scotland?

**Nicola Sturgeon:** That is an important question. The co-funding guidance that we published back

in March will be evaluated in the fullness of time in the same way that the guidance that I have mentioned will be once it has had a reasonable period of operation.

The thrust of everything that we and, I think, the Public Petitions Committee are trying to do is to improve access to and the availability of drugs on the NHS. The success of the work that we are jointly pursuing will be judged on the extent to which patients are more able to access drugs on the NHS without any consideration of co-payment or co-funding. That is the guiding principle for me.

My view is that, if we are successful, a patient will have to consider co-funding only if in all honesty a drug cannot deliver the benefit for them that they perhaps think it can. That would be based on the opinion of the clinicians who have been involved in their care. However, clearly, there is patient choice. Patients should still be able to pay for treatment privately should they choose. The guidance has tried to put in place a framework and principles that say that, assuming that certain tests and conditions are met, a patient who chooses to fund a part of their treatment privately would not lose the entitlement to other aspects of NHS care that they would otherwise have. It is about fairness. That is the approach that we are trying to take.

Rhona Brankin asked how the guidance has been received. It is early days. It has been fairly well received so far by organisations such as the British Medical Association. We know that some patients have already taken advantage of it—it is already in operation—but we require to give it a bit more time before we can evaluate it. In the fullness of time, we will be able to draw firmer conclusions.

I am confident that the approach is right, but the more important focus is on all the other work that we are doing so that the instances in which people find themselves relying on the guidance are as few as possible.

**Rhona Brankin:** Are you effectively saying that the scenario that Tina McGeever faced cannot happen again?

**Nicola Sturgeon:** I do not want to go into all the particular circumstances of Tina's case, so I will generalise rather than talk about that particular case. I might be wrong about some of this but, as I understand it, in the past, some people who have opted to pay privately for a drug have found that the other aspects of their care also have to be funded privately. The guidance seeks to ensure that, assuming that important tests can be met, the patient does not lose entitlement to other aspects of NHS care just because they choose to pay for a particular portion of it privately. That is the important difference between the new guidance and what existed previously.

If the other changes that we are making, the effect of which is to improve the availability of drugs on the NHS, are successful, I hope that fewer people—not nobody, because we cannot say that—will have to make such decisions.

**Rhona Brankin:** Apparently, the committee suggested in its report that some form of trial could be introduced whereby a board would agree to fund an initial trial of a drug to see whether it was clinically effective for the patient. Are such trials going on?

**Nicola Sturgeon:** We have not introduced trials of that nature at individual board level; we have introduced a patient access scheme at national level, which I think is more equitable and will help ensure consistency, the lack of which the committee has rightly criticised in the past with regard to other aspects of this issue. The patient access scheme means that drugs that otherwise might not be approved because of a lack of assurance about their effectiveness are given a chance, through whatever the detail of the scheme is. We are doing that at national level rather than at board level.

**Rhona Brankin:** So you would not see any opportunity for or advantage in doing that at board level?

**Nicola Sturgeon:** My preference is for what we are doing through the patient access scheme but, on an issue as emotive and important as this, I will not close my mind to anything that can help improve the situation. We will keep all this under review, but my strong feeling is that it is more equitable to have these kinds of schemes introduced nationally rather than locally. When you do these things at local level, you are more likely to end up with the postcode prescribing scenario that the committee has rightly criticised in relation to other aspects of this issue.

**John Wilson (Central Scotland) (SNP):** One issue that came up in the evidence that we received and in our discussions was about collection of data from boards. Some practitioners felt that there is little or no data collection from the boards. Has there been any improvement in the information that comes from boards and which is gathered by the Scottish Government? In relation to cancer care or any other medical care that health boards deliver, the issues that we are discussing are predicated on gathering the information that is necessary to make correct assessments of how the care is delivered. I seek assurances from the Scottish Government that the data that were referred to in our report are being collated by health boards and passed to the Scottish Government to allow it to make correct assumptions about the delivery mechanisms.

**Nicola Sturgeon:** That is a fairly big question. I will do my best to cover as much of the issue as I can verbally, but the committee might want to receive further information in writing. As I said, SMC recommendations are in effect binding on boards. We have no evidence that boards do not make available drugs that are recommended by the SMC, or the equivalent. We will always act on information that that is not happening. The committee has previously raised the issue of gathering information on exceptional prescribing. We are considering how we might do that in future when the new guidance is in place and boards have had an opportunity to implement it.

A range of work is under way on medicines utilisation, to use a shorthand name. The committee will be familiar with CEPAS, the chemotherapy prescribing and administration system, and C-PORT, the chemotherapy planning online resource tool. CEPAS networks all chemotherapy prescribing in Scotland and will in effect allow much greater information on what is being prescribed and to whom. That will go a long way to providing the information to which John Wilson refers. The hospital medicines utilisation database will provide an overview of prescribing activity across Scotland. Through those IT programmes, we are gathering more information than ever before, which will help to inform the picture of how well the measures that we are talking about today feed through to the patient. There is a range of information, and I am more than happy to provide it to the committee in writing.

**The Convener:** I want to pull together some of the core questions, although I know that you will give us fuller responses in writing. The rarer cancers forum's report on exceptional prescribing was produced after some of the committee's discussions. Do you have any views on the funding issues that are raised in that report? Are any of its recommendations at all relevant to our discussions on the petition?

**Nicola Sturgeon:** I assume that you are referring to funding in the more general sense, rather than co-funding. Funding will always be a challenging issue in the NHS. I say that in the context of NHS budgets that are rising. Next year's budget will be higher than this year's and this year's is higher than last year's. The nature of health care, particularly in relation to new drugs, means that NHS boards will always have to make difficult decisions. It is important that they have robust and transparent procedures in place for implementing SMC decisions so that they can take decisions and finance them in a managed way. I do not imagine that there is a health care system anywhere in the world in which the difficult issues of how to fund new technologies and drugs in a

sustainable way are not a challenge. We are no different in that respect.

**The Convener:** I think that you said that the deadline for comments on the draft guidance is the end of this week. I might have missed this earlier so, for my benefit, will you say when the committee will have a chance to look at the guidance?

**Nicola Sturgeon:** We have asked for comments by Friday. If it is okay with the committee, we will take some time to distil the comments and to revise the draft guidance in line with them. I ask Colin Brown what a reasonable time would be. Would it be a couple of weeks?

14:45

**Colin Brown:** Perhaps a bit longer.

**The Convener:** In the near future.

**Nicola Sturgeon:** Yes, in the near future. We will discuss the matter privately and come back to the committee with a more definitive timeline.

**The Convener:** The timescale is not really the issue; it is good to have established the principle.

Before we conclude our discussion, I would just like to say that the partnership that the committee has developed with the Government, which we have seen not only in the debate in Parliament but in ministers' willingness to come before the committee and, I hope, respond with other specific details, has been very helpful. As the cabinet secretary made clear in her response to the rather deep questions arising from Tina McGeever's situation, the fundamental principle is to try to ensure that this situation is better for the couples or individuals involved than it was a year or a year and a half ago.

**Bill Butler:** I am sure that you will put me back in order if what I suggest strays out of it, but would it, exceptionally, be in order for Tina McGeever to make one or two points to the cabinet secretary about what she has heard this afternoon?

**The Convener:** This is where the committee clerk comes in.

According to standing orders, Tina McGeever cannot ask any questions. However, if it helps, she can make some general comments. To be fair, we have had very useful and constructive discussions previously and again today about what has been a very difficult case.

**Tina McGeever:** What I have heard today has been extremely positive and I look forward to seeing everything being put into place. I feel that we are beginning to get somewhere and that real, practical solutions are being found to many of the problems that are faced by people who are going

through the same process that Michael went through. Thank you for that.

**The Convener:** Tina has been fantastic in her ability to come forward even in the most difficult of circumstances. I should add that, on Saturday, she will participate in a major conference on understanding and influencing your Parliament. She has certainly been very positive about the relationship that we have had with her over this petition.

On behalf of the committee, I thank Tina McGeever for attending the meeting and the Deputy First Minister and Cabinet Secretary for Health and Wellbeing for the response that we have had. We will continue the partnership approach that we have developed, certainly with regard to this petition if not on the more contentious issues that lie ahead of us. It is a good example of the committee and ministers working together to find solutions to the problems that people have experienced.

I thank everyone for their time this afternoon.

## New Petitions

### Schools (Health Promotion and Nutrition) Act 2007 (Fair Trade Products) (PE1292 and PE1290)

14:49

**The Convener:** The next item is consideration of new petitions. The first new petition is PE1292 by Laura Stebbings on behalf of Dyce academy fair trade group, which calls on the Parliament to urge the Government to amend the Schools (Health Promotion and Nutrition) (Scotland) Act 2007 to allow pupils to act responsibly in respect of their own health and learn about fair trade through running stalls selling fair trade products in their schools.

In its focus on certain broader issues, the petition links with PE1290 by Carol-Anne McGinty on behalf of a primary 7 group, Knowetop pupils against sweet ban—I believe that Knowetop is in North Lanarkshire—which calls on the Parliament to urge the Government to amend the 2007 act to allow school pupils to sell fair trade confectionery in school tuck shops.

I welcome to the committee three pupils from Dyce academy—Julia Standing, Erin Young and Laura Stebbings—and the school's deputy head, Ruth Teehan. As I said to the pupils earlier, they have an opportunity to present the case for their petition. Who will speak first?

**Julia Standing (Dyce Academy):** As part of the fair trade group at Dyce academy, we used to sell fair trade goods such as chocolate, fruit, nuts and Geobars. Because of the Schools (Health Promotion and Nutrition) (Scotland) Act 2007, we cannot sell most of those things any more.

**Erin Young (Dyce Academy):** We had a stall once a week, on a Friday, and we used to sell the goods. We got about £50 to £80 a week. Now, because of the 2007 act, all that we can sell is fruit. We used to subsidise the fruit with the profit that we made from the chocolate and other things, but now we cannot reduce the price of the fruit, so there is really no point in selling it at all.

**The Convener:** Laura, do you want to add anything?

**Laura Stebbings (Dyce Academy):** No—the others have said everything.

**The Convener:** Maybe the best thing is for me to invite members to ask questions about the experience of students at your school and their response to your being unable under the new rules to provide the stall.

**Bill Butler:** Good afternoon, ladies. When you were allowed to sell fair trade goods, before the 2007 act kicked in, what did you do with the profit—the £50 to £80 a week?

**Laura Stebbings:** We bought more fair trade stock. We were planning to buy fair trade footballs for the PE department, to promote fair trade. Quite a lot of it went to Fairtrade, I think.

**Julia Standing:** Yes, quite a lot of it went to Fairtrade itself.

**Bill Butler:** I am encouraged to hear that. That is a good co-operative model, or certainly a good social enterprise model, because you reinvested the profits in more goods to sell. Your stall was obviously popular when it was able to sell all the types of goods because people like chocolate and nuts and that kind of thing, but did it help to spread the message about why fair trade is a good thing?

**Laura Stebbings:** A lot of people came up to me and asked about the stuff that they were buying. They asked what fair trade is all about. I told them, and in a few minutes they joined the bandwagon.

**Bill Butler:** Did people who had not been in your fair trade group volunteer to be on the stall and take an active part in it?

**Julia Standing:** Yes. Anyone can join the fair trade group. We have a rota for who runs the stall. We all enjoy doing it.

**Bill Butler:** Because it builds confidence and you make new friends—that kind of thing? Perhaps it builds your confidence for appearing in public. All of us here like to appear in public. You are doing very well.

That is all the questions that I have at the moment, convener.

**The Convener:** You can tell that we are the shy, retiring type of parliamentarians.

**Bill Butler:** Especially the convener.

**The Convener:** When I heard Bill Butler's first question, I was worried about whether he was a specialist organiser in the tuck shop when he was at school. There might have been revealing statistics on what happened to the money that they raised from the tuck shop in those days.

There is a complication because the natural desire to encourage good eating habits in schools and minimise products that are bad for young people's health sits alongside the wish to ensure that youngsters understand their responsibilities as citizens of the world and the relationship between what they do and the possibility of helping other parts of the world to develop economically viable communities. We want to

explore some of those points with you to see what we can do.

**John Wilson:** I have some questions about what you actually sold at the tuck shop. What were the best sellers? Was it chocolate? There is a range of fair trade goods that are seen as nutritious. Was there a down side in the amount of chocolate that you sold?

**Laura Stebbings:** Our top sellers by far were Divine and Dubble chocolate bars. Then, it was Geobars.

**The Convener:** It is the same in our cafeteria.

**Robin Harper (Lothians) (Green):** There is a range of other fair trade products. It would be interesting to know which ones you sell. There is evidence that dark chocolate is quite good for the health, in moderate quantities.

My question is in two parts. First, what is the full range of products that you manage to sell? Secondly, have you worked with agencies in the school, for example with other departments or with the school doctor, on how to promote good health through the fair trade products that you sell, or alongside selling sweets?

**Erin Young:** We asked the home economics department if it could use fair trade sugar and other ingredients for baking. That helped to promote it.

**Robin Harper:** Very good. Are there other examples? You have answered my question, in that you say you have worked with the home economics department. That is a good example of how things can be improved. There is an unintended consequence of Government policy, and it can be shown what you are doing about it. That gives you a bargaining point with Government.

**Nanette Milne:** I am very pleased that Dyce academy has produced the petition. I was telling pupils about the Public Petitions Committee when I visited the school very recently. This has been a speedy return of a petition to the Parliament, on an issue that is clearly of importance to you. Well done for submitting it.

I do not know whether anyone around the table knows, but Aberdeen City has been recognised as a Fairtrade city. Dyce academy is trying to become a Fairtrade school. Do you know how many schools in Aberdeen have already achieved the status of Fairtrade school, and which schools they are? What do you have to do to be recognised as a Fairtrade school?

**Laura Stebbings:** Part of the Fairtrade website is devoted to Fairtrade schools. There are criteria for what schools must do to become one. For example, there needs to be a fair trade event

every term. We held a fair trade jewellery evening, when we were selling only fair trade jewellery—obviously. That counted as one of our events. They have to be held in three consecutive terms in the year. We also had to have minutes for one meeting each term. I cannot remember what else—it has been ages. We have been doing the petition and our banner for a while, so we have not done other things for ages.

**Nanette Milne:** Does selling fair trade produce form one of the criteria?

15:00

**Laura Stebbings:** Raising money for fair trade is in the criteria. I am not sure whether it is a set thing that happens regularly.

**Nanette Milne:** Did your stall count for anything else in your general education, such as business training or entrepreneurship? Was that a recognised part of your activities?

**Erin Young:** It allowed us to be global citizens and helped us to become a trading school.

**Laura Stebbings:** There is also the economics bit. It helped us to realise the actual value of money, such as how much so much money will get you and what the money can do for other people.

**Nanette Milne:** So it teaches about economic and health responsibility.

**Nigel Don:** Good afternoon, ladies. It is good to see you here. It is nice to see people from a school that is just up the road from where I stay.

You raise an extraordinarily important issue that once again reminds us of the unintended consequences of legislation. I am sure that you are aware of why the nutritional guidelines exist—I put on record the fact that I am married to one of the people who wrote them, so I have to be slightly careful about what I say. Clearly, the guidelines were not intended to mean that you could not sell fruit because it could not be subsidised by the other things that you sell. I am sure that that is an entirely unintended consequence.

Have you thought of any other ways in which one of the primary objectives of the guidelines, which is to get fruit into the hands of pupils of Dyce academy, could be achieved? We cannot just come along and say, “You must do this”; it looks as though we might have got things slightly wrong. Are there other ways of helping your colleagues to eat the right things, particularly fruit, that you could work around the things that you are allowed to do?

**Laura Stebbings:** Our school is two seconds away from Asda, so if we are cut off from chocolate and sweets in school, people will just go

to Asda. It is quite difficult to force healthy eating on people in that way.

Before I was in second year, I did not eat very healthily—I did not really eat fruit and vegetables—but when we were cooking in home economics, we made stuff that I really liked. That shows that stuff can be made in a way that is healthy but still tastes nice. We just need a bit more of that.

**Nigel Don:** It is wonderfully encouraging to find someone who has learned that at school. That is absolutely fabulous, but it still leaves us with the basic problem that you cannot sell the things that we know are not necessarily good for us—in fact, they can be bad for us if we eat too much of them—to cross-subsidise the things that we want to get into pupils’ hands. That is an unintended consequence of the legislation.

I will leave you with the thought that if you can come up with other ways of being creative and encouraging your colleagues to eat more fruit, that would be a good thing. I am sure we would love to hear your answers.

**Anne McLaughlin:** I congratulate you all and welcome you to the Parliament. We are always trying to encourage younger people to put in petitions, and they are always excellent and well-presented when we get them, so congratulations.

Laura said that she explains what fair trade is to people who ask about what they are eating, and two minutes later they say, “That’s great.” Politicians are always long winded—except me, obviously—and it takes them ages to explain anything. How do you explain fair trade to someone when they come to your stall and ask about it?

**Laura Stebbings:** I say something like they are paying a little bit extra and the extra money will not go into the pocket of some big boss or head of a company; it will go to the people who make the product, so that they can afford to go to the doctor, buy clothes, fix their house or whatever. They can afford to have a standard of living instead of living in poverty all the time.

**Anne McLaughlin:** That is the difference between most young people and most politicians: you got straight to the point and explained it very succinctly. Thank you very much.

**John Farquhar Munro (Ross, Skye and Inverness West) (LD):** Good afternoon, girls. I am pleased that you have come along and presented the petition to the committee. I am sure that what you were doing was an exercise in social enterprise and was innovative. It is encouraging to see young people taking an interest in the wider world and not just their own locality. I am sure that you were not trying to enhance profits for the

school by selling multiple chocolate bars; I am convinced that you were trying to promote the concept of fair trade. What disappointed or upset you most when it was decided that you could not continue with the business? Was it the fact that you could not sell the chocolate bars, or was it the fact that you lost the opportunity to promote and enhance the benefits of fair trade?

**Julia Standing:** During the past few years we did so well and sold so many products. The school has always been very generous in giving money to fair trade, but suddenly we cannot sell the products any more. That is the main disappointment.

**Laura Stebbings:** I cannot speak for the others, but for me the main thing was that when it was my turn on the stall I felt that every pound going in was that much more for one more farmer. It just felt good to help someone other than ourselves.

**Julia Standing:** It is nice to know that you are making a difference in the world.

**Laura Stebbings:** Yes—that is what I was trying to say.

**The Convener:** That is why you have friends with you.

**John Farquhar Munro:** That is an excellent response. We sympathise with you because you have lost an initiative that you established in your own community.

**Rhona Brankin:** Welcome and well done—good for you. I hope that your stall can continue in some way. I suppose that what you have come up against are the unintended consequences that politicians sometimes come up against when there are two competing policies. The issue raises very difficult questions. Do you think that schools should be allowed to sell whatever they like to pupils?

**Julia Standing:** No—not whatever they like; it should be within reason, of course. To my mind, as long as it is for the better, it is okay.

**Erin Young:** Fair trade lets us become more aware of the world. That is really important. Although we were selling chocolate, it was fair trade chocolate, and it is still important for everyone to know about fair trade. If we sell fair trade chocolate and so on, it is a good thing.

**Rhona Brankin:** It is a really difficult question, is it not? If you are saying, “We want to be able to sell fair trade chocolate,” other schools might say, “We want to be able to sell any kind of chocolate,” and if we were to change the legislation, that would allow schools to sell anything. It is a really difficult judgment to make. I understand your dilemma, and it will be interesting to explore the issue further.

**Robin Harper:** I will ask parliamentary-style, “do you agree?” questions. I liked Laura Stebbings’s presentation, which was concise. I, too, have seen the film about the cocoa farmers in Nigeria, who had absolutely nothing and lived in dire poverty, wracked by disease and exploited. However, after they went into selling fair trade chocolate, they got hospitals and roads, and their children were educated. Do you agree, Laura, that there is a great deal of difference between farming for chocolate and farming for opium or cocaine, for example?

**Laura Stebbings:** Yes.

**The Convener:** I am really glad that the teenager said yes to that one. You had me worried, Robin.

**Robin Harper:** The cocoa farmers are not trying to poison us. Of course, chocolate, like many other things that we routinely eat, is bad for us only if we eat too much of it. Do you agree?

**Julia Standing:** Yes, but it is not just about health and eating the right things; it is also about taking the right exercise.

**Nigel Don:** You tell them.

**Robin Harper:** Do you think that anybody would ever consider petitioning the Parliament about banning chocolate, restricting its sale in shops or preventing people from eating it in public places?

**Laura Stebbings:** No. It is not as if chocolate is a drug. They banned smoking in public places because it is really harmful to your health—you can get lung cancer and so on.

**Robin Harper:** You have made my point for me.

**The Convener:** Do you think that the current policy has led to a reduction in young people purchasing chocolate?

**Laura Stebbings:** If you feel as if you are being deprived of something, you will go home and say, “If I was allowed chocolate at school, then I would have had this much chocolate already. So I’ll have two chocolate bars right now to make up for that lost chocolate fix today at school.” I do not know—it is difficult to explain.

**The Convener:** We need to explore the issues that your petition raises. We need to debate the consumption of food and sweets. What if there was no control over that, and no awareness of the consequences? The evidence tells us that there is a demonstrable impact in our country on young people’s health and on people’s health generally—including the health of all of us round this table.

The petition raises a broader debate about the economics of some of the products. In some places, major companies benefit financially from the products. However, fair trade gives producers



in the poorest communities in the world the opportunity to benefit materially. In that respect, there is much better value from your selling fair trade products than would be the case if pupils went to Asda, Tesco or any other store. We need to explore whether there is guidance on the legislation that might allow for awareness about the role that schools play in fair trade.

The petition states:

"You can't force healthy eating upon people: they need to learn to make the choices that are right for them."

That is essentially what you did in your school. If everyone else did that—for example, when they shop—perhaps we would not have such a crisis.

I travel through to Edinburgh by train, and I usually buy a newspaper in the shop at the railway station. The shop assistants are forced to ask me whether I would also like a massive bar of chocolate at half price. I might not be thinking of buying chocolate, but if the assistant is front of me, promoting that all the time, I am tempted to buy it, thinking, "That'll sort me out for rest of the day." Obviously, you can see from my physique that I consistently ignore that temptation.

How do you feel about getting a chance, through the petition, to have your voice heard on the issue by your education authority and others? Is the school really in a difficult bind because of the law? Is that really your experience? You have been told that you cannot sell at all.

**Julia Standing:** Yes.

15:15

**Ruth Teehan (Dyce Academy):** There are two issues. First, the group is concerned that the profile of fair trade will diminish. We accept that chocolate is not the greatest vehicle for spreading a message and that there are side issues. There are many other fair trade products, but young people will not buy things such as tapioca and brown sugar; confectionery is their currency. Surely it is better to capitalise on that to create a profile for fair trade within the school than to have the pupils spend their money at a multinational store. Fair trade still has a profile, but we are concerned that that will be lost. The Friday fair trade stall was popular—the products were usually sold out within 10 minutes. The event was a great talking point and allowed us to raise the profile of fair trade.

Secondly, we are concerned that pupils will lose that crucial sense of global citizenship, which is central to the curriculum for excellence.

**Robin Harper:** I did not realise that the fair trade stall was open only on Friday; I thought that it was open every day. That emphasises how bizarre the effect of the legislation is. You are not reinforcing

the habit of buying sweets that many children have. I expect that quite a few pupils from the school buy sweets on the way in or at the nearest store—I will not mention its name again. Rather than reinforcing a daily habit, you are providing one opportunity to support fair trade. It should be seen purely as that.

**The Convener:** The petitioners are unfamiliar with the process, so I will describe the stage that we have now reached. Having completed the question-and-answer session, we will hear members' views on how they wish to deal with the petition. We need to take the petition to the next stage and to seek responses to it. I am open to suggestions from members.

**Bill Butler:** As the young women who have given evidence have explained, there is obviously a contradiction between the intention of the legislation and the unintended result. We could write to the Scottish Government with a number of questions. We could ask whether there is a risk that its 2008 guidance will have an adverse effect on encouraging young people to think about fair trade, global citizenship and the value of money—issues that the girls have raised with the committee today.

We could also ask the Scottish Executive—I beg your pardon, I mean the Scottish Government; I was going back in time there—whether it will amend the 2007 act to allow schools to sell fair trade confectionery alongside other fair trade goods and, if not, why not. I doubt that the Government will amend the act. If that approach is impossible, it could introduce a more balanced approach, through regulation, to make exemptions and to narrow the scope of the legislation's impact, instead of widening it, which is what appears to be happening in practice. Given that one of the 2007 act's aims is to promote a healthy, balanced diet, we should ask the Government how young people can develop a responsible attitude to the inclusion of a small proportion of confectionery in their diet if the sale of fair trade confectionery has been banned. Surely that drives them to Asda and other outlets.

**Nanette Milne:** I agree with Bill Butler. We could also ask the Government and some representative local authorities, including Aberdeen City Council—as we know, Aberdeen is a Fairtrade city—whether something positive could be gained in an educational sense. Could healthy, responsible eating be promoted alongside the promotion of fair trade, given what fair trade stands for? We could teach children to think more about what they are eating, from both a health point of view and a nutritional and ethical point of view. There might be an opportunity for us to promote healthy eating alongside the promotion of

fair trade, even if that means selling fair trade chocolate once a week.

**Rhona Brankin:** It is difficult to address the petition without undermining what the Government is trying to do on obesity; there may also be issues relating to age groups. It strikes me as a bit unreasonable to ban the sale of fair trade confectionery when it is being sold only once a week. The test of reasonableness could be applied. I might have concerns if my 11-year-old daughter were buying chocolate every day in school, when I am trying specifically to encourage her not to do that. However, we could ask the Government whether some flexibility could be exercised without opening the doors to any amount of sweets every day in school.

**Anne McLaughlin:** I was going to make a similar point. When we ask the Scottish Government whether some flexibility could be exercised, we should refer to Dyce academy, which sells fair trade confectionery only once a week and, according to the petitioners, has a supermarket practically at the school gate, as an example of the exceptions that could be made.

**Robin Harper:** The two most important issues have already been mentioned. In particular, when we talk to people about a balanced diet, we must mean a balanced diet. No one is saying that people should never eat anything sweet. I am on a diet at the moment. I have lost a stone in the past three months, but I am still having chocolate every two days—and enjoying it all the more.

**The Convener:** Members are keen to know the details.

**Robin Harper:** My diet involves eating just a little less of everything—there is nothing special about it.

We should ask the Government whether it thinks that there is a risk that the ban will have an adverse effect across the board—on encouraging children to think about fair trade and on the social, environmental, ethical, community and other benefits that are associated with that. The Government should be asked to give the issue some serious thought. I thank the petitioners for bringing it to us.

**The Convener:** We may also want to make contact with the Scottish Fair Trade Forum and the Scottish Parent Teacher Council. Many parent-teacher councils across the country must have helped to run fair trade stalls, the capacity of which may now be limited. I am not convinced that the three young students in front of us are part of a Colombian chocolate cartel dedicated to the smashing of imperialism and capitalism—although I thought that that was a great idea when I was their age.

**Bill Butler:** It still is for some of us.

**The Convener:** Some old die-hards are still here—well done, Bill.

We know, as do the petitioners, that there is a difficulty because of the legislation that is in place. We need to open up the debate to see whether there is an opportunity to revise it. We know that that is a big challenge, because of the compelling public policy issues that members have identified.

I know that the petitioners were a bit nervous about appearing before a parliamentary committee, but they did very well. Two of the youngsters who gave evidence are only in third year—that is testimony to their achievement. They backed each other up as well, which was a good example of collaboration. We appreciate their raising the issue. We will explore it and keep them fully informed of the petition's progress as we try to address the concerns that young students with a commitment to international aid and working together have raised. I thank them for their time and wish them luck with whatever they do in the future.

We will take a two or three-minute break before moving to the next item on the agenda.

15:23

*Meeting suspended.*

15:29

*On resuming—*

### **Stillbirths and Neonatal Deaths (PE1291)**

**The Convener:** I reconvene the meeting and thank the petitioners for their patience while we had a small break.

The next petition, PE1291, is by Tara MacDowall on behalf of the Stillbirth and Neonatal Deaths Society and is part of the why 17? campaign to save babies' lives in Scotland. The petition calls on the Parliament to urge the Government to undertake several initiatives to tackle the issue.

I welcome Ann McMurray, Marion Currie and Neal Long. As you have seen, petitioners have a few minutes to explain the thinking behind their petition.

**Ann McMurray (Stillbirth and Neonatal Death Society):** Every day in Scotland, a baby dies. Every year, 500 babies die just before or after they are born. For every 200 births, one baby is stillborn, and for every 300 babies who are born alive one baby dies in the first four weeks of life.

Such deaths devastate families, including mine. My first baby was born 25 years ago at 34 weeks' gestation by caesarean section and he died when

aged just one day old. I cannot believe that the stillbirth rate in Scotland has not changed significantly in the past 20 years. Scotland has one of the highest perinatal mortality rates in Europe. SANDS believes that many such deaths could be avoided. We ask the Scottish Government to address those personal tragedies as a major health priority.

We ask for awareness. Stillbirth is 10 times more likely than cot death, yet the problem is widely ignored. Premature birth rates are higher in Scotland than in England and Wales and they are rising. Our country's perinatal mortality rate will not improve if such issues are not considered a health priority among policy makers and health professionals.

We ask for a greater focus on training and resources in all units from antenatal to neonatal. Most stillbirths happen in apparently low-risk pregnancies. Why are the risks being missed? Training of all health professionals must include an understanding of the risks of stillbirth in pregnancy, and there must be standardised protocols for responding to those risks.

We ask for a greater focus on recruitment and resources in neonatal units in Scotland, where babies are still not guaranteed the minimum standard of one-to-one care that the British Association of Perinatal Medicine sets out. Some babies die because of poor care. NHS Quality Improvement Scotland's 2005 audit of deaths in labour attributed 44 per cent of cases to major sub-optimal care—in other words, if the mother and baby had been treated differently, the baby would be alive today.

We ask for more focus on research, review and audit. More than half of all stillbirths are unexplained—the baby appears to have been healthy and no one can tell the parent what went wrong. It is unacceptable to say that some babies just die; rather, it is that some babies' deaths are not considered a research priority. Lessons cannot be learned because those deaths are not subject to standardised review. Added to that is the fact that post-mortem rates in Scotland are low and falling, which means that information that is valuable in trying to understand the deaths is lost.

It is difficult for me to comprehend that nothing has changed in all these years to affect the number of babies who die before or shortly after birth. I urge the committee to start saving babies' lives by making that a priority health issue and to prevent the devastation that families feel when a baby dies.

**The Convener:** I invite questions, which Ann McMurray, Neal Long or Marion Currie can answer.

**Rhona Brankin:** In some countries, pregnant women are screened for potential infection in their babies. To what extent is infection with conditions such as streptococcus B an issue?

**Neal Long (Stillbirth and Neonatal Death Society):** It is an issue, but we are finding that a variety of issues contribute, so I do not want to major on that infection in relation to what Ann McMurray referred to.

It is always difficult to give precise percentages, but there is certainly evidence that almost 30 to 40 per cent of the unexplained stillbirths, which account for half of all stillbirths, could be avoidable. That suggests that the focus should be much more on resourcing, quality of care, risk assessment at an earlier stage and so on. Infection would be only one factor.

**Nanette Milne:** I am thinking more of perinatal mortality rather than stillbirth. I know that there are issues with a lack of available neonatal cots for looking after premature and other babies. Is that a significant issue in Scotland?

**Neal Long:** It is a significant issue. We are working closely with Bliss, which is the specialist organisation in that area. A lot of what we have said in the report that we launch tomorrow focuses on the issue that you raise, particularly the need for one-to-one care.

I feel that, in contrast to stillbirths, perinatal mortality has been much better dealt with, particularly in Scotland. In comparison, stillbirths have been a mushroom growing in the dark and have not been acknowledged in the same way that, for example, cot death has been.

**Nanette Milne:** Your petition states that, as a result of your activities in the Westminster Parliament, the United Kingdom Department of Health has agreed to host a stillbirth workshop to examine the issues and try to find a way forward. Is that the kind of initiative that you would like to be rolled out in Scotland?

**Neal Long:** Very much so. We have said to the Parliamentary Under-Secretary of State for Health Services in London that we want a national strategy. Having spent the past four or five years talking to some of the key researchers and clinicians throughout the UK, we are in a fairly good position to see what is happening and take a view with regard to the lack of knowledge among academics and research institutes, as well as what we are seeing internationally.

We want stillbirth to be treated as a major health priority, and we definitely want to develop a national strategy, which incorporates a range of things. We acknowledge that there is no quick fix. In Wales, there is a much closer link between policy makers and clinicians, so we think that we

could make a huge difference in Scotland. In some areas, such as data collection and the amount that is spent per head in maternity services, you are already ahead of the game. However, that is not translating into a reduction in the number of stillbirths.

There are some fairly simple things, particularly around data linkage, that could be hugely useful in terms of providing us with information.

**Nanette Milne:** Do you know whether Scottish health officials are in touch with those in England and Wales? If they are not, should we suggest that they get in touch with them?

**Neal Long:** It is beginning to happen. One of the advantages of our campaign taking the form of a UK roadshow is that we are ensuring that the various Governments look closely at what is happening.

We want to see what we can do to help with regard to resourcing the national strategies. We will act as an intermediary, as we know most of the key specialists. We have had a wonderful response in Scotland where, for more than 30 years, we have had a huge presence in terms of the number of people who have supported bereaved parents. We have also had a positive response from many researchers, who are saying that it is about time that stillbirths got their day in the sun.

**Robin Harper:** You have quoted the Royal College of Obstetricians and Gynaecologists but not the College of Midwives. What is your attitude to home births? Do you have figures that we could use to compare survival rates in properly supervised home births and births in hospitals?

**Neal Long:** I am afraid that that is one issue that we have not focused on. So much emphasis is placed on home births and choice, but the majority of parents who have experienced a stillbirth just wanted a positive outcome and a healthy baby. The issue is a little bit esoteric, in truth. There is no dramatic evidence to say that there is a greater likelihood of a stillbirth occurring with a home birth. You will appreciate that what our parents wanted was a live birth, so the place of birth is not a highly ranked issue for them.

Having said that, we are now working quite closely with the National Childbirth Trust, which has been influential in that debate. It, too, wants to ensure that risks are made far more widely known to parents. When my children were born, there was no suggestion at antenatal classes that there was a chance of a stillbirth. I was told that there was a chance of Down's syndrome and I was told about cot death, but stillbirth—which is 10 times more common than cot death—never came into the conversation. We must raise awareness of it,

first and foremost, and that is what we are trying to do through this campaign.

**Robin Harper:** I presume that there is on-going research of some kind into stillbirths. Is there any hint of what people should look for so that we can find out when stillbirth might be more likely? It seems that you are telling us that, at the moment, we do not know what to look for.

**Neal Long:** There are two answers to that. First, we know what we are looking for in terms of what we perceive as avoidable. There are a whole range of issues, which we have put in our report, and they come down to ineffective risk assessment in many cases. The majority of stillbirths still happen to women who are seen as being at low risk but who turn out to have been at high risk. We are obviously not picking up the risk factors early enough, although there are a variety of things that could be done to ensure that we do. There is therefore an issue around basic resourcing, risk assessment and so on, which we think could have an impact on what we have highlighted—the fact that 17 babies a day in the UK are either stillborn or die within the first 28 days of life.

Secondly, stillbirth is an area in which we clearly do not have enough information yet. The lack of post-mortems and real data from birth to death is hampering us. Very little research is being done into stillbirth. Some research is being done internationally, and we are part of the International Stillbirth Alliance, which is bringing scientists together to inform the debate internationally and in the UK, but the reality is that, because of the lack of focus, not much research is being pursued. Getting that research under way is one of our objectives.

**Robin Harper:** Thanks for highlighting that.

**The Convener:** Anne?

**Nigel Don:** Thanks very much, convener—

**The Convener:** No, Anne.

**Nigel Don:** Sorry. On you go, Anne.

**Anne McLaughlin:** Stay away from my microphone.

**The Convener:** I get easily confused between Nigel and Anne.

**Anne McLaughlin:** I want to ask Ann McMurray a question. You said that the number of stillbirths in Scotland is rising and is higher than in England and Wales. I assume that, because little research is undertaken into the causes of stillbirth, little research is done on why there is that difference. Are there suspicions? Do you have an inkling why there is a difference between the figure in Scotland and the figures in England and Wales?

**Ann McMurray:** The short answer is no. Because the Scottish population is concentrated in the cities, such as Edinburgh and Glasgow, there is probably more deprivation, obesity and drug abuse, which are factors in increasing pregnancy risks. However, the fact that nobody is studying even why babies are stillborn means that nobody is looking at why there is a difference between England and Wales and Scotland.

**Anne McLaughlin:** The fact that the majority of stillbirths involve mothers who are considered to be at low risk—a point made by Neal Long and in documentation accompanying the petition—seems significant. It would be interesting to understand why there is such a difference between countries that are so similar. However, as Neal Long said, if the research is not being done in the first place, how can we know why there is a difference?

15:45

**Ann McMurray:** Part of the issue is that people might not be looking out for signs that suggest that the person is potentially at high risk for stillbirth.

**Neal Long:** Let me just clarify the point about the comparative figures for the different parts of the UK. The stillbirth rate has not changed for the past 20 years in Scotland and for almost the past 15 years in Wales. In truth, there is not much difference in the stillbirth rates. Obviously, because birth rates go up and down and because Scotland, Northern Ireland and Wales have relatively small numbers of births, the stillbirth rate can fluctuate. However, there are not huge differences. For example, I sit on a board in the West Midlands, where many of the key issues—such as social deprivation, ethnicity, obesity and teenage pregnancy—are similar to what might be expected in a major conurbation such as Glasgow. Therefore, we are not really focusing on those comparative figures.

Our focus is more on the wide range of issues that could be addressed. For example, customised growth charts would be helpful, because most stillbirths are preceded by growth restriction. Often, parents have the perception that something has suddenly gone wrong, whereas the baby has actually been struggling for quite some time but that has not been picked up early enough.

**The Convener:** Do members have any other questions?

**Nigel Don:** The message that I am getting is that an awful lot of questions cannot be answered, which tells us that there is a genuine ignorance out there.

I want to go back to risk assessment. Clearly, the risks have not been correctly assessed if most of the problems occur in people who are not

regarded as at high risk. I want to tease out whether that is because the risks are not understood or because the risks are understood but not acted on. Is the risk assessment process perhaps defective, or are the risks just generally not understood?

**Ann McMurray:** Part of the problem is that many of the risks are not understood by the medical profession. That is why we are asking for better training for midwives and obstetricians and for protocols to be put in place so that people can respond and react to any risks that are picked up. For example, growth retardation is a big issue—many stillborn babies are small for their gestational age when they are delivered—but that does not seem to be picked up during monitoring because people no longer get the same scans or fundal height measurements and things are not standardised.

**Nigel Don:** That is one characteristic that seems to be a known factor—it is perhaps not totally understood, but it is known—but the process seems bad, in that growth is not measured and therefore not taken into account. Is it that the medical profession is aware of most of the factors involved and we just need them to be applied, or does research need to be done into what the factors are?

**Neal Long:** Throughout its 30 years, SANDS has established close relationships with health professionals. I would love to say that there is a wide awareness of the risk factors, but we have a lot of evidence now that even some basic concepts—for example, that age is a risk factor—are a complete surprise to one or two midwives.

Two things follow on from that. If people assume that everything will be right, they will not change the antenatal culture to look for risks. If we assume that there could be a risk, we can then work back from that to build in a risk assessment process so that we have a much better chance. We have a culture that does not really understand the potential risk and, as a result, perceives that things are likely to be all right.

**Nigel Don:** Let me extend the discussion. We tend to compare Scotland with England and Wales, but I assume that there are international perspectives. It is not helped by not having the same language, but I imagine that there is a European perspective, at the very least. To what extent can we learn from international perspectives?

**Neal Long:** We are learning a lot, and that is why SANDS has been closely involved with the International Stillbirth Alliance, which, like SANDS in the UK, was set up by parents in America who had had stillbirths. Those parents wanted to bring researchers, parents and clinicians together.

A lot of information is coming forward. I know that a classification review is being undertaken here, but it is very unhelpful for us that more than 66 per cent of stillbirths are classified as unexplained, which implies that they are unavoidable. One problem lies in classification systems, but there are now some good classification systems in various parts of the world, which we should unquestionably be learning more from. I hope that that will be taken on board in the review here. That is a starting point, and we can begin to focus more clearly on what research needs to be undertaken.

I return to the point that was made earlier. Part of the problem is that, if research is not carried out, the issues around babies not growing to their optimum size will not be answered. If a baby is not growing to its optimum size, why is that not happening, and why is it not being picked up? Some wonderful research is being done in Manchester to focus on the placenta—researchers are asking why oxygen and nutrients are not getting through to the baby. That is where we need the focus. Even without huge amounts of funding, we could get a huge amount of information, which could make an impact on the figure of 17 babies a day.

**Nigel Don:** If we take everything that you have said to be absolutely correct, and bearing in mind the fact that there are researchers out there, why is the medical profession not doing what you think it should be doing? Why does it take a parliamentary committee to tell the world that people should be carrying out research if there are lots of good medical researchers who presumably might be interested?

**Neal Long:** I am not sure that I can answer the question, but I think that it is because we have not been very effective at developing a national strategy. We have been doing things in a slightly piecemeal way. Some of the discussions and arguments that we have had with the Department of Health are about the fact that, although there are some laudable initiatives, they are not focused on what we think they should be in order to drive down the stillbirth rate. Some positive steps are being taken with regard to obesity, teenage pregnancy and so on, but there is not yet a direct impact on stillbirths. The issue is more around the development of a national strategy, which we are calling for in each country of the UK. I think that we could achieve that.

**Robin Harper:** I will summarise where we are, to my mind. The Royal College of Midwives and the Royal College of Obstetricians and Gynaecologists need to work together on this. There is a big gap in research and, eventually, the issue will be one of training and advice for midwives and doctors. That is why Government

should be involved: we need to approach it to ask it to give a steer to things in one way or another. Is that a good summary?

**Neal Long:** I think so. Since the launch of our “Saving Babies’ Lives” report in March we have found that people are suddenly waking up to the fact that stillbirth is a major public health issue. It is not just about the numbers; it has a huge impact on the parents. Surveys show that it potentially has a huge impact on their economic life later. Many people suffer economic problems because they struggle to get back into work—and that is aside from the impact on any other children in the family. There are huge resource issues, which will have an impact on Scottish NHS boards—and we are now focusing on specifically Scottish issues.

**Nanette Milne:** You mentioned the lack of awareness of known risk factors such as age. When I was a medical student, we were all very much aware of the risks of being an elderly primigravida, as women who delayed childbirth were known in those days. Of course, lots of people are doing that now. Is there a gap in undergraduate training? Are present-day medical and midwifery students being made aware of the risks? Is there an issue that needs to be addressed at undergraduate level?

**Ann McMurray:** I would say that there is. I do not know all the training that midwifery students get, but having been asked on occasions to go into colleges and universities to speak to them I know that they get one day’s training on bereavement, which includes all the agencies that deal with bereavement. That is all that they get in their time as students, and I am not sure whether doctors get even that. They do not know how to deal with bereavement, let alone know what the risks are and how common stillbirth is.

**Neal Long:** Sadly, it is often an optional part of training. We find that a lot of student midwives start to address the issue only when they approach us. We are addressing that as we are starting to look at the format of education. We would have thought that the RCN would be more proactive in setting out the agenda, but the reality is that delivery of the training is in the hands of the colleges, and we see quite a lot of fluctuations in it. As Ann McMurray said, bereavement is certainly low on the Richter scale of priorities.

**Robin Harper:** That is an extraordinarily important issue. Until recently, when people got their degrees and became lecturers at universities, nobody thought of teaching them how to teach, but now universities see that that is necessary. Doctors and nurses do an immense amount of counselling, but they do not do counselling courses.

**Neal Long:** That is true.

**Robin Harper:** It would be a good thing if they were trained as professional counsellors before they started.

**Neal Long:** Ann McMurray alluded to the fact that the quality of care that a person receives following a bereavement and what is said at that time has a huge impact on the rest of their life. We have done a huge amount of work on that, and over the past four or five years we have become very uncomfortable with the fact that, when we are not involved in that intervention, little seems to happen.

**Rhona Brankin:** I might have misunderstood. You said that the incidence is higher in low-risk groups, but you also said that there is a link to deprivation. Will you clarify that? I am not clear about it.

**Neal Long:** There are two things. On the whole, we are managing high-risk pregnancies to high-risk women much better. The majority of stillbirths still occur to women who are seen as at low risk, so we are obviously not picking that up. The things that we mentioned, such as social deprivation, obesity and smoking, are all factors. They are not causes or sole reasons in themselves, but they have to be taken into account as part of the mix.

**Rhona Brankin:** Thank you.

**John Wilson:** I want to ask about the not-at-risk group, which you mentioned in several answers. Can you define the not-at-risk group? I think that we need to understand it. We have talked about nutritional intake, deprivation, diabetes and other factors, but surely the medical profession should pick them up as the pregnancy progresses. How is the not-at-risk group identified and how is it treated differently from the at-risk group?

16:00

**Marion Currie (Stillbirth and Neonatal Death Society):** It depends on how you define a normal pregnancy. Most women will be treated as low risk to begin with, unless they have an immediate identifying factor such as obesity, deprivation or drug abuse. I, for example, was very much low risk and, if you are not seen as high risk, you are just put through the system. If you are low risk and if you do not present with a problem, you will very often be left to steer down a path with a number of antenatal visits at set intervals throughout the pregnancy. Unless something is picked up at one of those visits, it will be missed.

Until recently all we had in Lothian was a dating scan at 12 weeks. Women now get two scans: a dating scan at 12 weeks and a more detailed anomaly scan at 20 or 22 weeks. Beyond that, however, unless you present at hospital with a problem, the midwife will give you five minutes for

your appointment. Many women who feel that something is not quite right have found it difficult to bring their concerns up at these meetings because they are in and out the door so quickly. Indeed, many of our mums find that once they are classed as low risk and are in the system they simply go through on a conveyor belt. Moreover, midwives might not be looking at the whole issue or finding out whether there are any problems. Instead they are concentrating on getting Mrs So-and-so through and out the door.

**John Wilson:** Thank you. You have highlighted one reason why women feel that they cannot raise issues with midwives. Part of the petition is about raising public awareness of a woman's rights as a patient and the issues that she might face going through a pregnancy. The fact is that if women are not being made aware of those issues, they will not know to raise them with midwives. I certainly think that your evidence will help us to develop some of the questions that we need to ask about the issues that have been raised.

**The Convener:** I suggest that we pull together what we need to do for the next stage. I assume that the committee would prefer to continue its consideration of the petition, and invite members to indicate what they think might be the best course of action and the specific areas that they wish to explore further.

**Rhona Brankin:** It would be useful to ascertain from the Scottish Government whether it is aware of the extent of what is clearly a major issue, where Scotland sits in relation to other countries on the matter and what is being done about it at the moment. The petitioners might already have that information, but it would be useful for the committee to get it formally so that we can judge the adequacy of the Government's response.

**Nanette Milne:** I suggest that we pursue the training issues with the Royal College of Midwives, the Royal College of Obstetricians and Gynaecologists, the RCN and perhaps the Royal College of Pathologists.

**Robin Harper:** Perhaps we should also ask whether our maternity services and in particular our midwives are sufficiently resourced with staff and equipment.

**John Wilson:** Issues have been raised about the research that has been carried out and the data that have been collected. It might be useful for us to ask the Scottish Government what information is being gathered and how it is being used. In particular, we should seek to establish whether there have been significant improvements over the period in the medical care that the at-risk group receives and what impact that has had on the delivery of medical services to people in the not-at-risk group. We may get the response that

we traditionally get—that the information is not held centrally—but we should ask the Government what impact the strategies that have been developed over a number of years have had. The strategies may be working well for the at-risk group, but we may be missing people whom the medical profession identifies as not at risk because it is concentrating on the at-risk group.

**Rhona Brankin:** In our questions to the Government, we should ask what it perceives to be the factors associated with stillbirth and perinatal mortality.

**Nigel Don:** We could get the Government to step back from the issue by asking where stillbirth and neonatal death fits into its medical research strategy.

**Nanette Milne:** It would be worth asking the Government whether it sees having a national, UK-wide standard as important and whether it is willing to co-operate with the health authorities in Wales and England on the issue.

**John Wilson:** We should raise the important issue of bereavement counselling. It is extremely important that we get to grips with the issue of how the medical profession and other organisations are dealing with bereavement counselling, especially for parents who have experienced stillbirth or the death of a baby shortly after birth. I suggest that we write to Cruse Bereavement Care Scotland, to ask what issues it has identified in relation to the provision of bereavement care, and to the Government, to ask about the role of medical staff in local health boards. The evidence that we received today indicated that there are different approaches to bereavement care within the medical profession. It would be useful for us to explore the issue in questions to the Government.

**The Convener:** We will identify the appropriate bodies to approach in the bereavement arena. I know that SANDS also has experience of helping families and mothers to deal with bereavement; the petitioners are welcome to submit additional views and information at any time.

We will get responses to all the points that have been raised. We will try to make progress on encouraging research and the development of a national strategy, either in Scotland or by the UK Department of Health—whichever is more appropriate. We will also ask about the interventions at earlier stages that Marion Currie and Ann McMurray identified, based on their experience of how the health service works with expectant mothers during pregnancy and after delivery.

I hope that this has been a useful opportunity for the petitioners to bring the issue to our attention and that we will be able to make some progress. All of us have family members who have been

affected in similar fashion to the individuals who are involved in SANDS.

### **Physical Disability (National Reports) (PE1279)**

**The Convener:** PE1279, by John Womersley on behalf of the Disability Concern Glasgow charity, calls on the Scottish Parliament to urge the Scottish Government to establish processes to ensure that health boards and local authorities fully implement the changes that are recommended in national reports that are aimed at improving the wellbeing of people with a physical disability. Members have a copy of the petition. Do they have any comments on how to deal with it?

**Bill Butler:** It would be reasonable to write to the Scottish Government to ask what processes it has in place to address the point that the petitioner has made; whether, indeed, the petitioner has a point; whether, in light of the petition, it will ensure that changes take place; and what benefit there is in producing reports if there is no need for implementation. Perhaps those could be the starter questions.

**Robin Harper:** We could ask what recent representations have been made to the Scottish Government about its failure to implement the recommendations of reports from organisations that have inquired into improving the wellbeing of people with a physical disability. I hope that there will not entirely be a catalogue of failure. The Government should be asked to check performance on representations over the past few years and Governments' responses to them.

**The Convener:** Okay. We want to keep the petition open, and we specifically want to address the implementation of recommendations. I take members' comments on board.

### **Postcodes (PE1283)**

**The Convener:** PE1283, by Douglas A L Watt on behalf of Morvern community council, urges the Scottish Parliament to urge the Scottish Government to make representations to the Post Office plc to review all postcodes in Scotland to determine the adverse economic and social costs that misleading postcodes can have, particularly on rural communities, in terms of the late or incorrect delivery of mail to businesses and accessing correspondence.

I invite Peter Peacock, who has managed to get to the meeting, to comment on the petition. That will save me having to log on to the internet to see the wonderful YouTube video that he has produced. You can have too much of a good thing. On you go.



**Peter Peacock (Highlands and Islands) (Lab):**

Aye. Perhaps I will speak to you privately about how to access the technology. [*Laughter.*]

I am grateful for the opportunity to speak to the petition, which I fully support. A completely absurd situation, which looks as if it started with an administration error at some point in history, has developed. Morvern has been left classified as being Oban, although it is not adjacent to, contiguous with, coterminous with or adjoined to Oban in any particular way.

**The Convener:** I would never have understood those four terms, but I have colleagues here to help me.

**Peter Peacock:** Oban is not even the nearest significant town to Morvern—another service centre can be accessed more readily. A person can get from Oban to Morvern by a 120-mile road journey that is not straightforward, by a 73-mile road journey plus a short ferry crossing at Corran, just south of Fort William, or they can take the ferry from Oban to Mull, drive through Mull and take a second ferry to Lochaline. All those journeys will take a person through completely different postcode zones just to arrive back in Oban, although it is not Oban—it is Morvern, which has the same postcode as Oban.

The key question is whether the matter is of any practical consequence. The Royal Mail contends that it uses postcodes simply to organise mail deliveries and that, from its point of view, they have no other implications. I understand that, but the reality in modern life is that there are practical consequences for the community, which the petition clearly sets out. I will not labour what those consequences are, but I will highlight one or two of them.

Supplies are misrouted. Often, couriers do not reach Morvern—they end up in Oban and think that they are close to Morvern, but then they discover that they are not close. That means that packages, parcels, white goods and whatever else are left in Oban in the hope that somebody will pick them up there. Goods might be received several days late. If they are perishable products, that means that they are of no value. When a service engineer coming to service a gas boiler, fridge or washing machine phones to say, “I’ll be with you shortly—I’m just 20 miles from Oban,” people know that he will not arrive for a day or so, or that his chance of arriving at all is diminished.

16:15

The postcode may have implications for emergency services. Where emergency vehicles set off from to respond to an emergency is critical. If NHS 24 advises people to visit a hospital that is not local, that also has implications. The

emergency services have taken steps to adjust for the situation and local people have become aware of the pitfalls of making such calls, but visitors to the area—it attracts tourists—are not aware of those pitfalls. That is why the local general practitioner has had to advise people who are making such calls about where they are and are not, which sounds ridiculous.

People have raised with me and other representatives the question of identity. People feel strongly that Morvern is not Oban—it is nowhere near. The equivalent is saying that Glasgow is Dumfries, Aberdeen is Dingwall or Dalkeith is Perth—the distances are comparable.

The petition has strong local support. Dr Douglas Watt, who is the petitioner on Morvern community council’s behalf, conducted a survey that had a 40 per cent response rate and in which 90 per cent of respondents supported the position that is set out in the petition, as does the community council, which asked Dr Watt to pursue the issue on its behalf.

Royal Mail is a big and sophisticated organisation. It is perfectly capable of sorting the situation if it chooses to. A change would have logistical consequences for mail delivery, but they are perfectly capable of being sorted. I understand from the Scottish Parliament information centre briefing for the committee that

“Royal Mail is currently looking at the ... issue again”.

I hope that the committee’s attention to the petition will encourage Royal Mail to keep considering the matter and I hope that the committee will encourage Royal Mail to look at the issue positively.

The petitioner referred to other communities in Scotland that are affected by a misleading postcode, but my concern is purely about Morvern, whose case is acute and which has special geographic circumstances that set it apart from other situations. I hope that the committee will take the petition seriously and pursue action that helps to concentrate minds.

**Robin Harper:** Would changing the postcode be in the Royal Mail’s interests? It would save money if it reconsidered how the mail was delivered to Morvern.

Satellite navigation systems use postcodes. It would be interesting to know whether tourists who are navigating their way to Morvern have similar problems and are directed not into the middle of fields but along a circuitous route that they would rather have avoided.

**The Convener:** We will have more comments. Perhaps Peter Peacock can touch on the issues in discussion with the petitioners.

**Nigel Don:** I lived in a house whose postcode was changed, so I know that that can be done. That happened wholesale: the whole Wirral peninsula—which is reached by going to Liverpool and turning right but ensuring that a bridge is crossed—went from a Liverpool postcode to a Chester postcode. The letter “L” in the postcode was replaced with “CH” and everything after that remained the same.

It is inconceivable that Royal Mail could not sort the situation if it wanted to. Like Robin Harper, I find it inconceivable that the current system helps Royal Mail, given the geography that Peter Peacock described. Royal Mail has long since worked out that it needs two mailbags—one for Oban and one for Morvern. Perhaps we just need to encourage Royal Mail politely to do what it should have done several decades ago.

**Nanette Milne:** I agree with what has been said so far, although I am not sure that I would gently encourage the Royal Mail—I would be a bit more forceful than that.

**The Convener:** Just do not send a letter.

**Nanette Milne:** We should ask the Royal Mail a series of telling questions about how efficient the service is to places such as Morvern, which obviously has the wrong postcode. Why does the Royal Mail refuse to change it and what possible good reason can it have for not changing it? Does it not have a moral obligation to do something about the issue, particularly given that I understand that it sells postcodes to various organisations? We should ask some fairly searching questions and, at the same time, make it plain that we think that the situation is ridiculous.

**The Convener:** I think that there is broad support for the petition, but we will get some final comments from members.

**John Wilson:** The petition is worth while. Although it relates to Morvern, several areas throughout Scotland would welcome a review of postcodes by the Royal Mail. Areas not too far from where I live, such as Cumbernauld, Moodiesburn and Muirhead, still come under a Glasgow postcode even though their association with Glasgow is tenuous. In fact, Cumbernauld has always been associated more with Dunbartonshire rather than Glasgow. There are issues about how the Royal Mail allocated the postcodes, so it is worth while taking action on the petition. I hope that the Royal Mail will carry out a wider review of postcodes but, in the first instance, we should get the Morvern postcode issue resolved. Consideration should also be given to basing postcodes on how places see themselves and their natural affiliations with geographical areas, rather than on what seems to be random

decisions by the Royal Mail when postcodes were introduced.

**Rhona Brankin:** I welcome the petition. On the face of it, the issue seems insignificant, but I agree that it has huge implications on a range of issues, including community safety. I thank Peter Peacock for bringing it to the committee. As a newcomer to the committee, it is perhaps not for me to suggest what we should do about it. My first instinct is that we should write a letter. Alternatively, do we ask somebody to come and speak to us and to explain in person why something is the case? I am more than happy to take advice from members on how we should proceed with the petition.

**The Convener:** Are there any other comments? I see that Mary Scanlon wants to speak. I am being generous this afternoon, so on you go, Mary.

**Mary Scanlon (Highlands and Islands) (Con):** I am being generous, too. I just want to put it on record that, in relation to the petition, I fully support the Labour Party, which is fairly unusual.

**The Convener:** There are remarkable conversions in front of me in committees, but that is the best that I have heard yet.

Anne McLaughlin wants to speak. I encourage the same response if you can, Anne. After last Thursday, anything is possible.

**Anne McLaughlin:** Oh—you said that you would not mention that. I have forgotten what I was going to say, now.

I am forced to say that I fully support the petitioner and the petition, but I will never go as far as supporting the Labour Party.

**Mary Scanlon:** I support it only on this issue.

**The Convener:** It is a broad church, Anne, with a place for every soul.

There is broad support for the petition. We should certainly write to a range of organisations about the impact of inappropriate postcodes. We should include the emergency services, particularly given the move in recent years to national call centres and helplines for those services. Clarity is required to ensure that the emergency services can get to people. I would also like to hear the views of consumer or customer groups, because I am sure that there must be a regular issue for people. Although I have a technology phobia, I enjoy going on to Amazon to purchase CDs. I would hate to find that they were in Oban rather than Glasgow. Let us try to find out about that. We should also raise the matter directly with the Royal Mail and with the Scottish and UK Governments, to ask what endeavours we might undertake. There might be complicated reasons for the present situation, but

let us find out whether we can resolve the issue. Are members happy with the recommendations?

**Members indicated agreement.**

**The Convener:** I thank Peter Peacock for his time.

### **Medical Records (PE1287)**

**The Convener:** PE1287, from Elaine Pomeransky, calls on the Parliament to urge the Government to clarify the rights and options of patients once they have accessed their medical records and seen what has been written about them and by whom; the guidance that is given to health professionals on the sort of information that they should insert into patients' medical records, the language used and the appropriateness of any comments that could be considered libellous; and how it ensures that a process is in place to provide patients with the right to have a comment removed from their records.

There have been one or two other petitions on issues relating to patient medical records, but this is a brand new petition. The petition has some specificity—that is the best word that I can find. Members will have seen the submission that has been made to us. I presume that we will want to continue with the petition; we need to decide how best to do that.

**Bill Butler:** The petition relates to a difficult issue. We could write to the Scottish Government, the General Medical Council and the Nursing and Midwifery Council with a number of questions. For example, we could ask what safeguards are in place to ensure that all information that is contained in patients' medical records is accurate and what processes are in place to enable members of the public to challenge information about them that is contained in their medical records.

**Rhona Brankin:** It would be useful for us to get information from the Scottish Public Services Ombudsman, to see whether the issue has been raised. It has been raised on several occasions in my experience as an MSP. We should also seek the views of organisations that represent patients.

**John Wilson:** Bill Butler suggested that we write to the Scottish Government. We need to ask the Government what sanctions, if any, are in place to deal with medical practitioners who have included false information in medical records, and what action can be taken against them.

**The Convener:** Do members agree to take on board those observations and to explore with the relevant agencies the issues that have been raised?

**Members indicated agreement.**

### **Planning (Playing Fields and Open Spaces) (PE1293 and PE1250)**

**The Convener:** The final new petition for today is PE1293, from George Barr, which calls on the Parliament to urge the Government to ensure that existing planning policies such as Scottish planning policy 11 are rigorously followed by local authorities when considering developments on land that is currently used as playing fields or open spaces.

The petition is linked to PE1250, which is on our agenda under current petitions; I suggest that we pull them together. PE1250, from Mel Spence, calls on the Parliament to urge the Government to consider measures, under SPP 11, to ensure that sanctions are in place to prevent local authorities from proceeding with development on land that is currently used as playing fields or open spaces.

It is suggested that there are issues that we will wish to explore. I invite recommendations from members on what to do next.

**Nigel Don:** I suspect that other members will want to speak about issues relating to playing fields. I suggest that we ask the Scottish Government to clarify what it regards as the enforceability of a statement of standard planning practice and what it thinks are the criteria for implementation of any SPP.

**Robin Harper:** This is an extraordinarily important issue. Over the past 20 years, Edinburgh has lost literally dozens of football pitches to developments of one kind or another. We need to ask the Government how it is ensuring that planning authorities have a policy in place on the protection of playing fields; how many local authorities have completed their open space audits; what it is doing to ensure that local authorities undertake such audits; and what processes are in place to ensure that open space audits are taken into account during the development of local development plans.

16:30

**Rhona Brankin:** I am keen that we explore some of the slightly broader issues. Open spaces are important in ensuring that young children have opportunities to play, as well as being able to play more formalised games such as football or to use running tracks or whatever. I am interested to find out what is happening around Government policy on play and children in every community in Scotland having a right to access an area where they can plan safely and, indeed, adventurously.

**John Wilson:** I suggest that we write to the Scottish Government to ask whether any guidance has been issued to local authorities on what is meant by "valued and functional" in SPP 11. As

Nigel Don said, that is an important issue, which widens out the debate about the future development of SPP 11, because we are not talking just about traditional playing fields. As Rhona Brankin indicated, other aspects are involved, and we need to find out what, if anything, the guidance says about “valued and functional”. We are not talking only about football pitches or traditional play parks. We might be losing lots of play areas that have traditionally been used by people over the decades—and, in some cases, over the centuries—as a result of the developments that take place and how local authorities view them.

**Robin Harper:** I will add to what John Wilson and Rhona Brankin have said. The most important part of the issue is informal access to open space that we really must guard, not just football pitches or hockey pitches. The phrase “valued and functional” must apply to informal play space that children use in an informal way. It might not even have a play park on it—it might just be open space that children naturally use in their own way.

**The Convener:** There is broad agreement on pursuing those matters in relation to both petitions, so we accept those recommendations.

## Current Petitions

### Criminal Memoirs (Publication for Profit) (PE504)

16:32

**The Convener:** We move on to item 4 on our agenda, which is consideration of 13 current petitions.

PE504, by Mr and Mrs James Watson, who are in the public gallery, calls on the Parliament to take the necessary steps to prevent convicted murderers, or members of their families, from profiting from their crimes by selling accounts of their crimes for publication. It is one of the longest-standing petitions in our system. Mr and Mrs Watson have campaigned strongly for a number of years, given the tragic situation that they found themselves in because of the conduct of someone who was convicted of the crime in question. They have raised the issue at all levels over the past 11 or 12 years. We know that there is a broader debate, in which the minister who has responsibility for such issues in Scotland has engaged. How do members wish to proceed?

**Nigel Don:** I am sure that I am not alone in thinking that we are still in an unsatisfactory place. As Bill Butler will be, I am conscious that aspects of the Coroners and Justice Bill that is before the Westminster Parliament came to our Justice Committee for consideration. I think that that bill will do something to help—providing that it is passed in the form that it was in when it came before us—by making it slightly more difficult for convicted criminals to profit from their memoirs. I am sure that that is a step in the right direction. The sad part, which, as I pointed out at the Justice Committee, does not seem to be being addressed, is that if I were the world’s worst criminal—you might decide that I am—although I might not be able to write my memoirs and benefit from that, there is nothing in the present legislation that would prevent my son from writing those memoirs and profiting from them, and I might not necessarily object to that. Even the changes to the law that we are being told about, which may yet happen, do not go far enough—we know that.

The difficulty is that the Westminster Government does not seem to be interested, and it is not entirely obvious to us what we in Scotland can usefully and productively do. These are cross-border issues to do with publication. I do not think that we should regard the petition as satisfactorily resolved in any sense. The problems are being forced on us more acutely and clearly, and I am not sure that I can see a good answer.

**Bill Butler:** I agree. We could write to the Scottish Government about the forthcoming consultation on defamation, asking what specific measures will be included that will be directly relevant to the petition, what the timetable is for the consultation and whether the petitioners will be involved in the preparatory work for it. It is reasonable to ask those questions.

I agree with Nigel Don that there seems to be a problem with the families of those who have been convicted of heinous crimes being able to profit from those crimes.

**The Convener:** I am aware that the family members are here, and that the petition has been in the system for a long time. We want to get the best possible answers, but we are constrained by our ability to influence the legislative framework at the UK level. We should take Bill Butler's comments on board and raise the matter with the relevant Government minister to see whether we can bring the issue into the discussion on defamation. I hope that we can get support from elsewhere in the UK, too.

**Anne McLaughlin:** I am in complete agreement with everything that has been said so far. We ought to congratulate Mr and Mrs Watson on what they have managed to achieve and the fact that they have persisted with the petition for such a long time. It is not as if they have not got anywhere; what they have achieved is magnificent. Yes, we want to achieve more, but they have taken a huge step forward and should be congratulated.

**The Convener:** I have dealt with the family in the past and I know what they have been through. No one would wish that on anyone. They have been committed to getting justice so that other families do not have to face the terrible realities that they have had to face through the conduct of those responsible. We will keep the petition open and try to use our role on the committee to seek a positive conclusion for the campaign that the petition raised.

**John Farquhar Munro:** I see from our notes that Mrs Watson has requested a meeting with the Minister for Housing and Communities.

**The Convener:** Yes. I think that the family has met the minister, and that the meeting has been described as a positive development.

### Violence against Women (PE1103)

**The Convener:** PE1103, by Susan Moffat, calls on the Parliament to urge the Government to prioritise the continuing development of strategic work on violence against women by following the three Ps approach of active prevention, adequate provision of quality support services and

appropriate and effective legal protection. Mary Scanlon, who has been very patient this afternoon, is keen to speak to the petition.

**Mary Scanlon:** Thank you, convener and members of the committee, for allowing me to speak to the petition, which is on an issue that I have been concerned about for some time. I have been working on it with John Wilson, and we had a helpful meeting with the minister quite recently.

I am asking the committee to broaden the petition. I will set out my concerns. Over the past nine years, there has been a 33 per cent increase in incidents of domestic violence in which the victim was female and the perpetrator male; the increase in incidents in which there was a male victim and a female perpetrator is 163 per cent; and the increase in incidents involving a female victim and a female perpetrator is 500 per cent. Incidents involving a male victim and female perpetrator now make up 12 per cent of all incidents. The majority of incidents undoubtedly involve male perpetrators and female victims, and I commend all the work that has been done in that area—I do not wish to take away from the services for women and children in domestic abuse situations.

However, I point out that the best service for a male victim of a female perpetrator is a telephone helpline in England. That is a serious concern. Six councils in Scotland provide information about that helpline, and two police websites in Scotland tell male victims to phone the helpline. That is the only service. Very few sites provide links to that information, although the Scottish Government website provides information on domestic abuse.

I note that there are support services to help male perpetrators address their behaviour, but there are no services in Scotland to help women perpetrators of domestic violence address their behaviour.

Most services that provide aid to female victims—and quite rightly too—also make provision for children. Scottish Women's Aid is one such service. However, because no organisations in Scotland are specifically designed to provide services for male victims of domestic abuse, there are no services for the children of male victims. I see that the matter is mentioned in today's *Business Bulletin*, and I hope that I have raised it at the appropriate time.

There is not only unfairness here, but injustice. I am concerned about the children of male victims. Is it possible for the committee to take this opportunity to widen its approach to the petition in order to look after the children of male victims and the children of female victims of female perpetrators in Scotland?

Thank you for giving me the time to make my contribution; I wanted to put on record some of those figures and bring the matter to the committee's attention.

**The Convener:** Are there any immediate comments on those practical issues?

**John Wilson:** I declare an interest. As Mary Scanlon pointed out, for some time she and I have been working on the issue, particularly where domestic violence is perpetrated by women against men or in same-sex relationships.

**Nanette Milne:** Mary Scanlon has made some valid points. There is definitely an issue about female-to-male violence and violence in same-sex relationships. I hope that, if possible, we can develop her concerns. Obviously, we will be guided by what we are allowed to do in the context of the petition, but if possible, I would like to keep the petition open so that we can pursue the issues that she raised.

**Robin Harper:** Is it within our remit to widen the scope of a petition? I take on board Mary Scanlon's points—it is important that we address them—but would it be better for a separate petition to be lodged on general family violence that includes all the specific points that she mentioned, rather than opening a general set of inquiries on the back of PE1103, which we could close today? All the issues that the petition raised are being addressed by the Government.

16:45

**The Convener:** That is the dilemma for us. Committee members are in no way disinclined to address the points that Mary Scanlon has raised, but we cannot do so through the framework of PE1103 without a response to that effect from the petitioner. It might be worth while identifying who might best raise those points directly by submitting another petition, to which the committee would give a fair hearing. That would allow us to consider the wider issues that such a petition might raise so that we could address in more detail the concerns that Mary Scanlon has highlighted. I know that MSPs cannot lodge petitions, but campaign groups, pressure groups or other individuals who have seen this emerging problem might wish to do so. The new petition could then be hosted on our website, where I am certain it would receive broad support. That might be the best course of action, given that the structure within which we operate does not give us the power to make dramatic changes to the petitioner's intention.

Do other members wish to comment before we conclude our consideration of the petition?

**Bill Butler:** I am sympathetic to the general concerns that Mary Scanlon has raised—who

would not be?—but, in light of the convener's guidance, which I am sure is informed by the clerk's advice, I agree that we cannot significantly broaden or change the terms of a petition. The convener's wise words should be acted upon.

I tend to agree with Robin Harper that the Government has done all that it was asked of it in relation to PE1103. The petitioner has not got back to the clerks, so the petition should be closed as we can do nothing else with it. However, that does not preclude another petition being submitted in the terms that Mary Scanlon outlined.

**Mary Scanlon:** Those comments are helpful. Obviously, MSPs may not lodge petitions, but I will ensure that a petition is submitted to the Parliament to highlight the issues that I have raised today. I thank members for their assistance.

**The Convener:** We appreciate your contribution. I am conscious that you wanted to put those points on the record, but a new petition might be a better way of amplifying the issues.

I recommend that we close PE1103. A subsequent petition might well give us an opportunity to address the issues that Mary Scanlon has raised. Is that agreed?

*Members indicated agreement.*

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

**The Convener:** PE1124, by Louise Robertson, on behalf of the League Against Cruel Sports, Advocates for Animals, the International Otter Survival Fund and Hesselhead Wildlife Rescue Trust, calls on the Scottish Parliament to urge the Scottish Government to amend the Nature Conservation (Scotland) Act 2004 to ban the manufacture, sale, possession and use of all snares. The issue has been previously considered both in the Parliament and in this committee.

Do members have any comments on what we should do with the petition?

**Rhona Brankin:** Obviously, I am new to the committee but, having read the briefing paper and the correspondence, I am not satisfied with the Government's response. I am in favour of inviting the minister to come to answer questions on the issue.

**Robin Harper:** I draw the committee's attention to some of the information that we have received. The Government's response states that

"There is no legal requirement for snaring operators to record numbers of target or non-target species caught",

so we really do not know what is happening in that respect. For example, we do not know whether there has been a reduction in the number and use

of illegal snares. Across the board, there is a paucity of information that needs to be addressed.

**Bill Butler:** The response from the Scottish Government official is wholly unsatisfactory, as it just repeats that one sentence and does not answer any of the committee's specific queries. On that basis, it would be helpful to us, so that we can come to a reasoned and informed view, to invite the responsible minister to the committee to discuss the matter. If the official had been more specific, perhaps that would not be necessary, but I feel that the response that we got back—not from a minister in the Scottish Government but from this particular official—is bordering on insulting. I do not think that any of us are here to be insulted, do you, convener?

**The Convener:** I hope not—I will need to bear that in mind the next time that I am convening a meeting of the committee.

Members have suggested that we invite the minister along to discuss the issue—I hope that we take the insult point on board when the minister is in front of us. Are we agreed?

*Members indicated agreement.*

### **Scottish Agricultural Wages Board (PE1139)**

**The Convener:** PE1139, by John Quigley, calls on the Parliament to urge the Government to retain the Scottish Agricultural Wages Board. Given that the Scottish Government has announced that it will retain the board but will not expand its remit at this time, do we want to close the petition? Do members have any comments?

John Wilson and Bill Butler, who have previously raised issues in connection with the petition, want to comment.

**John Wilson:** I welcome the Scottish Government's decision to retain the Scottish Agricultural Wages Board. There is some disappointment that it did not take the opportunity to widen the board's remit, but I am glad that it has been retained and that it will continue to operate in the areas in which it was originally established to operate. Now that the board is to be retained, I hope that we can get the Government to review its role and remit and expand those so that it can cover workers in related industries throughout Scotland.

**Bill Butler:** I have nothing to add. I echo John Wilson's comments and his disappointment at the non-expansion of the board's remit. I hope for better in future.

**The Convener:** I support the suggestion that has been made. For the record, I note that a number of members have been involved with one

of the main trade unions that campaigned to retain the board, so that people are aware—just in case there are any conflicts of interest—that members have included in their entries in the register of interests their affiliation with that trade union.

### **Disabled Parking (PE1149)**

**The Convener:** PE1149, by Kenny Shand, on behalf of Disability Help Scotland, calls on the Parliament to urge the Government to introduce legislation to allow for parking bays for disabled drivers with mobility impairments—for example, outside the individual's home—and for such bays to be legally enforced.

The petition has been before the committee a number of times and I think that we have explored it as far as we can. The Government has stated that it will not introduce legislation to ensure that residential parking bays are allocated to specific individuals requesting a bay. It has also indicated that is of the view that allocating a bay solely for the use of one person would result in other blue badge holders being unable to park in a location that was convenient for them. I do not know whether members still wish to express concern. We may wish to close the petition, but I will hear from members first.

**Nigel Don:** From my experience as a councillor in Dundee, I recognise individuals' disappointment that they cannot have their own space on the road, but the counter-argument is clear: there are not enough parking spaces generally in our conurbations, so it is not really acceptable in the grand scheme of things for someone to have a space that is not on their land but which is private to them. This is one of those compromises in relation to which I think that the Government has probably come up with the right answer. In some places the approach will seem unreasonable, but we need to recognise that there has to be one rule and that this is probably the right one.

**The Convener:** Okay. Do members agree to close the petition on those grounds?

*Members indicated agreement.*

### **Further Education (Students with Complex Needs) (PE1180)**

**The Convener:** The next petition is PE1180, from Tom and Josie Wallace, which calls on the Scottish Parliament to urge the Scottish Government to ensure that students with complex needs are supported in achieving further education placements and that appropriate funding mechanisms are provided to enable such placements to be taken up. The petitioners had the opportunity to bring the petition directly before the committee and Alex Fergusson, in his role as the constituency member, has spoken on it at the

committee on a number of occasions. We have also had a private briefing on the issue. Alex Fergusson would like to comment on the petition today. After he has done so, we will try to pull together a response.

**Alex Fergusson (Galloway and Upper Nithsdale):** I am just here to see where your deliberations are leading you on the petition. As you know, I have taken a considerable interest in the petition ever since it was originally sent to the committee. Having spoken to Mr and Mrs Wallace this afternoon, I understand that there are a few questions that are yet to be satisfactorily answered. However, I am not here to say anything today as I have nothing further to add since the last time that I was here. I might have something to say if you decide to close the petition, but I am very happy simply to listen to your deliberations, if I may.

**The Convener:** As always, I listen carefully to any representation that you make, Presiding Officer. Hopefully, we can keep the petition open.

Do members have any comments? I know that many members have commented on the matter before. I think that we should keep the petition open, as I know that members feel that we have not received a full and proper response to a number of questions.

From the information that we have received from the family, we know that the case is a difficult one, and that the family has felt quite a lot of frustration while trying to navigate the further education opportunities for their growing son.

Do members have any suggestions about whom we might wish to take up certain issues with?

**Nigel Don:** The silence in the committee represents the fact that we face a little bit of a structural problem. Clearly, this is one of those petitions that came from an individual case but which recognised that that individual case was only one of many around the country and that there was therefore a general principle that needed to be addressed. At this point, it appears that the individual case is being progressed, which is good. We recognise that there is a general issue, but it is perhaps so general that it is difficult to know quite how to take it forward without going round the houses and discussing the whole thing. I am therefore looking for a bit of help from my colleagues with regard to which bit of the petition we should be progressing. Perhaps the issues have grown so wide that we should be kind of closing the petition, although I do not particularly want to close consideration of the whole issue. Alternatively, perhaps we should try to focus on a particular issue that now appears to be more important than the generality.

**Nanette Milne:** I am at a loss to know whom we should go to for answers. It is clear from the Equal Opportunities Committee's inquiry into barriers facing disabled people in education that there is a lack of residential colleges, that further and higher education providers are not well prepared to take disabled students and that support is not consistent across the country. There are many questions that could be asked along those lines. We should perhaps write to the colleges or the Government to ask how many residential places have been created since 2006 and how many more will be made available in the next few years. We should ask how higher and further education providers are preparing for disabled students, because providers are supposed to be proactive rather than to react only when a disabled student comes to them. We should also ask about how consistent provision is across Scotland and whether there is any proof that students with additional support needs are finding the system more accessible.

I am not 100 per cent sure whom we would ask those questions of, but I will be guided on that.

**Bill Butler:** I do not think that we should close the petition. We were wondering what questions we could ask, but it seems that there are many questions to pose. I think that most if not all of the questions that have arisen should be posed to colleges and the Government, so that we can get information about what is really happening in institutions as well as what the Government thinks is happening.

The last time that we considered the petition, Alex Fergusson drew attention to the possibility that a postcode lottery exists in relation to funding for such placements. We could ask the Scottish Government whether it can demonstrate beyond question that there is no postcode lottery for opportunities to access funding to secure further education placements. What statistical evidence can the Government present to support its contention that there is no such postcode lottery? What is the longer-term perspective for those people who have very specific needs, as outlined in the petition? We should not close the petition, as there are a number of questions that we can ask.

17:00

**Rhona Brankin:** To what extent are the Government and others aware of the level of compliance with the various pieces of legislation and guidance that currently exist? In the first instance, we should ask the Government and other governmental and non-governmental bodies their views on the extent to which FE and higher education institutions comply with legislation and



guidance—and we should ask them how they know.

**Robin Harper:** We could scope the possibilities for setting up a specialised residential college in Scotland. There are residential colleges in England, which I believe are extremely successful. Such a college here could be based on an existing one, but it would have specially designed accommodation and teaching courses. Such facilities would be of considerable benefit. The demand for such a college would probably exceed the Government's expectations. The all-round advantages by way of efficiencies, expertise and quality of education would be enormous.

Let us cut to the chase: we should be asking the Government to scope the demand and assess the possibilities for a dedicated residential college.

**Nigel Don:** We are beginning to clarify the issue, and I support what Robin Harper has said. We should now be asking for the relevant statistics. What does the Government know about the number of youngsters with considerable disabilities who need further education? The Government will say that the information is not held centrally and that it is for local authorities to make their own provision. We know that. Having asked that question, we must follow it up by asking whether the Government is bothered that it does not know the answer because only local authorities know it. It bothers us, at any rate, so could the Government find out, please?

**Robin Harper:** I did not put what I said a minute ago exactly as I wished. The Government should scope the potential demand. Not enough people are demanding such facilities, because they are not available—people have the sense not to ask for things that they know are not there; they are put off from demanding it. However, the Government should scope the potential demand, and then it should provide for it.

**The Convener:** There is substantial capital investment in new colleges in Glasgow and the west of Scotland. The proposals reflect a different way of designing facilities and services to make them more amenable and accessible to individuals with complex needs. I do not have the answer; I just know that a £350 million investment programme is expected for those colleges, all of which will serve a wide geographical area. We will need to see how that is factored in. I know that Glasgow College of Nautical Studies in my constituency is looking at that issue. Because it is a nautical college, it has always had a residential element. How does it factor that in as part of a wider federation of colleges? If a college is doing residential development anyway, could it factor in two or three units that could be much more adaptable, given the needs that we are talking about?

We have to pull all this together. There are three or four key points. I do not know whether members wish to add anything. We want to keep the petition open. We want to explore these issues. As ever, I will leave the final wise words to the Presiding Officer.

**Alex Fergusson:** You are a sensible man, convener; I have always said so.

Rhona Brankin is absolutely right: there is already legislation and guidance. However, the cold reality is that people such as my constituent's son are just not being picked up and are in effect being abandoned by the system. The comments that you have all made are right. Central Government will say that this is a local authority responsibility. It is, but local authorities do not have the resources necessary to provide the £60,000 a year that this child needed to go to the residential establishment that everybody said would best suit him. He went there for one year and it suited him best—he had never been better. He is now at home, having been abandoned by the system, and is backsliding—that is the only way that I can describe it. The petition resulted from an individual case, but there is a national impact, which is exactly what such petitions have to be about. The questions that you are going to ask are hugely relevant if we are to address this properly in future. That is what we must aim to do if we are to live in an equal and just society.

**The Convener:** I know that Rhona Brankin was alluding to the variety of different acts that further education establishments—and any other operational facilities—have to abide by. We need to drill down and ask a series of questions of the Government and the Scottish Further and Higher Education Funding Council about how they are addressing the issue.

**Rhona Brankin:** This is slightly difficult for me, because I was not involved in looking at the petition previously, as I have only just joined the committee. It strikes me that one of the key issues is funding. The fact that a local authority could have two or three young people with immensely complex needs that can be met only by intensive and expensive support systems leads us to look at whether there are different approaches to take. South of the border, funding can follow the individual. That raises issues that are fundamental to how we support young adults who have complex additional support needs, which we need to address.

**John Wilson:** I have said this before but, as I understand it, educational establishments, as well as public bodies, come under the Disability Discrimination Act 1995. It might be worth writing to the Equality and Human Rights Commission in Scotland to find out how many approaches it has had about access to further and higher education.

We need to look at higher education establishments as well as further education colleges in relation to access to opportunities for all students who wish to progress their academic careers. Although I agree with Robin Harper, who talked about residential provision in the further education sector, we should not limit the opportunity for anyone in Scotland who wishes to pursue an academic career at whatever level. We need to ask questions not only of further education principals but of the universities. Some of the brightest brains in academia today have experienced disabilities, and continue to contribute to meaningful debates on a range of issues. We need to broaden the debate.

**The Convener:** It appears that members wish to keep the petition open. We will continue to pursue the issues that it raises and our dialogue with the petitioners.

### **Bone Marrow Services (PE1204)**

**The Convener:** PE1204, from Jessie Colson, on behalf of the Richard Colson Severe Aplastic Anemia Fund, calls on the Scottish Parliament to urge the Government to recognise and promote the life-saving impacts that bone marrow testing and donation can have on people with life-threatening illnesses, and to provide adequate funding to the Scottish National Blood Transfusion Service to support bone marrow services and encourage more donors.

We have had a number of discussions on the petition. The constituency member, Michael McMahon, who has supported the petition on its journey through the petitions process, is here today. He is welcome to comment, after which we will decide whether to keep the petition open or whether it has reached the end of the road.

**Michael McMahon (Hamilton North and Bellshill) (Lab):** Thank you for giving me the opportunity to speak again on behalf of my constituents. I have spoken to them recently about the petition's progress, and I must convey to the committee the sense of frustration that they feel. They feel that the purpose of the petition seems to have got lost somewhere along the way.

The petition is about expansion of bone marrow donation and the provision of additional resources, if necessary. However, all that has emerged is a clarification of the partnership that will exist from now on between the SNBTS and the Anthony Nolan Trust. The petitioners are not critical of such a partnership. It is helpful for the Anthony Nolan Trust to know where it sits in relation to the SNBTS so, in that respect, the clarification is helpful. However, that response does not address whether there will be any mechanisms for expanding the number of donors, or whether any

additional resources will be made available to enable that to happen.

My constituents are looking enviously across the border at how the situation is progressing there. The same partnership exists there between the blood transfusion service and the Anthony Nolan Trust, but things are being done differently in Scotland, in that there has been a delineation of the roles of the organisations. However, it is not that issue per se that concerns my constituents. They are concerned about what will be done to expand the number of bone marrow donors, whether additional resources will be made available, and, if so, how much and when. Those issues have not been addressed.

We have received clarification about what the Anthony Nolan Trust and the SNBTS are going to do, but we do not yet know what will drive the expansion of the number of donors who are available so that people can receive potentially life-saving bone marrow donations.

My constituents are deeply frustrated. I am glad of the committee's support in taking the issues forward and of the meetings with the Government and between the ANT and the SNBTS. All those things are worth while and have expanded the knowledge of my constituents. I believe that my constituents have helped to expand the knowledge of those organisations in return. However, the purpose of the petition has not been addressed, and that is where the frustration lies.

17:15

**Robin Harper:** According to the information that the committee has received, the Scottish Government will research the approach that is taken in Germany to increase recruitment to the bone marrow bank. However, we will not get the results of that research until August 2010, which the petitioners may feel is rather a long time from now. Perhaps we could ask the Government to hurry things up; after all, we are talking about another eight months. That seems an unconscionably long time to take over what I cannot believe can be all that complicated a matter. I also note that there is going to be a follow-up meeting in 12 months to explore how effective the proposed measures have been in raising the profile of bone marrow donation and whether anything further is required. It seems that the Government is doing something, but not an awful lot.

**Rhona Brankin:** I do not think that enough action is being taken. For example, we should ask the Government why the approach between the blood transfusion service and the ANT in England has not been replicated in Scotland.

**Bill Butler:** Although we agree in principle that the Scottish Government is trying to move things forward, the question is about the length of time that it is taking. There is no question but that it has given its support in principle. However, as Rhona Brankin has just pointed out, what action is being taken to hurry things along and find more donors? After all, that is the main objective.

As a result, we should ask the Government to tell us, alongside the welcome research that is being carried out, the action that is being taken to ensure that the conclusions of that research can be implemented speedily and whether it will commit to providing any additional resources that might be required to do that. That would bring together the two necessary parts of the equation for action. We have got agreement in principle and research is being carried out; that is welcome but, in tandem with that, we need the Government's promise that it will act expeditiously on the research's conclusions and provide any additional resource that is necessary.

**The Convener:** Members have made a number of good suggestions, particularly on research and parallel approaches, that we can pursue. We will keep the petition open for now, but I should say that this is another of those petitions that we have been unable to resolve but are reluctant to close.

I thank Mr McMahon for his time and patience.

### **Clostridium Difficile (Public Inquiry) (PE1225)**

**The Convener:** PE1225, from Michelle Stewart, calls on the Scottish Parliament to urge the Scottish Government to instruct, with immediate effect, an independent public inquiry under the Inquiries Act 2005 into the outbreak of *Clostridium difficile* at the Vale of Leven hospital so that wider lessons for the whole national health service can be learned. In light of the Cabinet Secretary for Health and Wellbeing's statement last week to Parliament, I suggest that we suspend consideration of the petition until Lord MacLean has concluded his inquiry and announced his recommendations. We can then consider the petition in light of those conclusions. Are members agreed?

**Members indicated agreement.**

### **Biological Data (PE1229)**

**The Convener:** PE1229, from Craig Macadam, calls on the Scottish Parliament to urge the Scottish Government to establish integrated local and national structures for collecting, analysing and sharing biological data to inform decision-making processes to benefit biodiversity. Again, we have previously discussed the petition, and I invite members' comments on how we should

proceed with it. I note that the Scottish Government science group has invited the petitioner to consider how to use information in environmental statements, which should lead to improvements in this area.

**Robin Harper:** Although it is very kind of the science group to invite the petitioners to discuss the use of environmental statements, it does not answer in any way the petition's call for the Government

"to establish integrated local and national structures for collecting, analysing and sharing biological data".

It would have been more instructive had the Government simply said yes or no to the petitioner's question whether it will consider establishing such structures.

**Bill Butler:** Robin Harper's point is reasonable. It is good that the science group is meeting the petitioner but, without rehearsing Robin's point, I agree that we should ask the Government whether it will consider setting up these "local and national structures".

**The Convener:** If members are happy to pursue those matters, we will keep the petition open. However, as soon as we get answers to those questions, we will have to consider whether we have reached the end of the road for the petition.

### **Scottish Class Action Procedure (PE1234)**

**The Convener:** PE1234, from Peter Brown, on behalf of Leith Links residents association relates to the instigation of a class action procedure or similar in Scots law. Given that the petitioner feels that Lord Gill's review of Scottish civil courts and the favourable reception of its recommendations make the petition redundant, I recommend that we close it.

**Nigel Don:** I agree, because there is nothing else that we can do about it. However, it is worth putting on record that nothing might happen desperately fast. It is not just a matter of the courts saying, "Aye, we'll do that." The Government itself will probably not have to do anything, but the courts are going to have to work out how to deal with the recommendation, and that will not be an overnight decision.

**The Convener:** Thanks very much for that. Does the committee recommend closure?

**Members indicated agreement.**

### **HM Prison Kilmarnock Contract (Independent Review) (PE1241)**

**The Convener:** Because of practical considerations, PE1241 has been moved to a meeting in January. The petitioner has been made aware of the fact.

### **Voluntary Sector Mental Health Services (Funding Framework) (PE1258)**

**The Convener:** As we have already considered PE1250 with another petition, our final current petition is PE1258, from John Dow, on behalf of TODAY—Together Overcoming Discrimination Against You and Me—which calls on the Scottish Parliament to urge the Government to introduce a fairer funding framework for all local, regional and national charities. I suggest that we suspend consideration of the petition until the Scottish Government has issued its guidance and good-practice materials on the procurement of social care services, which are expected to be published in February. In its response, the Government should specify how the new guidance addresses the issues raised by the petitioner. We are also awaiting the publication of the Local Government and Communities Committee's report on local government finance, which will cover issues of material interest on funding for the third and charitable sectors.

### **New Petitions (Notification)**

17:22

**The Convener:** Our final item is notification of new petitions. I ask the committee to note these petitions. If members have any comments to make on how to address them, they should do so directly to the committee clerks.

Our next formal meeting is on 1 December. I ask members to stay around for a few minutes for a post-meeting discussion.

*Meeting closed at 17:22.*

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