



OFFICIAL REPORT
AITHISG OIFIGEIL

Public Petitions Committee

Thursday 28 June 2018

Session 5



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Pàrlamaid na h-Alba

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PUBLIC PETITIONS COMMITTEE

12th Meeting 2018, Session 5

CONVENER

*Johann Lamont (Glasgow) (Lab)

DEPUTY CONVENER

*Angus MacDonald (Falkirk East) (SNP)

COMMITTEE MEMBERS

*Rachael Hamilton (Etrick, Roxburgh and Berwickshire) (Con)

*Rona Mackay (Strathkelvin and Bearsden) (SNP)

Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Finlay Carson (Galloway and West Dumfries) (Con)

Maurice Corry (West Scotland) (Con) (Committee Substitute)

Gillian Gunn (Scottish Government)

Emma Harper (South Scotland) (SNP)

Professor Jason Leitch (Scottish Government)

Alison Preuss (Scottish Home Education Forum)

Mark Ruskell (Mid Scotland and Fife) (Green)

Lesley Scott (Tymes Trust)

Richard Shearer (Scottish Government)

CLERK TO THE COMMITTEE

Sarah Robertson

LOCATION

Committee Room 1

Scottish Parliament

Public Petitions Committee

Thursday 28 June 2018

[The Convener opened the meeting at 09:16]

New Petitions

Getting It Right For Every Child Policy (Human Rights) (PE1692)

The Convener (Johann Lamont): I welcome everyone to the 12th meeting in 2018 of the Public Petitions Committee. We have apologies from Brian Whittle; Maurice Corry is attending as a committee substitute.

Item 1 is consideration of new petitions. The first petition for consideration is PE1692, on an inquiry into the human rights impact of the getting it right for every child policy and data processing. The petition was lodged by Lesley Scott and Alison Preuss on behalf of Tymes Trust and the Scottish home education forum. The committee will take evidence from the petitioners this morning. I welcome Liz Smith MSP, who is in the public gallery to hear the evidence.

As members will be aware, I am the deputy convener of the Education and Skills Committee, which is currently involved in the scrutiny of the Children and Young People (Information Sharing) (Scotland) Bill. It is the convener's role to facilitate debate so, in considering the petition this morning, I will chair the item but will leave it to my colleagues to ask questions.

I welcome Lesley Scott and Alison Preuss to the meeting. You have the opportunity to make an opening statement of up to five minutes, after which we will move to questions from the committee.

Lesley Scott (Tymes Trust): Thank you. We will split the five minutes between us, if we may.

I thank the committee for inviting us to the meeting.

Tymes Trust—or the young ME sufferers trust—is the only national ME charity dedicated to children and young people who have the neurological disease ME and their families. In recent years, the trust has seen an escalation in calls to our advice line about families being referred and situations being escalated to child protection services. On further investigation, not one of the more than 200 families who have faced such a situation and contacted us has been found to be at fault. However, those interventions can

cause catastrophic trauma to the families involved, whether they be families with ME or not. Some families never recover from the overbearing and traumatic experience and become terrified of approaching services for help. The evidence that was submitted to last year's "Postcards from the Fringe" event confirms that.

The petition asks for an independent public inquiry into historic and current practice under the GIRFEC approach. As the Scottish Parliament information centre briefing states:

"This petition relates to the current legal situation rather than the prospective legislation from the 2014 Act and 2017 Bill."

The 2016 ruling from the United Kingdom Supreme Court found that aspects of the Children and Young People (Scotland) Act 2014 were unlawful and breached article 8 of the Human Rights Act 1998. As a result, parts 4 and 5 of the 2014 act could not be implemented, but the Scottish Government continues to encourage local authorities, health boards and other organisations to prepare for implementation of the act by continuing to implement GIRFEC. However, parts 4 and 5 of the 2014 act are the getting it right for every child approach. It is as though the UK Supreme Court ruling had never happened.

Wellbeing as a concept lies at the heart of GIRFEC. Despite the Supreme Court's ruling that wellbeing is undefined and that the safe, healthy, achieving, nurtured, active, respected, responsible and included—SHANARRI—indicators are undefined and, in some cases, notably vague, wellbeing remains the threshold at which practitioners gather and share information on families in far too many cases. When families object or question such an approach, they are often escalated to child protection procedures on such spurious bases as non-engagement.

The UK Supreme Court judgment records that

"personal autonomy is an important principle underlying the guarantees of the ECHR",

which states that

"the family is the natural and fundamental group unit of society and is entitled to protection by society and the state."

In practice, GIRFEC is the antithesis of those principles, and a full public inquiry is needed to reveal and correct the on-going assault on family life.

Alison Preuss (Scottish Home Education Forum): I reiterate Lesley Scott's thanks for the opportunity to come before the committee.

It is hard to condense what has become our lives' work into a few minutes. Home educators have been at the sharp end of the SHANARRI stick right from the outset, and we have evidence

of multi-agency professionals getting it wrong and acting outwith the law.

Home education might be a minority activity but, when the rights of minorities are trampled on, the rights of everyone are trampled on—that is a basic founding principle of human rights law. Home educators recently conducted a survey in which it was found that the major drivers for home education were unmet additional support needs, including chronic illness and disability, safety issues in schools and the GIRFEC cult, which has also led to parents abandoning nurseries and other care settings because of excessive data gathering that amounts to profiling. For example, background checks on home-educating parents have no legal basis, but they have found their way into local policies. Entire families have had their health, police and social work records accessed without their knowledge. That is contrary to national guidance, the general data protection regulation and convention rights.

In mid-May, I wrote to the education directorate to raise serious concerns, but I have had no reply. We have found that being ignored by public bodies is quite commonplace and that even lawyers' letters now go unanswered—we might say that that is due to non-engaging professionals. The problem is that they are all working to practices and policies that have remained uncorrected since the Supreme Court judgment, including the 2014 child protection guidance, which shifted the threshold for data processing without consent.

We found from the minutes that it was a series of backroom deals that caused the threshold to be dropped to the subjective notion of "wellbeing" from "significant harm" in 2013. That was a year before the Children and Young People (Scotland) Act 2014 was passed and three years before the data processing provisions were due to come into force—they never did, of course. The minutes also said that the public were deliberately kept in the dark because there might be an adverse effect. We sounded the alarm at the time, but we were completely ignored and excluded from the debate.

The Government needs to get its story straight. Either GIRFEC data collection and sharing is consent based below the risk of significant harm or it is not. If it is, that is absolutely fine and the higher GDPR threshold will apply. If it is not, we have been misled and there still needs to be a legal basis that satisfies article 8(2) of the European convention on human rights. "Wellbeing" does not cut it, as the Supreme Court said.

Human rights are self-defined whereas SHANARRI wellbeing outcomes are state dictated, as parents have found, and are open to dangerously subjective interpretation. Families have been denied remedy for wrongdoing, having

been told that it was all legal when it was not. Even if they had a spare £15,000 for judicial review, legal time bars might well have kicked in.

Meanwhile, inaccurate information is still being peddled by public and third sector bodies, which adds insult to injury. I stress that our evidence is comprehensive and that it comes from public records, freedom of information responses, families' subject access requests, correspondence and recordings.

We need an independent inquiry into this debacle. There is also a need for victims to relate their experiences to MSPs privately rather than those experiences being paraded in the national press before another assault on human rights is voted through.

The Convener: Thank you very much for that. We will move on to questions.

Rona Mackay (Strathkelvin and Bearsden) (SNP): Good morning, Lesley and Alison. In your petition, you refer to numerous public meetings that have been held since 2013. Can you give us some details about those meetings, such as who was present, who arranged them, and whether Scottish Government representatives were present?

Alison Preuss: The NO2NP campaign, which we are heavily involved in, organised the meetings to raise awareness among the public about what was happening on the ground. Lesley Scott and I both spoke at the meetings. I cannot tell members offhand how many meetings there were, but there were several, and they were all over Scotland. They were very well attended.

Rona Mackay: Were any Scottish Government representatives present?

Alison Preuss: No. They were welcome to attend, but they did not come.

Rona Mackay: Were they invited?

Alison Preuss: They were open meetings.

Lesley Scott: Yes—they were open meetings for anybody who wanted to go to them. I believe that John Mason came to one in Cathcart.

Alison Preuss: Yes—some MSPs came.

Lesley Scott: If people from the Scottish Government wanted to go, they could have.

Rona Mackay: How many meetings were there, roughly?

Lesley Scott: I would guess that there were between 30 and 40.

Rona Mackay: How well attended were they?

Lesley Scott: They were very well attended. As we went on, in some cases, we got more than 80 people, I think.

Alison Preuss: There were more than 100 at some of them.

Lesley Scott: It varied, depending on where we were. We went all over Scotland—right up to the north and right down to the Borders. It depended on where we were.

Rona Mackay: What was the result of the meetings? Was any action taken at the end?

Alison Preuss: We compiled evidence from families who attended the meetings. Several of them spoke about their experiences. They spoke publicly to an extent, but obviously they did not want to compromise their children's privacy, so they sent us details of what had happened afterwards, which we have kept as evidence.

Lesley Scott: The meetings gave families an opportunity to know that they were not alone and to speak to people about what was happening to them and look for ways to counter that. In a lot of cases, there was actual harm as a result of data being shared and the consequences of that. I dealt with one family who were referred to the children's panel four times in one academic year. A sick child was involved, as well. In a lot of cases, the effect is traumatic.

Angus MacDonald (Falkirk East) (SNP): Good morning. To follow on from Rona Mackay's questioning, you have said that, in all the meetings since 2013, you have heard about unlawful data collection and sharing that has led to a loss of trust in services among families. You have given us one example, but can you give us any other specific cases—without mentioning any names or details, obviously—with regard to the circumstances around data being shared?

Alison Preuss: I can think of one recent case involving a family who had been referred to social work for the first time, allegedly on child protection grounds, although it was based on wellbeing concerns, because the family declined the services of a health visitor whom they did not get on with very well. The family lived in social housing in the east end of Glasgow, and the health visitor then alerted the housing service, which came to inspect her house. The family found that violating and humiliating. The children's panel had already thrown that case out in previous years, but it was escalated further. There was a determination to build a case against the family, whose only wellbeing need was a bigger house because they were overcrowded, but that did not appear. There was no practical help whatsoever.

Eventually, the case was escalated to an initial conference, at which I advocated. I was delighted

that social work maintained the threshold that should be maintained, which is the risk of significant harm, and that no further action was taken. That was totally traumatising for the family, who have six children, two of whom are grown up. They really want their voices to be heard.

Angus MacDonald: Will you expand a little on why people have said that the issue has led to a loss of trust?

Lesley Scott: I am with a charity that deals with the neurological disease ME, and we find that, in that situation, information from parents is not given any weight, but the information from any professional involved is. That is repeated with people who do not have ME. Part of the point of the process is that people do not have to repeat their story to professionals—it is taken once and then the professionals repeat it and share it among themselves. However, if the information is wrong, the wrong information is shared and repeated, and parents are not given the chance to correct it. They lose confidence in the processes and practices around them and they lose trust, because the resulting procedures and actions do not help; they actually harm families.

Rachael Hamilton (Ettrick, Roxburgh and Berwickshire) (Con): I was at one of your meetings in East Lothian, which I found very useful. Following on from Rona Mackay's question, I would like to know about the 90 written submissions that you got. Were they part of those meetings or were they separate? Did you go directly to people or did people come to you?

09:30

Lesley Scott: That was a separate thing that Alison Preuss and I set up. Tymes Trust and the Scottish Home Education Forum were excluded from giving evidence to the Education and Skills Committee at the time so we decided to take our own evidence because parents were not being given the chance to tell their stories, which is why we feel we need a public inquiry. We set it up on our own and we put out the word that if people had a story about their information being shared illegally or if there was an experience that people would like us to know about related to GIRFEC, they could give it to us. We set up a website; we also had a public meeting. Evidence flooded in through the website.

Rachael Hamilton: So you gathered evidence directly through the website.

Lesley Scott: Yes. NO2NP put out an email and Facebook posts as well, inviting people to give evidence to us. It was a direct request to parents and families to tell us about their experiences.

Rona Mackay: I am slightly puzzled. You refer to the “intense engagement” that the Deputy First Minister committed to and you

“question the extent to which the organisations engaged by the Scottish Government fully reflected the range of views on these matters or focussed on organisations who were supportive, in principle, of the ‘wellbeing’ agenda and compulsory named person scheme underpinned by GIRFEC and the CfE.”

I am slightly confused by that. Are you supportive in principle of GIRFEC and the curriculum for excellence?

Lesley Scott: No, because we have seen what is resulting from practice on the ground.

Alison Preuss: Anybody would say that getting it right for every child is great, but there is no definition of “it” and there is no definition of “right”. That is the problem; once the state decides what “right” and “wellbeing” mean, we have a major problem because they are open to such wide interpretation.

Rona Mackay: Did your organisation make an effort to contact the organisations that the Government was engaging with to tell them about what was happening?

Alison Preuss: Yes—we work quite a lot with various third sector organisations that support children and families but they all seem to have bought into the legislation, apart from Clan Childlaw, which expressed the same concerns as we did about it. We had a significant legal opinion from someone who was instructed in an important case in Haringey just before the threshold was lowered in Scotland. We pointed that out to all the other organisations, to the Government and to MSPs, but it was dismissed. It turned out that the lawyer we commissioned to write the legal opinion that we submitted in the first stage of the consultation on the 2014 act used exactly the same case law and exactly the same arguments that the Supreme Court finally agreed with.

Lesley Scott: Wellbeing sits at the heart of GIRFEC and, as the Supreme Court said, wellbeing is undefined. SHANARRI is used to define it, but SHANARRI is undefined. It is totally subjective. In the evidence that has been given to the Education and Skills Committee by many practitioners, there is no universal definition of wellbeing that everybody accepts. Groups of people within an organisation may have a collective understanding of what it is within their own group. Outwith that group, you are met with another definition. You cannot base anything on something that is so totally undefinable.

Rona Mackay: Can I clarify whether you are supportive of GIRFEC but question its wellbeing aspect?

Alison Preuss: We are supportive of promoting the safeguarding and wellbeing of children—who would not be supportive of that? The Supreme Court was. However, we are not supportive of the measures that are being implemented to direct parents to promote wellbeing in a specific way. That is where the problem lies and that is why the judgment went the way that it did.

I do not want to get bogged down in legal terminology, but—

Rona Mackay: Sorry—the judgment referred to the data protection and data sharing element; it did not refer to—

Alison Preuss: It referred to human rights and how human rights interact with data protection.

Maurice Corry (West Scotland) (Con): Good morning, ladies. In the petition, you mention that

“many families were unaware of the roll-out of the scheme, let alone the existence of any single point of contact in so-called ‘trial’ areas.”

Do you have any view as to why people were unaware of the scheme?

Lesley Scott: We have minutes from a meeting that show that it was purposely rolled out quietly so that it could be implemented before families were told about it.

Alison Preuss: It was to be embedded across services before families were told about it. That is in Government minutes.

Maurice Corry: So it was to be slipped out.

Alison Preuss: The Highland pilot was much lauded but nobody knew who the named person was or who the point of contact was. People had services forced upon them that they did not want and met gatekeepers to services that they did want. That is where the problem lay, really.

Lesley Scott: We held a meeting in Inverness a few years after the supposed implementation and people there had no idea about the scheme. They just did not know what a named person was and had never met one. The named person is meant to be the central contact when you have an issue or problem, but if you do not know that they exist, how can you approach them with the problem?

Maurice Corry: Did many people know who their named person was?

Lesley Scott: No; they did not even know that the named person existed.

Alison Preuss: As a home educator, I know that families have had to submit freedom of information requests to find out who the point of contact is for home-educating families. We have had redacted information back just giving us the director of children’s services. There is supposed

to be a point of contact—that has been the case since 2007, under statutory guidance on home education—but we still do not know who they are.

Rona Mackay: Did you contact Highland Council, which clearly knew what the named person scheme was, and put your concerns to it?

Alison Preuss: Yes. Various people made complaints but they were never recorded anywhere. With certain local authorities, we still find that complaints that are made by parents are not recorded as such and are ignored. That means that the Scottish Public Services Ombudsman cannot take on the case because it has not gone through the complaints system. If an authority will not accept an issue as a complaint, the parents have to go to judicial review—there is no alternative. Therefore, there is no complaints system and no acknowledgement that parents are complaining.

Rona Mackay: That responsibility lies with the local authority.

Alison Preuss: Yes—well, we would like to think so.

Angus MacDonald: For clarity, did you say that the complaints that were made to Highland Council were not acknowledged?

Alison Preuss: They were not acknowledged by the head of services at the time, who said that nobody had complained about the named person scheme, which was not true. We have copies of complaints from parents to Highland Council that went unacknowledged and unresponded to.

Angus MacDonald: Thank you. It is good to get that on the record.

As you identify in your petition, the Education and Skills Committee is the lead committee for the scrutiny of the Children and Young People (Information Sharing) (Scotland) Bill. That committee has concluded that it cannot give further consideration to the bill until it has an opportunity to scrutinise the accompanying draft code of practice on information sharing. What is your understanding of any progress on the code of practice and the membership of the expert panel that has been set up to guide and oversee its drafting?

Lesley Scott: The situation that we are talking about is happening and has happened so, although what happens with the code of practice is important for the future, it does not affect historical and current practice, which is what we are talking about.

Alison Preuss: We want the wrongdoing that has happened in the past and that is happening currently to be acknowledged and addressed in

some way so that parents have access to justice, which they have been denied.

The Convener: How do you envisage an independent inquiry working? What should its remit be? Is there a standard that you would establish for what a public inquiry would look like? What sort of timescale would it work to?

Alison Preuss: We have discussed that. We feel that an independent Queen's counsel with a track record in human rights would be the ideal person to chair such an inquiry and invite evidence from people who know about the issue—lawyers, because it is the law that is important in this context.

How human rights and data protection interact is the bit that people are finding difficult, which is why the independent panel is struggling. If you read the minutes, which are partial, you can see that there is obvious tension between the law and policy. I think that committees have been wrestling with that, too.

It is a very specialised area. I have spent the past 15 years looking into it, because I worked on the contact point campaign in England—the contact point database was abolished in 2010. I also campaigned against the snoopers charter, which raised the same issues: a legitimate aim, with totalitarian measures to implement it.

Lesley Scott: We would not want a long timescale. GIRFEC has been operating on the ground in practice for quite some time, and families have been waiting a long time for recompense. I do not know what the shortest timescale would be, but the shorter, the better.

Rachael Hamilton: As Angus MacDonald said, the Education and Skills Committee has said that it cannot reach a conclusion on the bill until it has been able to consider the draft code of practice. Ms Scott, will you expand on what you said in response to him?

Lesley Scott: We are asking for an inquiry into historical and current practice. The code of practice and the deliberations about it do not affect current practice, because GIRFEC is in place and has been for a number of years. Implementation has varied across Scotland. The whole purpose of the legislation was to provide for consistent implementation, rather than to introduce new practice, because the practice was already happening on the ground. We are asking for an inquiry into that. Whatever the draft code looks like does not affect the current or historical situation. Families need to be heard and they need recompense, and the practices that have gone on need to be brought to light.

Rachael Hamilton: Should the bill have been considered earlier?

Lesley Scott: The approach should not have been implemented. The legislation came after it had been implemented.

The Convener: I thank the witnesses; that was an interesting exploration of the issues. Do members have comments or suggestions for action?

Angus MacDonald: In the first instance, I think that we need to seek the Scottish Government's view on the action that has been called for. It would also be helpful to write to the Information Commissioner's Office, to seek its views on the petition.

The Convener: I think that the point that we would want to make to the Government is that the issue is not future solutions but what the Government will do to address the concern that practice drove certain behaviour, which had not been legislated for at that point. It would be worth writing to the Scottish Government and to the ICO, as you said.

Rachael Hamilton: Alison Preuss mentioned an unanswered letter to the education directorate. I do not know whether there is anything that we can do to get the information that has been requested.

Alison Preuss: My constituency member of the Scottish Parliament has taken up the issue. She said that she would write to the directorate. I have not heard back yet.

The Convener: We can flag that up in the correspondence. Not responding is different from responding in a way that the questioner does not like; it is frustrating in itself.

We will write to the Scottish Government, indicate the issues that have been raised and ask it to respond. We will underline that this is not about the future but about what the Government is going to do to address what has happened—if it agrees that there is a concern about what has been flagged up. We will write to the Information Commissioner's Office as well.

When the responses are received, the petitioners will have an opportunity to reflect on them and put a further submission to the committee.

I thank the petitioners for their attendance today. It has been a useful session. I suspend the meeting briefly, to allow the petitioners to leave the table.

09:45

Meeting suspended.

09:46

On resuming—

Title Conditions (Scotland) Act 2003 (Review) (PE1691)

The Convener: PE1691, on a review of the Title Conditions (Scotland) Act 2003, was submitted by Christopher R Hampton on behalf of the steering group of Bowman's View.

Members have a copy of the petition and the briefing prepared by SPICe and the clerks, which provides background information on the Title Conditions (Scotland) Act 2003. The briefing also notes that the Scottish Government has recently indicated to SPICe that it has no current plans to amend section 64 of the 2003 act as it applies to sheltered housing complexes or otherwise.

Do members have any comments or suggestions for action?

I was an MSP when the legislation was considered. There are interesting issues about burdens in relation to certain housing complexes and the inability to move to another factor, including the provision that there needs to be a two-thirds majority to remove a factor. I remember at the time that the issue was highly technical and there were a lot of concerns and issues about protecting the characteristics of a sheltered housing complex.

I find the argument in the petition compelling.

Rachael Hamilton: I agree. I was surprised to see that property owners can only vary the terms, rather than remove a factor altogether. There are also minimum age requirements. There is a case for taking the petition forward.

Angus MacDonald: Judging by my case work, I think that there is a strong argument in support of the petitioner's viewpoint. I am struck by the Justice Committee's report from 2013, in which it noted that the complexity of the current law can create barriers to switching property factors. However, in its response to that report, the Scottish Government took the view that no change to section 64 of the 2003 act was required. It may be time for the Government to look at that again, and I am therefore happy to move the petition forward.

Rona Mackay: I agree with Angus MacDonald. The petition raises important issues. I had not realised the effects on sheltered housing. There is a more general concern about factors and how democratic the process for changing them is.

It is time that we moved the petition on. We could ask the Government, the Scottish Law

Commission and the Law Society of Scotland for their views, and move it on from there.

The Convener: We agree to write to the Scottish Government, the Scottish Law Commission and the Law Society of Scotland, seeking their views on the action called for in the petition. The petitioners will be able to respond to those submissions.

Child Funeral Fund (PE1697)

The Convener: The last new petition for consideration is PE1697, by Michael McGuire, on the child funeral fund. The petition calls for the Scottish Government to establish a child funeral fund similar to the fund that the UK Government has established in England and Wales.

As members will be aware from the clerk's note, the Scottish Government has recently announced funding that will remove all local authority charges for burials and cremations for people under the age of 18. The petitioner has indicated that the Government's announcement addresses the action that he is calling for in his petition and he is therefore content for the petition to be closed.

In correspondence received by the clerks, the petitioner expresses his gratitude to the Scottish Parliament for the consideration given to his petition. He also highlights the impact that the Government's decision will have on many people and he states that that is reflected in the comments section of his petition.

The petitioner also wishes to highlight his personal experience as a bereaved parent. He explains that, when he lost his son, Kyle, he had to go back to work three days after the funeral for financial reasons. The petitioner states that, because of that, he missed out on vital time to grieve over the death of his son and to be there for his wife, which is an impact that he still feels, nine years on. The petitioner is of the view that the Government's announcement will be

"far reaching and help so many families at a time where the lights have simply gone out in their lives".

Do members have any comments before we reflect the wishes of the petitioner in closing the petition?

Rachael Hamilton: I note our sympathy for the petition. We can tell by some of the petitioner's comments how strongly he felt about the issue and how he felt that he was speaking on behalf of many other people in the same situation. I am pleased that the Scottish Government has announced that it will remove all local authority charges for burials and cremations for those under 18.

Given that the petitioner has indicated that he is content for us to close the petition on that basis, I suggest that we do so.

The Convener: Does the committee agree to close the petition on that basis?

Members indicated agreement.

The Convener: We close the petition under rule 15.7 of standing orders, on the basis that the petitioner wishes to withdraw it.

It is good to note that the petitioner is withdrawing the petition not out of frustration but in recognition that he has secured progress. I am sure that we want to thank the petitioner. It is never easy to take your individual experience and use it to try to make a difference for other people. He has managed to make that difference out of his dreadful experience. We are grateful to the Scottish Government for responding to that because, as the petitioner says, it will make a difference to the lives of people who are grieving.

09:52

Meeting suspended.

09:54

On resuming—

Continued Petitions

Diabetes (Continuous Glucose Monitoring Sensors) (PE1619)

The Convener: The next item on the agenda is consideration of continued petitions. We last considered PE1619, by Stuart Knox, on access to continuous glucose monitoring at our meeting in March, when we agreed to write to the Scottish Government, national health service boards, the Scottish Intercollegiate Guidelines Network and the petitioner. Responses have now been received and are included in our meeting papers.

Members will recall that we agreed to invite the Scottish Government to provide evidence on the petition. It was anticipated that the Cabinet Secretary for Health and Sport, Shona Robison, would be in attendance for today's evidence session. However, as members will be aware, the cabinet secretary resigned from her position on Tuesday this week and therefore will not be present at our meeting today. We record our thanks to Shona Robison, who has been willing to engage with the Public Petitions Committee on her responsibilities as cabinet secretary and we wish her well in her new role.

I am however pleased to welcome from the Scottish Government Professor Jason Leitch, national clinical director for healthcare quality and strategy; Gillian Gunn, team leader with the strategic planning and clinical priorities team; and Richard Shearer, senior policy officer in that team. Thank you for attending. You have up to five minutes to make an opening statement if you wish to do so, after which we will move to questions from the committee.

Professor Jason Leitch (Scottish Government): Thank you for having us. Forgive the short-notice change of personnel.

I will outline the position and will then be happy to take questions as best I can. I know how difficult it can be to manage diabetes. I am a dentist and oral surgeon. I am a clinician and have been for 26 years. With that in mind, we must ensure that health technologies have clear evidence of their safety and clinical and cost effectiveness with appropriate evidence-based guidelines on their use.

Before we go further, perhaps I should clarify the difference between two technologies, although I am sure that members have grasped this over their months of looking at the subject. The technologies are continuous glucose monitors and

flash glucose monitors—FreeStyle Libre is the example that the committee has been looking at. They are two different types of device. Without going into technical details, continuous glucose monitors have a strong evidence base. They provide alarms and warnings of impending hypoglycaemic attacks and can be used in conjunction with insulin pumps. FreeStyle Libre, a flash glucose monitor, cannot be used like that. It does not provide real-time continuous glucose monitoring or alarms.

We took the step of referring the topic to the Scottish health technologies group, which is an organisation that looks independently at the available evidence clinically and cost effectively. The current position is that seven NHS boards have included FreeStyle Libre in their local formulary. I look forward to the advice statement from the health technologies group, which I expect in July, to assist the remaining NHS boards to identify how they might best consider adoption of the technology in an open, equitable and manageable process.

We have encouraged those boards who have introduced it to share their experience with other boards, and we have asked those boards to ensure that they accurately record the introduction of all diabetes devices into our Scottish care information diabetes collaboration, which is one of our best e-health and technology systems, to help to inform that developing evidence base.

I am happy to take any questions.

The Convener: Thank you. I welcome Emma Harper MSP for this item.

One of the issues that the committee heard during its fact-finding visit on the petition last year was that there had been delays in NHS boards receiving the initial £2 million funding during 2017-18. Can you respond to that?

Professor Leitch: I will let Gillian Gunn deal with the delay, although I would put that word in inverted commas. The funding was for continuous glucose monitoring and pumps, not for flash glucose monitoring. They are two different things. The funding that went to the NHS boards was for continuous glucose monitoring and insulin pumps.

The Convener: You talked about putting the word in inverted commas. Are you arguing that there was no delay?

Professor Leitch: No. I simply do not know, which is why I wanted you to ask Gillian Gunn.

Gillian Gunn (Scottish Government): There has been no delay in issuing the funds that were announced and committed to by ministers. The funds went out on time for the beginning of the 2017 financial year and again in this financial year.

The Convener: Somebody has got it wrong then. There has not been a delay.

Gillian Gunn: There has been no delay in the Scottish Government issuing the funds to all health boards as described in the director's letters of last year and this year.

The Convener: We received evidence from NHS Forth Valley that it had to revise how it planned to spend the allocated funding because VAT was not included. Can you clarify that and say whether the guidance is sufficiently clear about the actual funding that is available to health boards?

Gillian Gunn: The funding that was allocated to the boards for insulin pumps and continuous glucose monitors did not include VAT. Boards have funded the VAT from their own resources. The funding for insulin pumps and continuous glucose monitors is to buy the technologies and to increase the amount of people receiving CGMs and insulin pumps.

10:00

The Convener: So if we want to quantify what the £2 million means, we would have to calculate what the boards would have to find for the VAT.

Gillian Gunn: There are differences in how the boards fund the technologies. The amounts that have been given will depend on which technologies they buy for individual people. A range of continuous glucose monitors is available, and a range of insulin pumps. Boards will purchase the ones that are most appropriate for the individuals that they see.

The Convener: If the Scottish Government is providing funding, would it not be reasonable for it to factor in how much extra it costs to deliver the technology? To me, it does not seem to be reasonable to say, "We are giving you this amount of money to address a problem but, as a consequence of that, you will have to find more money." Presumably, when there is not much money, most health boards will have to incorporate the cost of VAT into the amount that they have been given and therefore there might be a reduction in the number of people who will be able to be helped.

Professor Leitch: The boards have the money to spend as they want on this subject. Let us be careful not to confuse that with what the petition is about, which is flash glucose monitoring.

The Convener: I am not confusing the issue. Please forgive me. I understand what the difference is, because we have been given the evidence on that. I am asking whether, when the Scottish Government provides funding, it calculates the VAT implications at that point, and

whether it therefore gives a transparent report on how many people will be able to be helped by the moneys that are being provided.

Professor Leitch: The money would come along with a commitment and a target for the number of people who would get insulin pumps and continuous glucose monitoring. Such numbers are public and published, and we are on target to meet them.

The Convener: That includes the cost of VAT, then.

Professor Leitch: Correct.

The Convener: Are you suggesting that NHS Forth Valley is mistaken in thinking—as it has stated—that it was getting X amount of money to provide X amount of support, but then discovered that it had to pay the VAT as well.

Professor Leitch: I am suggesting not that it is mistaken but that the money that it got to meet its target—for want of a better expression—for continuous glucose monitoring and insulin pumps has enabled it to reach its target. That will have to include VAT.

The Convener: It included VAT. So when NHS Forth Valley says that it did not realise that, it is wrong.

Professor Leitch: No. I am sure that it is telling the truth in saying that it did not realise that. I am not suggesting that it is lying.

The Convener: Is it just ill-informed?

Professor Leitch: Perhaps there is a misunderstanding between the two organisations—us and it.

The Convener: Is it unusual for VAT not to be factored in?

Professor Leitch: Many of the technologies that are purchased by the national health service include VAT. When we give money for a specific purpose or technology such as this—which we do not do very often, as we give boards a block grant to spend for the health of their populations—that money comes with aims and targets for each board to meet. That has to include the whole costs of the technology.

The Convener: So your targets were informed by the costs with VAT.

Professor Leitch: Correct.

The Convener: So it is not the case that health boards would separately have to find the money for VAT, which is what we heard earlier.

Professor Leitch: That is my understanding. I am happy to talk to NHS Forth Valley and correct any confusion.

The Convener: It seems to me to be a significant issue. We seem to have had two separate messages from the evidence that we have had already.

Let us move on to Angus MacDonald's question, and we will come back to that point.

Angus MacDonald: Good morning, panel. I have taken on board your clarification regarding funding for continuous glucose monitoring. When the committee was on its fact-finding visit to Dumfries and Galloway a few months ago, we discussed the cost of using glucose monitoring technology compared with that of traditional pinprick blood tests. We heard from diabetes sufferers and pharmacists that there was not much of a cost difference, but a consultant whom we met suggested that there was. That suggestion took account of access to peripherals, such as testing strips. Can you clarify for us what cost analysis you have undertaken on the costs of pinpricking compared with those of continuous glucose monitoring and flash glucose monitoring?

Richard Shearer (Scottish Government): Because of the population that continuous glucose monitoring is targeted at, the most important thing is matching the technology to the individual. We know that it costs more, but that is because of the additional features, such as the alarms and the ability to be linked to a pump. On that basis, the cost analysis is more to do with what it costs to deliver. We know that there is an offset against it.

With flash glucose monitoring, there is a point at which it costs the same as, or less than, finger pricking, and that point is between eight and 10 finger pricks a day. For someone who does fewer than eight finger pricks a day, flash glucose monitoring costs marginally more, whereas it costs marginally less for people who do more pricks than that because, with flash, there is a fixed cost. Regardless of how often someone scans, the cost of scanning does not increase, but if they finger prick, there is a cost attached to each test strip.

Maurice Corry: Good morning, panel. The 2017-18 guidance that was provided to NHS boards on future funding said that there would be an increased emphasis on continuous glucose monitoring devices, but the more recent 2018-19 guidance does not contain a similar statement. Why is that? What other guidance might NHS boards be provided with as regards future funding for such devices?

Richard Shearer: The initial letter went out at a time when we planned to initiate fewer CGM devices in the first year than we ended up initiating. After that letter was sent out, discussion took place with boards, which had identified marginally fewer people for insulin pumps than they had been able to identify for CGM devices, so

we ended up funding roughly 50 per cent more CGM devices in the first year than we had planned to. We are now on a trajectory of initiating about the same number of devices, or slightly more, each year rather than the increasing trajectory that we had originally planned on.

Professor Leitch: It is important with all new technology such as CGM to use it with the appropriate people. Only quite a small number of people benefit from that much more expensive technology—people who have regular hypoglycaemic attacks and who cannot notice when their blood sugars are going off, for want of a better expression. Although continuous glucose monitoring is slightly more invasive in nature, it is very useful in that small group of people, because we can link it technologically to the insulin pump to control their insulin.

Gillian Gunn: The phased approach for continuous glucose monitors is enabling us to make sure that we have a workforce that has the appropriate skills. That is an important part of the introduction of new technologies.

The Convener: Is it the eventual ambition to end pinprick testing?

Professor Leitch: Do you mean globally?

The Convener: No, not globally.

Professor Leitch: With the present technologies that are available, it would appear that pinprick monitoring will continue for the foreseeable future until cheaper and easier-to-use technology becomes available.

The Convener: But if we discount the issue of cost, pinprick testing would be recognised as less than optimal for people.

Professor Leitch: Indeed. If the diabetes community—patients, families and medical staff—can find a technology that fulfils that purpose that is non-invasive, that will be a big change. We appear to be in a period of technological advancement that is moving us towards that.

Richard Shearer: CGM, for example, requires calibration through finger pricking on a daily basis, and the Driver and Vehicle Licensing Agency has rules on finger pricking and driving. In future, as Jason Leitch said, we hope to have a non-invasive approach, but at the moment all the technology that we have still requires the use of finger pricking.

Maurice Corry: From reports that I have read, I understand that we are not that far from non-invasive technology being available—I am talking about a matter of a couple of years. Is that correct?

Richard Shearer: Are you referring to the artificial pancreas?

Maurice Corry: Well, in layman's terms, I am talking about not having to prick.

Richard Shearer: That is potentially the case, but the artificial pancreas is still at an early testing stage. As with all technology, we would expect it to go through comprehensive clinical trialling. There would then be the issue of roll-out, and manufacturers would have to be able to achieve the required scale of numbers. The clinical appropriateness of any technology for particular sub-groups of the condition would also have to be considered.

Rona Mackay: Professor Leitch, you said in your opening statement that the Scottish health technologies group is undertaking a national appraisal of FreeStyle Libre as there is a lack of published data about the clinical and cost effectiveness of flash glucose monitoring. Will you explain why FreeStyle Libre was added to the Scottish drug tariff if there is insufficient information about its clinical or cost effectiveness?

Professor Leitch: The Scottish drug tariff is a different bar from the bar for getting into formularies. The tariff requires safety and no detriment, but it does not take account of clinical or cost effectiveness. It is the first step towards delivery as a prescribed medicine or device. The next step is that local formulary committees in boards make a decision—yes or no—for their local formularies. That is informed by local evidence from inspectors, pharmacists and clinicians, but we try to help nationally by doing national investigations using the SIGN guidelines; we use the SMC for drugs and the Scottish health technologies group for devices. In this case, that has happened pretty quickly. It joined the tariff in November, and in July we will get a report from the health technologies group, which will give us more evidence—or combined evidence—that will allow us to go back to boards and continue the journey.

Rona Mackay: So a drug is added to the drug tariff before all of that has been scoped out.

Professor Leitch: Correct. It is the same as in the other UK countries. Each country has its own drug tariff. For medicines, you get European approval, then individual country approval in the drug tariff, and then it is added to formularies. In England, the regional clinical commissioning groups decide what is in the formularies, and in Scotland the health boards decide.

Rona Mackay: You said that the appraisal is due to be published in July. Have you had any engagement with the group on the findings so far? Do you have an indication of what they might be?

Professor Leitch: I do not. The group deliberately acts independently. It is part of Healthcare Improvement Scotland, but it takes

independent evidence from independent witnesses. I am led to believe that I will get the findings in the next few weeks.

Rachael Hamilton: I have had letters from constituents about FreeStyle Libre. In April, I received a letter from Shona Robison, which states:

“the Scottish Government is committed to increasing the access to Continuous Glucose Monitors (CGM), which when used in combination with insulin pump therapy, has been clinically proven to significantly reduce HbA1c levels and hypoglycaemic episodes.”

The 2017-18 guidance that was provided to NHS boards stated that there was increased emphasis on continuous glucose monitoring devices, but the 2018-19 guidance—the most recent guidance—does not contain a similar statement. Why is that? What other guidance have NHS boards been given on funding, given that the guidance for the two years differs?

Richard Shearer: In the second letter—the 2018-19 letter—we sought not to repeat the 2017-18 letter, in order to make it simpler for boards. The principles were established in the first letter and the first round of funding. We sought to clarify the similarities with the first year—the target group is the same—and set out the funding, in order to reduce the scale of the correspondence.

Professor Leitch: To be clear, I add that we still believe what was in the first letter. We believe that continuous glucose monitoring connected to insulin pumps is appropriate for a small number of the difficult-to-control group of diabetics—that is not a particularly pleasant phrase—and provides a real step-change in their lifestyles: they can live normal lives where previously they could not. We still believe that technology to be clinically effective and cost effective for that group.

Rachael Hamilton: Can you clarify what the future will be? You said that the treatment is appropriate for the difficult-to-control group. What is the future direction for NHS boards?

10:15

Richard Shearer: For CGM, we review the guidance that we have issued in relation to the group that we are targeting our funding at. We do that with our national diabetes specialist nurse, who is focused on technology and is assisting boards in the roll-out and implementation of CGM and insulin pumps. That will ensure that we are still focused on the correct group. It might be that we will move on to the next priority group. For example, if we have managed to initiate CGM for as many of the hypoglycaemic unawareness group as are willing to take on the technology, we will look at the next clinically indicated group beyond that, in terms of risk.

Rachael Hamilton: What is the guidance to the boards on the funding part of that?

Richard Shearer: That guidance will come in the annual director's letter. If we get to the point at which we move to the next indicated risk group, information with regard to the annual funding will be contained in the director's letter.

Emma Harper (South Scotland) (SNP): Good morning. I am co-convener of the cross-party group on diabetes. I have type 1 diabetes and am a pump user and an intermittent flash monitor user, so I understand the technology and how it works. I have a constituent who has a seven-year-old who is not having seizures at night any more, following the introduction of flash monitoring, and that is fantastic.

I am curious about how we support and educate the patients, nurses and staff. NHS Dumfries and Galloway has set criteria that people must meet in order to qualify for a flash monitor: they have to do six tests a day, they have to agree to the uploading of their results and they have to have attended the dose adjustment for normal eating—DAFNE—course. The process is complicated and the staff will have to be trained if they are to support people with type 1 diabetes. What are your thoughts on that?

Professor Leitch: You raise an important point about the new technologies. The patients and families have to be trained, which has implications for them and the training of the diabetes nurses and general practitioners, as, presently, the technology is provided in secondary care. Further, we have to ensure that our staff keep up with changes in those technologies. The Scottish diabetes group and third sector organisations help us with all of that.

It is absolutely correct that boards will set criteria for the inclusion of whatever that new technology is, just as they would for insulin pumps or any other device for a home-based process, such as dialysis. We will provide guidance, as we often do, either through the work of Healthcare Improvement Scotland or through the Scottish Government, in order to equalise that guidance as best we can across the territorial boards.

Emma Harper: I love the idea that technology is reducing the need for finger sticks, because that process causes people pain. However, I assume that we still have to use the finger stick process as a way to calibrate the flash monitors, which means that we will not completely eliminate finger sticking. Is that correct?

Professor Leitch: That is correct at present. I imagine that the companies are working tirelessly behind the scenes on technologies that will eventually replace the more invasive elements of diabetes care. Just now, the machines require a

test to enable them to calibrate themselves. When people go for secondary care diabetes care, they have actual blood tests, not pinprick tests. In order to monitor their continuous care, blood testing is required. I cannot see that requirement disappearing soon.

Emma Harper: I assume that, as more people are introduced to CGM and flash, boards will monitor their haemoglobin A1c levels to show that there is an improvement, because long-term blood glucose control will reduce the complications that are associated with diabetes. In the long term, there will be cost savings.

Professor Leitch: That is correct, if what you say comes true. That is why the SCI-diabetes process is important. I am glad that NHS Dumfries and Galloway wants to know the data. As you will know, because you are probably on SCI-diabetes, that system monitors eye problems, foot problems and hypoglycaemic admissions. We will be able to relate that to the technology that the individual is using, which will give us more information. At present, the Scottish health technologies group can really look only at published evidence, as it does not have Scotland-wide evidence from thousands of patients, but eventually it will have that.

The Convener: I have a couple of questions to conclude the session. The committee has heard previously that the SIGN guidelines for diabetes type 1 management are out of date and have not kept up to date with technology. How do you respond to that?

Gillian Gunn: We are engaging with Healthcare Improvement Scotland to look at the SIGN guidelines. We have sought advice and are progressing that work with Healthcare Improvement Scotland and SIGN.

The Convener: What is the timescale for that?

Gillian Gunn: There is no timescale at the moment. We are looking to see how SIGN guidelines may be updated. We are aware that the National Institute for Health and Care Excellence guidance has recently been updated and we are looking across all the national guidance that is currently available.

Professor Leitch: I undertake to answer that question more fully. I will ask SIGN.

The Convener: Sorry?

Professor Leitch: I will ask for a timescale.

The Convener: It would be useful to know that. I accept that there may be a moving target but, when you say that you are going to do something, it is always helpful to have a timescale.

Professor Leitch: SIGN has a waiting list and a pipeline for new guidelines and for updating its

guidelines. The one that you refer to will be in that pipeline somewhere. SIGN is also reviewing the nature of how it creates guidelines, exactly because of the pace of change in healthcare. The traditional method is to have quite a long period of evidence gathering of, sometimes, two or three years. As you say, however, the situation can move during that time, so SIGN needs a slightly more agile version. It may change its processes, which would help for diabetes care, asthma care and other issues.

The Convener: It would be useful to get more information. I understand the point that technology is a moving feast. We can be sorting a problem when there is perhaps something already developed that changes the landscape completely.

I understand that ministers have asked NHS boards to provide quarterly updates on the progress made in relation to the additional funding that we spoke about. What does that information tell you and what do you understand the continuing challenges for health boards to be in relation to how they use the funding?

Gillian Gunn: The information from boards tells us that they are on track to meet the targets that we have set. Going forward, we know that the cost of the technologies has an impact on boards, which is why we have been supporting the process nationally. We need to work with the boards as we progress through this period of funding so that they can embed the costs in their resources in future.

The Convener: So the funding will be mainstreamed at a later stage.

Gillian Gunn: Insulin pumps for children are already mainstreamed. The additional funding for adult pumps is to help boards to further progress what is already mainstreamed in their budgets.

The Convener: Will you continue to keep an eye on the targets and whether they have been met?

Gillian Gunn: Yes.

The Convener: Thank you very much for your responses. I appreciate that you had to come along at short notice.

Do members have any comments or suggestions for action, given what we have heard?

Rona Mackay: Obviously, we will reflect on the evidence that we have heard, which was useful. We should continue the petition until the national appraisal has been published, which will happen shortly, and then we can take stock of where we are.

The Convener: It might be worth while to invite the new cabinet secretary to come at some point to give us an update from her perspective on

where we are on the issue. Part of it is about testing whether the funding is adequate to meet the targets and whether there continue to be issues around that, but there is also the issue that the guidance is behind the technology, so it would be useful to hear what progress there has been on that, as well.

We are agreeing to continue the petition. We will reflect on the evidence that we have heard and we may factor in another session with the new cabinet secretary to allow her to respond to some of the submissions that will, no doubt, follow this session. As I said, the petitioner will have an opportunity to submit comments on what we have heard today.

I thank our witnesses again. I suspend the meeting briefly to allow them to leave.

10:24

Meeting suspended.

10:29

On resuming—

Alzheimer's and Dementia Awareness (PE1480)

Social Care (Charges) (PE1533)

The Convener: The next two petitions for consideration are PE1480, on Alzheimer's and dementia awareness, by Amanda Kopel, on behalf of the Frank Kopel Alzheimer's awareness campaign, and PE1533, by Jeff Adamson, on behalf of the Scotland against the care tax campaign, on the abolition of non-residential social care charges for older and disabled people.

As members will note from our papers, the petitioner for PE1533 continues to express concerns about how money for free personal care will be distributed to people who need it, despite having met Scottish Government officials who agreed to assess his proposals. The committee might also wish to note that regulations were recently approved by the Scottish Parliament with regard to the action called for in PE1480 to extend free personal care to people under 65 who require it, regardless of their condition.

Do members have any comments or suggestions for action?

Angus MacDonald: Given the positive progress with PE1480, in that the Health and Sport Committee recently approved regulations that address the action that was called for, which was extremely good news, we could close the petition under standing orders rule 15.7.

The Convener: I certainly thought that it would be reasonable to recognise the progress that had been made and to close that petition.

I think that there is a lot left to explore around the issues that were raised by the Scotland against the care tax campaign's petition, PE1533. We need more exploration around the questions of the definition of care and the importance of care from a human rights perspective. For example, someone should be able to work and achieve their potential, but the care tax might prevent them from doing that, or they might deny themselves the support that they need because they cannot afford it. I found the evidence pretty compelling.

Rachael Hamilton: We might perhaps write to the Scottish Government as there are still some points that have not been addressed that were recommended, and it is unclear how the money will be distributed and whether it will go directly to the person or to local authorities. There are some unanswered questions remaining.

The Convener: Yes. The petitioner clearly feels quite strongly about the proposals that the campaign identified. If the conclusion is that the money goes to local authorities and not directly to those who need the support, there is still a question there.

Rona Mackay: I agree that we could do with some clarification on that side of it. Although it is great news that the actions have been approved initially by the Health and Sport Committee, there are still some questions that we could put on the other issue that you mentioned.

Maurice Corry: I agree. We should get all the information on the table.

The Convener: I was quite struck by the range of individuals and organisations that support PE1533 as a result of direct experience. There was a presentation by a disabled young woman who said that her student loan was factored in as part of her income against what she might have to pay for her support. We might want to further explore whether we can afford a circumstance in which people are brought together to look at such issues. Certainly, in the first stage—

Rona Mackay: In the context of our new social security powers, it would be timely to do that.

The Convener: I suggest that we write to the Scottish Government to seek an update on its assessment of the proposals from Scotland against the care tax. In previous considerations, there was an issue about cost. I do not know how confident we felt about how rigorous the assessment of costs would be; if I remember correctly, COSLA and individual local authorities highlighted that. It would be useful for the Scottish Government to reflect on that, too. It should also

address the broader question of the definition of care, because people's need for care might be not simply about personal care, but about things that they need support with in order to be able to work or whatever.

Are we agreed that we will close PE1480, recognising the progress that has been made in that regard, and that we will write to the Scottish Government to seek an update on the assessment of the proposals that the Scotland against the care tax campaign put forward?

Members indicated agreement.

The Convener: We thank Amanda Kopel. Everyone was aware of her campaign and its power. As a result of the petition that she took forward, and the compelling way in which the case was argued by the campaign, there has been progress, for which we thank her.

We will continue PE1533 in order to be fully satisfied that the petitioner's concerns have been addressed.

A75 (Upgrade) (PE1610)

A77 Upgrade (PE1657)

The Convener: The next two petitions for consideration are PE1610, by Matt Halliday, on upgrading the A75, and PE1657, by Donald McHarrie, on behalf of the A77 action group, on the A77 upgrade. I welcome Finlay Carson to the table for consideration of the petitions, and I recognise that Emma Harper remains in position to participate in our consideration of these two petitions.

Members will recall that, at our last consideration of the petitions in March, we reflected on the evidence heard from the Minister for Transport and the Islands and agreed to write to the Scottish Government and to hauliers and ferry operators. Responses have now been received and are included in our meeting papers. Members will note from that information that the petitioner raises concerns that the information that was used to decide the standard of road for the Maybole bypass was out of date and inaccurate.

Written responses received also highlight a number of issues that we have heard repeatedly being raised by different stakeholders; those issues include the heavy goods vehicle speed limit not being appropriate, particularly on the A77, the quality of the road being poor, and competition from ports elsewhere in the UK threatening the long-term economic future of the ferry ports in the area. I was struck by the number of submissions that we received and by the substantial points that they made.

Do members have any comments or suggestions for action? Might it be worth while hearing from Finlay Carson and Emma Harper first? We can go round the table after that.

Finlay Carson (Galloway and West Dumfries) (Con): I want to highlight the dire situation down in the south-west with both the A75 and the A77. At this time of year, some parts of the A77—as mentioned by one of the ferry operators in relation to the conditions and maintenance on the road—have trees and vegetation growing right over the white line. Instead of the A77 getting wider, which we would all like to see, it is growing narrower by feet every time that there are new leaves on the trees.

Last autumn, I drove the route with David Allan, the route manager, and I highlighted some of the areas where immediate maintenance was required. Unfortunately, that work has not been done, and we have stretches of the road that cannot possibly come up to the standards that should be required of a road with trunk road status, with regard to line of sight and visual stopping distances on corners. If nothing else, that needs to be addressed seriously. We now have lorries cutting the hedges on the verges, rather than them being cut back by contractors, and that is just unacceptable.

Emma Harper: I am interested to hear about actions moving forward, because both the A75 and the A77 are important routes for the economy of the ferry ports at Cairnryan and Stranraer and for the surrounding area. Finlay Carson has absolutely highlighted the issues. Certain parts of the road are troublesome because lorries have a hard time passing one another.

Recently, I asked the minister, Humza Yousaf, about reviewing the speed limit from 40mph to 50mph at Stranraer, at the request of a lorry-driving constituent. I welcome the review of the A9 speed cameras and the speed limit increase there. I am interested in keeping the petition open so that we can continue to look at improvements for the infrastructure in the south-west of Scotland.

Finlay Carson: We were led to believe that an additional piece of work was coming forward in the form of a review, which was commissioned in March, but it appears that that review will only feed into the national strategic transport review, so we are probably looking at three years before there are any conclusions. Realistically, we are probably looking at six years before any action can be taken on the A75 and A77, and that needs to be looked at seriously. The process needs to be accelerated, and doing the review could be slowing the whole thing down. I spoke to someone at Transport Scotland who suggested that it could be six years by the time the review is done and that, if any work is identified, by the time it went through

consultation, it could be six years before any plans actually came on to the table. That is totally unacceptable.

Rachael Hamilton: On 29 March, the then transport minister committed to increasing the speed limit. However, subsequently, the Scottish Government said that there was no plan to increase the speed limit. We now have a new transport secretary—Michael Matheson. The convener will guide the committee on what we should do following comments from committee members, but perhaps it would be in our best interest to get clarification on that, given that two members have concerns about the speed limit.

Angus MacDonald: It is certainly disappointing to note the comments from P&O Ferries, which Finlay Carson alluded to, that highlight that

“the condition of both”

the A75 and the A77

“has worsened significantly”

over recent months, and that

“surface repairs have not kept up with the rate”

of

“deterioration.”

When we were down in Dumfries and Galloway on our fact-finding visit, we heard about the potential loss of the ferry ports, which is clearly a concern. It is extremely disappointing that the condition of the roads has worsened, particularly given the coverage that the petitioners have secured during the consideration of the petitions and the fact that the matter has been on the Government’s radar. I am disappointed to hear the reports and I share the concerns that have been expressed.

Maurice Corry: The two recommendations are very appropriate. We also need to bear in mind the economic angle, as the poor road conditions that have been highlighted are endangering the future viability of the economic corridor. The decision might be taken out of the Government’s hands by the commercial sector, and we do not want that to happen. That has been reflected by Emma Harper and Finlay Carson.

The Convener: It would be worth while asking the Scottish Government about the PE1657 petitioner’s specific concerns that the information that was used to select the standard of road for the Maybole bypass was out of date and inaccurate. We want a response on that point and to know what plans AECOM Ltd has to engage with both petitioners on the south-west Scotland transport study. That study will be important to inform their thinking. We can agree to do that.

Is there anything else that we could look at? The economic element has been a thread through the issue. It is not just about the roads, the frustrations of individual drivers and the risk to people who go up and down the roads; the economic impact of not being able to move more quickly on the roads is significant.

Rachael Hamilton: When AECOM Ltd, which has recently been appointed, undertakes the study and gets evidence from stakeholders on the roads, how can we be confident that Transport Scotland will consider the economic impact as part of the study? We could take our own evidence. I have just joined the committee, but Angus MacDonald said that the committee had been down to Dumfries and Galloway. Did you speak to anyone who is involved in the matter?

Angus MacDonald: We had a round-table discussion.

Rachael Hamilton: Was the economic impact discussed?

Angus MacDonald: It was.

Rona Mackay: Yes—very much so. Every time that we discuss the petitions, there seems to have been slow or no progress. Transport Scotland has said that the study is at an “early inception stage”, which raises alarm bells and suggests that it will drag on and on. We need to write to Transport Scotland to point out the worsening state of the roads and the urgency of the matter, because the ports will not wait for ever.

The Convener: We should also write to the new transport secretary to highlight that it has been an on-going issue and that we are developing a project that is not fit for purpose, which is a concern.

I wonder whether it would be worth while to have a round-table discussion in Parliament with interested groups. There is a frustration that people have identified the issue but do not know what action is being taken. Having a discussion with Transport Scotland, Government officials and stakeholders might be a useful way forward.

Finlay Carson: One of the frustrating things is that engineers have looked at some road improvements on the A75 but they were shelved for various reasons, so we know that plans for road improvements on the A75 have already been drawn up. We have heard the economic argument over and over again. I do not see that waiting six years is acceptable when we know what the answers are to all the questions.

A round-table discussion would be a great opportunity to get some answers and to ask questions about what sections of the roads have had improvements designed and engineered that are sitting on a shelf just waiting for someone to

give them the nod. I have used freedom of information legislation three times to get information about how much land the Scottish ministers own along the A75 and have been knocked back every time. It was suggested that providing that information was not in the public interest. That is utter nonsense, given the number of respondents to the petition. A round-table discussion would certainly give us the opportunity to get those questions on the record and, I hope, get some answers.

10:45

Emma Harper: It would be worth while finding out where the information that suggests that the ferry operators are considering alternative routes is coming from. I do not know whether they are. The haulage companies seem to have put out that rumour. If the ferries moved, that would be pretty devastating. I have tried to find out information about that. It would be great if the new transport secretary could take the road to get there, meet people at the ferry terminal at Cairnryan and get the views of stakeholders.

Maurice Corry: I have a question for Emma Harper and Finlay Carson. What pressure have Dumfries and Galloway Council and the Convention of Scottish Local Authorities put on Transport Scotland? We really need to involve them.

Finlay Carson: Once again, I was quite disappointed. I asked the council questions about what lobbying of the Scottish Government it had done. There has been very little. I know that it has stepped up somewhat in the past few years. The council put together a strategic plan for improvements to the A75 and the cost—I think that the plan was produced 15 to 20 years ago—and that sat on the shelf. Some of the economic arguments have already been had, and there are documents that lay out improvements and when they should be scheduled. That was on the back of the potential reduction in traffic to the ferry terminals with dual carriageways opening up at Holyhead and Heysham.

Maurice Corry: I have experience of a problem with the A83 going to Campbeltown and Rest and Be Thankful. Unless the councils—even individual councillors—push hard, they get nowhere with Transport Scotland. That is important.

Angus MacDonald: A round-table discussion would help to keep the Government’s mind concentrated on the issue; if it has not been, a round-table discussion would ensure that it is. Given the evidence that we took on the fact-finding mission, I would be keen to ensure that P&O and Stena Line are included in a round-table discussion, as their positions are significant.

The Convener: That consideration has been useful. We have highlighted the PE1657 petitioner's concerns, and we want information on how the petitioners will be engaged with by AECOM Ltd. We will consider a round-table discussion with the relevant stakeholders, and we will take into account everything that people have said about who the relevant stakeholders are. I think that we want to write to the Scottish Government to highlight that the issue is a big one in the new cabinet secretary's in-tray and that we would welcome any response from him.

Members indicated agreement.

The Convener: I thank Finlay Carson and Emma Harper for their attendance.

Ocular Melanoma (MRI Scans) (PE1629)

The Convener: The next petition is PE1629, by Jennifer Lewis, on magnetic resonance imaging scans for ocular melanoma sufferers in Scotland. We last considered the petition in December 2017, when we agreed to write to the Scottish Government and the chief medical officer about three issues that the petitioner had identified.

The note by the clerk provides a summary of the Scottish Government's response on the establishment and work of a group to develop guidance and recommendations on surveillance, peer-reviewed evidence and national services division policy. The petitioner and Iain Galloway have responded to the Scottish Government's submission, and they appear to feel that no significant progress has been made on the issue. Iain Galloway has raised a number of questions that he thinks remain unanswered by the Scottish Government, and the petitioner has made a number of comments on the detect cancer early programme in the context of the petition.

The petitioner and Iain Galloway make compelling points about more needing to be done to address the concerns that they have identified. One on-going frustration is the fact that, because the incidence of the cancer is low, it does not get the attention and understanding that it merits. We can understand the frustrations of the petitioner and Iain Galloway. They see something straightforward that would support sufferers of the cancer with early identification of problems in the liver, and the Scottish Government's response was, I felt, defensive.

I welcome members' comments on how we might take the petition forward.

Maurice Corry: This is an interesting matter, on which I have had a prior discussion with you, convener.

I would like the Scottish Government to look at what happens in Liverpool, Sheffield and

Southampton, which are all top dogs on the matter. They have got the formula right—I know that from a friend of mine whose son has had the condition and has gone through the process. It is clear that Liverpool has the right pathway for it, as do Sheffield and Southampton. Therefore, I would like to ask the Scottish Government to examine what they do and pick up on all the plus points. Clearly, those places are delivering what the petitioner asks for.

The Convener: It struck me that the Scottish Government's argument was that the approach has not been proved or peer reviewed. However, we know that practice in other parts of the United Kingdom is different. I would have seen the point if the Government had said that its priorities were different, but it seemed to be questioning the evidence base, which would be to question the evidence base that is used in other parts of the United Kingdom. I was quite taken aback by that.

Rona Mackay: I agree with Maurice Corry. The petitioner's comment that

"ABSENCE OF EVIDENCE IS NOT EVIDENCE OF ABSENCE"

is apt, because that approach does not lead us anywhere. More questions have to be asked about whether there is a way forward, so that the petitioner's concerns are responded to. It is a strong petition, so we need to keep it open and take it forward.

The Convener: There is also the issue that I flagged up about whether, if a cancer is rare, the process is not the same as for more common cancers. I understand why people would be gravely concerned if that was the case, although I do not think that it would be intentional. Perhaps there is simply a lack of understanding and awareness of the issue. How the health service could address that problem is an interesting question.

Rachael Hamilton: It must be quite frustrating to know that it is possible to receive MRI-style treatment south of the border but not in Scotland. It is a strong petition because of the aspect of patients not having choice and being forced to travel. That is an anxious process for people who are already unwell.

The Convener: The petition makes the point that people would rather travel if they were going to get the most appropriate and most effective treatment. The concern is expressed in the papers that a local hospital might not spot the condition because of a lack of expertise and the cancer might progress. It is horrible to start thinking about the might-have-beens in such circumstances.

Maurice Corry: My concern is that we are not gripping the fact of what is available elsewhere.

You probably remember our hearing from a gentleman who had been through the condition. I talked to him afterwards, and he absolutely reflected what I have just said.

Rona Mackay: We might want the new Cabinet Secretary for Health and Sport to give evidence on the matter.

The Convener: In the first instance, we will write to the Scottish Government, asking it to respond to the questions that Iain Galloway posed, the petitioner's comments on the detect cancer early programme and the questions about how it deals with rare cancers and the extent to which it appreciates that sufferers of the same condition in other parts of the United Kingdom expect different treatment. We could flag up that we want to hear directly from the cabinet secretary on those matters at a later stage. Do members agree to take that approach?

Members indicated agreement.

The Convener: I thank the petitioner and Iain Galloway for their substantial and helpful submissions.

Mountain Hares (Protection) (PE1664)

The Convener: The next petition, PE1664, is on greater protection for mountain hares. I welcome Mark Ruskell MSP, who is here for this discussion.

When we last considered the petition, in May, we noted that the Scottish Government intended

“to explore the prevention of mass culls of mountain hares, including legislation and a licensing scheme.”—[*Official Report, Public Petitions Committee*, 10 May 2018; c 2.]

That intention was set out by the First Minister in response to a question from Alison Johnstone MSP.

As members will recall, those actions are in addition to the independent grouse moor review group that the Scottish Government set up to look at the environmental impact of grouse moor management practices, including mountain hare culls. The group is expected to report in the spring of 2019.

The petitioner states that he is encouraged by the action that has been taken by the Scottish Government to

“explore options to prevent the mass culls of mountain hares”

but highlights that urgent action is required to protect the mountain hare population.

Do members have any comments or suggestions for action? Perhaps it would be useful if Mark Ruskell said a few words.

Mark Ruskell (Mid Scotland and Fife) (Green): I have a couple of comments to make.

Other petitions have related to concerns about the management measures that are employed on driven grouse moors, including PE1615, by Logan Steele, on raptor prosecution and the need for a licensing regime. The Environment, Climate Change and Land Reform Committee, on receipt of that petition, has been carrying out some good scrutiny of that issue, which is one aspect of the concerns that petitioners have about driven grouse shooting. The Werrity review, which is looking at licensing, has come out of the committee's scrutiny work on the issue and follows its discussions with the cabinet secretary.

It is logical for PE1664 to be forwarded to the Environment, Climate Change and Land Reform Committee on the same basis, because it looks at a particular management measure that driven grouse moor estates are using that is controversial and about which there is a lot of debate. It would seem sensible for the petition to be considered in the context of the wider discussion and for the committee to feed in on the issues.

The petitioner talks about the start of the open season, on 1 August, and the more immediate issues about what will happen this year while the review is under way and there may not be the constraint on the culling of mountain hares that they want to see. Again, that is an issue that the Environment, Climate Change and Land Reform Committee may be able to consider as part of our wider evidence taking on biodiversity and the scrutiny of Scottish Natural Heritage.

Those are my thoughts. Angus MacDonald, who is on this committee, also sits on the ECCLR Committee and may have his own thoughts on the matter.

Angus MacDonald: I concur with Mark Ruskell. There is a strong argument to refer the petition to the ECCLR Committee, given that the Public Petitions Committee would simply be waiting for the Scottish Government's reassessment of the data on large-scale mountain hare culling, which is not yet available. It makes sense to refer the petition in order to tie it in with the ECCLR Committee's other work.

The Convener: We would expect that committee to respond once the Scottish Government's reassessment of the data on large-scale mountain hare culling was available. If we were to refer the petition, we would highlight that as an important aspect.

Angus MacDonald: Indeed.

Rachael Hamilton: Why was a petition lodged? Why did the petitioner not wait for the review if they thought that we would refer it straight to the ECCLR Committee?

The Convener: The petitioner would not have known what we would do with the petition.

Data is one element of the petition and, if we were to hold on to the petition, that is what we would be looking at. However, the argument has been strongly made that the petition should be considered in the context of the broader issues of the subject committee, and that approach makes sense. Once we got the information, we might simply refer it on in any case.

Do we agree to refer the petition to the committee with the long title that I can never remember? Tell us what it is, Angus.

Angus MacDonald: It is the Environment, Climate Change and Land Reform Committee.

The Convener: Do we agree to take that approach?

Members indicated agreement.

Multiple Births (Support for Families) (PE1683)

11:00

The Convener: The next petition is PE1683, by Jennifer Edmonstone, on support for families with multiple births. At our first consideration of the petition, we agreed to write to a range of stakeholders. Members have a paper that summarises the responses that have been received to date. The Scottish Government has set out a range of policies and initiatives that it is taking forward, which appear to be broadly welcomed by the petitioner and other stakeholders, including the Twins and Multiple Births Association—TAMBA—the Multiple Births Foundation and Home-Start. However, the stakeholders seek clarity in some areas, particularly in relation to childcare and peer support, and consider that there is room for improvement in the level of emotional support and understanding among healthcare professionals. Do members have any comments or suggestions for action?

Rachael Hamilton: The evidence mentions that the Scottish Government has the power to top up child benefit. There is also a suggestion that the Irish model of child benefit for twins, triplets and higher-order multiple births is fairer. If we write to Maree Todd, I wonder whether we could ask her to consider that in her response.

The Convener: There is an argument that that element would be for the social security secretary, who is now—I have forgotten her name.

Rona Mackay: It is Shirley-Anne Somerville.

The Convener: Yes. There is a question about that, which I am interested in exploring. I was struck by the quality of the substantial evidence from Home-Start, TAMBA and the petitioner. There is a financial issue, but there is also an issue about support. Couples do not plan to have two children, and there could be an impact on their working life, perhaps if they were going to support their family by both working. That has an effect. There is also a question about support with the emotional impact.

I am interested to know how the Scottish Government sees its role in supporting some of the third sector organisations. People are referred to those organisations, but they do not necessarily have resources directed to them to allow them to do their job really well. I am sure that all of us will know, from our local areas, about the fantastic work that Home-Start does with families who are really under pressure. I am interested in the Scottish Government's views on the issue of benefits such as child benefit, but I also want to know its view on the emotional and personal support that families require.

Rona Mackay: We should write to the Minister for Children and Young People, putting those points to her, and then take the petition on from there. We should keep it going.

Rachael Hamilton: We should write separately to Shirley-Anne Somerville regarding the funding issues.

The Convener: The petitioner's point about the baby box is interesting. People will have their own views about the baby box, but the idea that the reusable stuff should be removed from it for subsequent children is interesting. I do not know whether the Scottish Government is reviewing the baby box system, although I am sure that it will do that at some point. We should ask whether it has thought through the implications for people who have more than one child at a time and whether it will amend the provision of the reusable stuff in the baby box. That is an interesting and quirky idea that the Scottish Government might want to consider.

Angus MacDonald: Given that we have the circular economy bill coming up at some point, that is well worth looking at.

The Convener: Absolutely.

We recognise that there are substantial issues. They are the kind of issues that people probably have not thought about unless they have been caught up in the situation. We appreciate the response from the petitioner and from all the others who have given us such thoughtful evidence. In the first instance, we will write to the Minister for Children and Young People on the specific issue around personal and emotional

support and we will perhaps get an update from the new Cabinet Secretary for Social Security and Older People on what the Government is considering in relation to support for families.

Maurice Corry: As a father of twins the first time round, I understand the issues. It certainly was a shock. We had to make some decisions about who was going to go out to work. I have a lot of empathy with the petition.

The Convener: Thanks very much for that.

Private Water Supplies (PE1680)

The Convener: The final petition for consideration is PE1680, by Angela Flanagan, on private water supplies in Scotland.

As members will recall, at our previous consideration of the petition, in March, we agreed to seek the Scottish Government's views on the action that is called for in the petition. The Scottish Government's written submission explains that the Private Water Supplies (Scotland) Regulations 2006 were reviewed and updated as recently as last year. The Government also states that regulatory powers over the drinking water quality of private water supplies should remain with local authorities and that it does not support the petitioner's call for an equal right of appeal in the planning process.

In her written submission, the petitioner expresses her dissatisfaction with the Scottish Government's position on the action that is called for in her petition.

Do members have any comments or suggestions for action?

Maurice Corry: We should close the petition. I was in Ayrshire the other day, with NFU Scotland, and we had a water expert from one of the Ayrshire councils present. It was clear that the councils have a really good grip on the matter and are now implementing the updated regulations. Although that is causing some concerns for farmers in relation to their own springs, the general feeling was that there is a clear direction of travel with the local authorities implementing the regulations, so that approach clearly has some traction.

Rona Mackay: Given the fact that the regulations were reviewed and new ones introduced last year and the fact that the Government has made it clear that it will not go beyond that, we should close the petition.

Angus MacDonald: It is clear that the Government is digging its heels in when it comes to a third-party right of appeal. There does not seem to be any appetite in the Government to introduce such a right into the Planning (Scotland)

Bill, but we will have to wait and see. That is one aspect of the petition that is unlikely to move forward.

The Convener: I have no doubt that a community right of appeal, as I think it is being called, will be debated during scrutiny of the bill, and the petitioner might be able to influence that. The Scottish Government's position is clear, but how the parliamentary arithmetic works out is another question. That is where that matter would be resolved.

I can see the argument for centralising the regulation of private water supplies, but it would probably mean that the people who were responsible would be less aware of the localised nature of some of the issues, which are very different in different parts of Scotland. It is one thing to monitor closely what local authorities do and how well they understand some of the challenges that the petitioner has identified, but it does not feel to me that the solution would be to take that regulation to the centre, because the geography of Scotland is so diverse.

Rachael Hamilton: I agree. The drinking water quality regulator for Scotland has been delivering training to local government environmental health officers to ensure that they are up to date on the rules and regulations. The key point is that all local authorities are up to date with their training and know what they are doing. They have a good handle on the situation. As you say, convener, if the system was changed, perhaps the people responsible would not have a handle on the local issues.

Maurice Corry: That was demonstrated in the Ayrshire hills. We were standing at a spring and the head of water engineering from the council explained what happens. I was impressed with him. He was absolutely on the ball. The council has done it for years.

There will be local issues. One of the problems that came up in Ayrshire concerned a farmer fertilising a field and the fact that the water catchment area might change from year to year. That involves local knowledge, so one size does not fit all. There is strength in the system that we have.

The Convener: There might be an issue about the capacity of local authorities to continue. Perhaps we need to underline to local authorities the fact that the issue is really important so that, when they manage their budgets—we know that there are massive pressures on them—they realise that it matters to the health of local communities.

Angus MacDonald: I have a clarification to make for the benefit of the *Official Report*. I should have referred to the equal right of appeal rather

than to the third-party right of appeal. That issue goes back too many years.

The Convener: Absolutely. As I was the planning minister at the time, I recall that issue very well.

I think that we agree that we will close the petition under rule 15.7 of the standing orders on the basis that there is no support from the Scottish Government for the action that the petition calls for. On balance, we feel that the important regulation and the protection of people's water are probably best done at a local level.

Members *indicated agreement.*

The Convener: I thank the petitioner very much for engaging with the committee and highlighting issues of concern to her community.

I wish everybody a very good and enjoyable recess, and I thank you all very much for your support in the committee's work over the past year. We can be proud of a lot of what we have achieved. If nothing else, we have allowed people across our communities to raise issues that really matter to them and that we might not have thought of otherwise. I thank everybody who has engaged with the petitions process, our clerks and members.

Meeting closed at 11:11.

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