



**OFFICIAL REPORT**  
AITHISG OIFIGEIL

# Public Petitions Committee

**Thursday 2 February 2017**

**Session 5**



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Pàrlamaid na h-Alba

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**PUBLIC PETITIONS COMMITTEE**  
**2<sup>nd</sup> Meeting 2017, Session 5**

**CONVENER**

\*Johann Lamont (Glasgow) (Lab)

**DEPUTY CONVENER**

\*Angus MacDonald (Falkirk East) (SNP)

**COMMITTEE MEMBERS**

\*Maurice Corry (West Scotland) (Con)

\*Rona Mackay (Strathkelvin and Bearsden) (SNP)

\*Brian Whittle (South Scotland) (Con)

\*attended

**THE FOLLOWING ALSO PARTICIPATED:**

Max Barr (Struan Lodge Development Group)

Iain Galloway (OcuMel UK)

Jennifer Lewis

Kenneth Mathieson (Dunoon Community Council)

Michael Russell (Argyll and Bute) (SNP)

**CLERK TO THE COMMITTEE**

Catherine Fergusson

**LOCATION**

The James Clerk Maxwell Room (CR4)



# Scottish Parliament

## Public Petitions Committee

Thursday 2 February 2017

[The Convener opened the meeting at 09:00]

### Continued Petitions

#### Criminal Injuries Compensation Scheme (PE1612)

**The Convener (Johann Lamont):** I welcome everyone to the second meeting in 2017 of the Public Petitions Committee and remind members and others in the room to switch their phones and other devices to silent.

Agenda item 1 is consideration of continued petitions. The first petition for consideration is PE1612, by Graham McKinlay, on a change to the criminal injuries compensation scheme's same-roof rule. Members will recall that we heard evidence from the petitioner at our meeting on 10 November last year. As a result of that evidence session, we were keen to get more information on why an apparently arbitrary date was set for the application of the rule. The meeting papers include a note by the clerk and written submissions that seek to explain the rationale behind the date.

The submission from the Criminal Injuries Compensation Authority provides relatively in-depth background information and says that there have recently been legal challenges to the same-roof rule provisions.

Victim Support Scotland's submission acknowledges that

"changing the rule was the right decision"

at the time, but it provides an example of the problems that the arbitrary nature of the date can create, and it argues that the creation of a new scheme could provide "clarity, consistency and fairness".

The Scottish Government's submission indicates that it has

"no plans at this time to consider seeking a change to"

the current scheme or

"to establish a separate compensation scheme".

The petitioner's response to those submissions is set out in full in the note by the clerk.

I ask members for their suggestions on what action we should take on the petition.

**Brian Whittle (South Scotland) (Con):** On the face of it, there seems to be a level of

discrimination. We could write to the Cabinet Secretary for Justice. Really well-laid-out points have been made, and maybe we should send them to him for his consideration.

**The Convener:** Obviously, the decision was made a long time ago, but Victim Support Scotland's evidence says that people have different experiences depending on where and when the abuse took place, even though the abuse may be exactly the same. I find that evidence very powerful. Although the Scottish Government has said that it has

"no plans at this time"

to change the scheme, I wonder whether we might ask it to reflect on Victim Support Scotland's comments and maybe look at the issue further.

**Rona Mackay (Strathkelvin and Bearsden) (SNP):** I agree. Seeking clarification on where the Scottish Government is on the issue is the route to go down at this stage.

**Maurice Corry (West Scotland) (Con):** I agree.

**The Convener:** The petitioner has made the point that somebody needs to sort the issue. The only people who can sort it now are in the Scottish Government. I suppose that there are issues for the Scottish Government. It seems that, in the past, the concern was about no one even being able to assess the potential cost of having retrospective legislation as opposed to prospective legislation. That might still be the case, but it would be worth having a conversation about that with the Scottish Government.

We will write to the Cabinet Secretary for Justice and invite him to respond to the points that Victim Support Scotland has made in order to find out more information about why the Scottish Government has "no plans" to consider establishing a separate compensation scheme. Perhaps in reflecting on Victim Support Scotland's evidence, the Scottish Government can consider whether that evidence gives it the potential to consider the issue further.

**Members indicated agreement.**

#### Parking (Legislation) (PE1616)

**The Convener:** The next petition for consideration is PE1616, by John Shaw, on parking legislation. Members will recall that the petition seeks to make it an offence to park in front of a dropped kerb. The meeting papers include a note by the clerk and a copy of the written submissions that have been received.

The issue of responsible parking was raised in a member's bill by Sandra White MSP in the previous session of Parliament. That bill fell, partly due to concerns about legislative competence.

Further powers have now been devolved, and members will see from the submissions that have been received that the Scottish Government will shortly consult on responsible parking with a view to legislating on the issue. The Scottish Government has advised that the consultation process is due to be completed by the end of March this year. It has also explained in its submission that it has established a responsible parking stakeholder working group to inform the development of the consultation.

Do members have comments or suggestions for action?

**Maurice Corry:** I think that we should just wait until we get the results of the Government's consultation in March. It would not be fair to push the issue any further until we know the results of that consultation.

**Brian Whittle:** I do not think that we should close the petition. The right course of action would be to defer it.

**Rona Mackay:** On balance, we should defer it. To be honest, I was quite torn on this one, because of the consultation and the likelihood that legislation will be brought forward. The petitioner could always come back with another petition. However, on balance, I think that it would not do any harm to defer the petition until the consultation closes.

**The Convener:** It is fair to say that we welcome the fact that the Scottish Government is consulting, and we should probably recognise some of the challenges.

**Rona Mackay:** The issue is out there, and it is being investigated.

**The Convener:** We can understand absolutely the issues that the petitioner has raised, but sometimes I go about the communities in which I live and work and I think about what the consequences of the proposal would be. It would be a challenge, and it will be interesting to see what the consultation process brings back. However, there is certainly no doubt that irresponsible parking has a massive impact on particular groups. I do not know whether I need to say this to the petitioner, but I assume that he will engage in the consultation process. Perhaps people more generally will also be interested in responding to it.

Do members agree to defer consideration of the petition until the consultation is complete?

**Members indicated agreement.**

### Health Study (Vaccination) (PE1617)

**The Convener:** Petition PE1617, by Angus Files, calls for a health study of vaccinated

compared with non-vaccinated people. The Scottish Government's response to our request for its views on the petition provides some telling statistics and makes it clear that the Government has no plans to carry out such a study. In the petitioner's submission, he contends that he is calling for a retrospective study using existing data.

Do members have comments on how we should proceed?

**Brian Whittle:** I am kind of torn on this one. I find the suggestion that there is an inability to collect data on the issue quite strange.

**The Convener:** Is that not because, in order to have data, we would have to have people who have not been vaccinated and who do not know that they have not been vaccinated? My presumption is that vaccination has saved lives and eradicated diseases, and it can only be done en masse.

**Brian Whittle:** Data could be collected on the occurrence of diseases over a period of time. That kind of data must be available. Having said that, I am not sure what the data would tell us.

**Rona Mackay:** Personally, I am not sure what could be achieved by such a study. The vaccination programme is important. I do not think that what the petitioner is asking for is feasible and I cannot quite see the point of it.

**Angus MacDonald (Falkirk East) (SNP):** The Scottish Government is adamant and is not prepared to move on the issue, so I do not see where we can go. If the Scottish Government is digging in its heels, with some valid and salient points, we have no option but to close the petition on the basis that the Government has confirmed that it has no plans to commission a study as proposed by the petitioner.

**The Convener:** It does not feel to me that there is pressure on the Scottish Government on the issue from the medical profession or more broadly. I presume that an issue is being raised about whether vaccination works. My view is that there is evidence that vaccination works but, in most cases, it works only if everybody in the general population is vaccinated.

**Maurice Corry:** We should close the petition on the grounds that Angus MacDonald has set out and because the proof is there already.

**Brian Whittle:** On the basis that I am not sure that the data would actually tell us anything, I am with you on that. It is interesting, though.

**The Convener:** It is.

Do members agree to close the petition on the basis that the Scottish Government has confirmed that it has no plans to commission a study as

proposed by the petitioner and that it has provided evidence to support that position?

**Members** *indicated agreement.*

### **Motorcycle Theft (PE1618)**

**The Convener:** PE1618, by Carl Grundy, on behalf of riders club Edinburgh, calls for the police to be given more powers to combat motorcycle theft. The committee has received submissions from the Scottish Government and Police Scotland.

The Minister for Community Safety and Legal Affairs notes that, in her view, Police Scotland has sufficient powers to tackle the issue. She explains that the Scottish Government takes a tailored approach to young people's individual needs, that it focuses on early intervention and diversion where possible, that issues about sentencing are a matter for the court and that driving offences are reserved to Westminster.

Police Scotland notes that it has launched Operation Soteria to address the issue. It has conducted youth engagement activities as part of the work, which has revealed that the crime is driven by thrill-seeking behaviour and peer pressure. Police activity has therefore focused attention on diverting young people from the crime through engagement and outreach. In its view, a multi-agency approach is required to tackle the crime.

Members will be aware that a number of us met the petitioner informally to discuss the terms of his petition, and a summary of that meeting is provided in the clerk's note. The petitioner raised a number of concerns about community safety, insurance and the impact on motorcycle tourism.

Do members have comments or suggestions for action?

**Brian Whittle:** After we met the petitioner, I had an informal chat with Edinburgh MSPs to ask whether they recognised the issue and, if so, what they thought about it. It seems that this is an issue and that the police are starting to tackle it.

The work on early intervention is interesting, but how can we better understand how it is working? Would it be worth while to speak to the police or an organisation such as YouthLink Scotland to understand whether the work is effective?

**Rona Mackay:** It is clear from Police Scotland's letter of last November that it has taken the issue on board and that many initiatives have been put in place to try to combat motorcycle theft. What it is trying to do is fairly comprehensive. The multi-agency route is certainly the one to go down, and we should write to YouthLink Scotland and find out what it can suggest. I cannot think of any way in

which the police could be more proactive, but I acknowledge that motorcycle theft is still a huge problem. It is a difficult one.

**The Convener:** The frustration in the petitioner's comments lifts off the page. It is not as though he does not want to engage with young people or does not understand the behaviour. We should write to the police and to YouthLink Scotland to ask for their views and an assessment of the effectiveness of the action that is being undertaken. The petitioner seems to be saying that a lot of things have already been tried. Part of the frustration is that the continuation of bike theft impacts on people's ability to enjoy motorcycles and that the cost to them is massive.

**Maurice Corry:** It would also be worth while to write to VisitScotland to seek its views. We see the trend increase over the summer months, so there will be an impact on tourism as well.

**The Convener:** We agree that we should write to YouthLink Scotland and VisitScotland, and we are interested in knowing how the interventions are working. It is one thing to say that there is a multi-agency approach—I cannot remember how the minister described it; it was an unusual phrase—but it felt to me as if the petitioner had heard it all before. We need to know that the agencies are taking the points seriously and being proactive.

**Rona Mackay:** I assume that Police Scotland monitors the level of motorcycle theft. We need to know whether it is increasing or decreasing. Maybe it has passed its peak and the trend will go away. That would be the optimistic view.

**The Convener:** We will ask Police Scotland about that, too. We recognise the strength of feeling in the petition and the concerns that people have, and our view is that action on the issue must be sustained if the petitioner's concerns are to be addressed. Do members agree that we should progress the petition in the way that I outlined?

**Members** *indicated agreement.*

### **Sepsis Awareness, Diagnosis and Treatment (PE1621)**

09:15

**The Convener:** The next petition is PE1621, by James Robertson, on sepsis awareness, diagnosis and treatment. The clerk's note provides an overview of the submissions received, with comments from the Scottish Government, Healthcare Improvement Scotland and national health service boards referring to the Scottish patient safety programme and the prioritisation of sepsis as a workstream within that programme.

A number of submissions refer to the sepsis six and the national early warning score system, and health boards indicate support for the action called for in the petition while noting that there has been a demonstrable increase among healthcare professionals of the awareness of sepsis.

The petitioner, however, notes the comments of some boards in relation to any “unintended consequences” of a public awareness campaign and would like a co-ordinated approach to raising public awareness to be developed across the country.

The UK Sepsis Trust and the Fiona Elizabeth Agnew Trust provide illustrations of the work that they have undertaken to raise awareness among health professionals and the public.

It is worth commenting on the number of submissions that we have received. We appreciate so many people and boards taking the time to respond. Do members have any comments or suggestions for action?

**Rona Mackay:** At the outset, I declare an interest, as the petitioner is a constituent of mine. He asked me to mention that his submission does not comment on the Fiona Elizabeth Agnew Trust’s submission, because at that point he had not seen it.

I support the petition and I suggest that we write to the Scottish Government to see whether it has plans to start a public awareness campaign across Scotland. Some boards have said that awareness has been raised and that they are doing what they can, but it is a big issue and there needs to be an initiative to ensure that we take the issue on board and roll out a campaign.

**Angus MacDonald:** I am struck by the fact that, in relation to raising awareness among the public, Dumfries and Galloway NHS Board, Forth Valley NHS Board and the Western Isles NHS Board have raised concerns about potential unintended consequences and suggest that it might cause alarm and generate an increase in worried patients attending their general practitioner or an accident and emergency department. It would be good to get the Scottish Government’s stance on that if we write to it. Clearly, a balance has to be struck.

**Maurice Corry:** It is important to get the Scottish Government’s view and to establish where it is on this. As Angus MacDonald says, there are different situations through the counties, so it is important that we establish a baseline.

**The Convener:** I would be a bit concerned if the reason for not having a public awareness scheme was that people might become aware. Issues about the worried well or people who are prone to be concerned about conditions must be more than

balanced out by the benefits of raising professional awareness and making people aware of how they can keep themselves well.

Do we agree that we will write to the Scottish Government to ask about its plans for a public awareness campaign and ask it to address the point that Angus MacDonald raises about what judgments it makes about unintended consequences?

**Members indicated agreement.**

**Rona Mackay:** That point was made by a minority of boards, but it is still worth asking the question.

### **Local Authority Education Committees (Church Appointees) (PE1623)**

**The Convener:** The final continued petition for consideration this morning is PE1623, by Spencer Fildes, on behalf of the Scottish Secular Society, relating to unelected church appointees on local authority education committees. The meeting papers include a note by the clerk and copies of the submissions received since our previous consideration of the petition in November.

The Scottish Government indicates that it has no plans to change the provisions, but refers to its education governance review, which has recently closed, and which sought views on the legislative framework that should be put in place to support education in Scotland.

The Convention of Scottish Local Authorities regarded that review as an opportunity for community representatives to participate actively in the consideration of education services. It also noted that, with regard to the action called for in the petition, its members did not feel that non-elected representatives carried undue influence.

Submissions from Muslim and Jewish representatives did not directly support the action called for in the petition but considered that there might be options to more widely reflect diversity in communities.

The Scottish Parent Teacher Council suggests that education committees could

“reflect the population of our schools more effectively”.

The Equality and Human Rights Commission referred to its submission on the previous petition on this issue, PE1498, in which it comments on the requirements of the public sector equality duty. That was echoed by representatives of the Jewish community, and the petitioners, who note that, to date,

“none of these issues have been addressed”.

The petitioners maintain their position that the system is unfair and discriminatory, particularly in



the light of changing demographics. Do members have any comments or suggestions for action?

**Maurice Corry:** We need to ask the Scottish Government, having carried out the education governance review, to assess the position of unelected church appointees in view of the public sector equality duty. We should refer to the issue of faith community appointees, too.

**The Convener:** Okay. We need to find out when the Scottish Government will publish the findings of the education governance review. It is clear that the Government does not plan to address this issue—I do not think that there would have been a specific question about it in the review consultation. It is perhaps an issue that people would have to have raised. We can ask the Government about that. It may be worth checking whether the Government has reflected on the position of unelected church appointees in view of the public sector equality duty.

**Rona Mackay:** We just need more information about what was in the review.

**Angus MacDonald:** I think that the closing date for submissions to the education governance review was 6 January. I was interested to see the submission from my local authority. It may be some time before the Government gets round to replying, given that the closing date has just passed.

**The Convener:** We would just be looking for the timescale at this stage. We do not propose to close the petition until we have asked the Scottish Government specifically whether it has fulfilled its responsibilities with respect to the public sector equality duty. It is clear that there are strong feelings on both sides of the argument—what is interesting is whether there is a middle ground somewhere. We would want to know about the governance review and anything that comes out of it. On the point raised by the EHRC, I assume that the Scottish Government's response to any of these questions will be assessed in light of its obligation under the public sector equality duty.

If there are no other suggestions, is it agreed that we follow that course of action?

**Members indicated agreement.**

09:23

*Meeting suspended.*

09:24

*On resuming—*

## New Petitions

### Service Delivery for the Elderly or Vulnerable (Consultation) (PE1628)

**The Convener:** The first new petition today is PE1628, on consultation on service delivery change for the elderly or vulnerable.

I welcome Michael Russell MSP, who is in attendance because of his interest in this petition.

The petition is by R Maxwell Barr, on behalf of Struan Lodge development group and Dunoon community council. Mr Barr joins us this morning and is accompanied by Kenneth Mathieson, the convener of the Dunoon community council. I thank Mr Barr and Mr Mathieson for attending this morning and invite them to give a five-minute opening statement, after which I will invite members to ask questions.

**Max Barr (Struan Lodge Development Group):** We are grateful for this opportunity to speak to you. I am sure that you have all managed to read the petition, so I will not go over what it says but will simply move on to the key points that arise from it.

As you know, the petition concerns the guidance for changes to health and social care service delivery. The guidance on informing, engaging and consulting people in developing health and community care services is in chief executive letter 4, which was issued in 2010. The guidance therefore relates to the period before the integration of health and social care and the existence of integration joint boards, which means that it refers only to NHS boards. It therefore allows integration joint boards and health and social care corporate bodies to dispute the legitimacy of the guidance. The spirit of the arrangement is that the guidance's legitimacy should be accepted, but the fact is that the arrangement gives those bodies the chance to object to it.

I want to point out one or two things in the guidance. Clause 8 of the guidance refers to bodies that no longer exist in local areas—they certainly do not exist in Argyll and Bute. I think that the names have been changed and new bodies have been created. Again, that leaves scope for people to be missed out.

Clause 14 in the guidance states that the Scottish health council does not comment on clinical or financial issues. Therefore, if a board decides to treat a change to service delivery as a clinical or financial matter, it can exclude the SHC

from comment. In the case of Argyll and Bute, a financial plan was created last June that dealt with the eviction of 12 people from a care home within six months. There seemed to be no need to involve the SHC in that decision, despite the fact that, under any circumstances, kicking 12 people out of their home surely constitutes a major change.

Equally, if a board prepares a plan that has 68 individual actions in it to save a total of £8.5 million, it seems that, because each individual action is a minor change, the sum of all the parts is also viewed as minor. However, I think that a saving of £8.5 million should be viewed as the result of a major change, and major changes need to be considered by the SHC, so the boards know how to go about their consultation processes and their engagement and communication work. In our case, we are eight months beyond the point at which a decision was made, and the SHC has not made a decision. It seems to me that there should be some way of dealing with these matters.

I have made two very specific points, but they indicate the difficulty that the SHC has in balancing its co-operation function and its monitoring function in relation to the work of the boards. These examples show that the guidance needs much more clarity in respect of that relationship. That would be particularly helpful in a situation in which the board does not consider a change to be major but the community stakeholders do. If the kind of change is not identified beforehand, things move on and there is a process of engagement, but it is then too late for the change to become a major change. Whether something is a minor or a major change needs to be resolved prior to any decisions being made by boards.

I will say a little bit about how the boards should communicate and engage with communities. The guidance allows boards to develop their own processes. That is fine, but it would be helpful if the guidance compelled boards to publish details of their communication and engagement process. In some cases, there will be bodies such as ours, which are not normally involved in the engagement process but have an interest in specific issues. If process information was included, we could apply for inclusion, rather than being excluded from the start.

Finally, I make the point that boards that behave in a proper manner do not really need guidance, because openness and transparency happen quite normally. However, in the case of boards such as the Argyll and Bute IJB, which failed in that regard last June, guidance is required, and that guidance must be clear and definitive in order to ensure compliance.

We are concerned not only about Argyll and Bute. This is a new set-up for the integration of health and social care, and there will be other integration joint boards throughout Scotland that will run into the same problems.

09:30

**The Convener:** Thank you very much for that. Reflecting on what you said and on your petition, we are interested in the general lessons that come from a specific experience and we are keen to explore that with you. You are dealing with local authority forms of accountability and engagement, as well as those of the health board. Is that part of the issue? I would have thought that some of the organisations that might get involved at local government level on the health side would not necessarily be consulted. Do we need to do something about that?

**Max Barr:** That is an interesting point. There was a council move to close Struan Lodge three years ago, but the community disputed that and it was kept open.

This time, now that there is an integration joint board, it has been kept open largely because of the political dimension and our ability to go to our elected representatives and to get them to do something. In this case, we were not consulted before it happened. The board made a decision in June after being given a number of opportunities to change their decision at prior board meetings, and we had to get our MSP and our local councillors to intervene. There has been an intervention and there is a pause in the process. There is some community engagement, which is working reasonably well, but there is still an argument about whether it is a major or a minor change.

**The Convener:** Is it your point that, if it is defined as a minor change, it is too late to change it by then? That is a broader question that we are wrestling with across Scotland.

**Max Barr:** Absolutely. We have a situation in which we are being consulted about something that has already been decided. We had a public meeting about it and people came along and said, "What is the point in talking to us? You have decided what you want to do." The situation does not help to get the public on side. We are talking about a funding issue and everybody understands and recognises that money is short and that there are not hundreds of thousands of pounds that we can draw on. It is therefore important that communities are involved and get together to find ways forward that will work for them.

**Rona Mackay:** Good morning, Mr Barr and Mr Mathieson. Mr Barr, I want to return to the guidance, which you talked about in your opening

statement. Could you expand on that a wee bit and give us the key points that you would like to be included in any guidelines?

**Max Barr:** Sure. The first one is that the guidance extends to integration joint boards.

Next, clarity about what is a major or a minor change is absolutely fundamental.

Any communication with local communities has to be before the decision is made—that is key to the whole thing, as there is no point in doing it afterwards.

Further, they must ensure that they communicate with the right bodies, because there can be a plethora of local groups, and it must be very difficult for the board and the health and social care partnership to know exactly who they should go to.

That leads to another point about compelling them to publish their communication processes in advance, so that groups with an interest can apply to be involved.

**Rona Mackay:** You are saying that we need better signposting.

**Maurice Corry:** I declare an interest as a councillor on Argyll and Bute Council. I was also chairman of the Argyll and Bute integration joint board in June 2016, so I am fully aware of what Mr Barr is talking about and the angle from which he is coming. Regarding what we can do to learn lessons and to do things better, I would like to keep it at a generic level.

I welcome the six-month moratorium that is in place at the moment to try to get the issue resolved and have greater engagement with the local community.

Your petition mentions that decisions about service delivery can be particularly distressing to service users. I will concentrate on that part. What could be done in the consultation process to minimise the stress that is caused to elderly or vulnerable service users while ensuring that their views are heard? That relates back to my earlier comment.

**Max Barr:** That is easier to answer from a Struan Lodge point of view and more difficult to answer from a general point of view. The Struan Lodge development group had a strategy document, and we could have been properly consulted on that strategy document and what it was about. We could have been engaged in talking to the relatives of the residents of Struan Lodge.

With all other care homes around the country, the key is to engage with the relatives early on in the process. We have to take on board that, when we are dealing with vulnerable adults who are well

into their 90s, a care home cannot be shut in six months. If there is a financial problem, we have to work round that, because it takes far longer than that to deal with those issues. If a 90-year-old is thrown out of a care home within six months, they will not fit into a new home. A resident came from Bute to Struan Lodge, and they were lost for a while—they wandered round the care home lost and did not know what to do.

It is important that the residents are consulted and dealt with early on.

**Maurice Corry:** As our briefing paper points out, I asked the Cabinet Secretary for Health and Sport about this, although the Minister for Public Health and Sport responded. It is clear that the statutory responsibility for delivering or commissioning services at local level is left to the NHS board and the joint board. However, I welcome what you say. We have to be big enough to say that this is a generic issue, and we need to look at whether there are similar issues anywhere else in Scotland. I thank you for bringing the issue to our attention. It is very difficult to do. Certainly, it is important that there is engagement with the families.

**Brian Whittle:** Good morning, Mr Barr and Mr Mathieson. Your petition focuses specifically on the elderly and vulnerable. Have you considered that other groups in society might be particularly affected by how a consultation process is conducted?

**Max Barr:** Our interest has been because of Struan Lodge, so we have concentrated on that. In our strategy document, we tried to look at other aspects. Mental health is another issue on which proper guidance is needed. Again, that is about dealing with vulnerable people. Basically, it is about dealing with vulnerable people at any level—it does not matter what age they are.

**Angus MacDonald:** Good morning, gentlemen. It is clear from your experience that local authority budgets have an impact on the delivery of services and influence decisions on service change. Is there a requirement for greater awareness of and public involvement and engagement in the budget setting process? Would that help?

**Max Barr:** That could be done by consulting and talking to people and having more public meetings. Those of us who are involved are certainly aware. Basically, we are looking at what we can provide to help the IJB. We hope to publish a document by the end of this month. We are trying to raise money and to find ways of being commercial, if you like. Neither the NHS nor the council tend to think about that but, if there is no money—we cannot expect Governments just to hand out money if there is no money—communities in local areas have to look at these

things and see what they can do to help. That is where we are coming from. There is a growing understanding that there is not enough money, and everyone is suffering. Priorities are also a big issue.

**Kenneth Mathieson (Dunoon Community Council):** Along with Max Barr, I am a member of the Struan Lodge development group, and I have been a staff member at Struan Lodge for 10 years. The way that we have been treated has been shambolic. On 29 June last year, the IJB decided to close Struan Lodge's 24/7 care. That decision was leaked and people were running around madly trying to get staff together in a meeting. Letters that were not really applicable were sent to residents and their families. We were told that we were shutting in six months and that was it. In effect, we were told "The decision's made and it's final, and we're answerable to nobody."

That happened three years ago, and we still have some residents from that time. It was very hard on them and the staff members to be treated in that way. The IJB has failed miserably in its consultation. I am in the communications engagement group, but the IJB went down the route of the conversation cafe. A motion was put forward to Dunoon community council to say that that was not the route to take. We knew that, although the outlying districts are very important, there are only about 3,000 people there, whereas there are 12,000 people in our area. However, I had to fight to get more meetings in our area, which was eventually agreed to.

The last time that the IJB tried to shut us, there were 47 or 48 spare beds, but now there are no spare beds. We asked where they would put our residents and the reply was, "All over Scotland", with suggestions for residents like, "Why don't you move to a care home beside your daughter?" The situation is unbelievable, and something needs to be done because if that situation is not a major change, I do not know what is.

The proposed major change should have been dealt with first, but things were done the wrong way round. The IJB is like an inverted pyramid in that it is top-heavy, which means that it will collapse at the bottom. The officers who I have met do not give us information freely. We have had to go to Mr Russell MSP and local councillors to get information, but even they struggle to get information from the officers. It is not acceptable for us to be treated in that way by anybody, and there needs to be some accountability.

What they are doing now amounts to a box-ticking exercise. I asked them what would happen at the end of it and they said, "Nothing. Struan Lodge is shutting." How is that an example of informing and engaging? If we mention the word "consultation" to them, they choke: "That's not

consultation. It's informing and engaging." However, they have nothing to inform us about because they do not know what they are doing.

**The Convener:** Thank you very much for that. To be clear, we are not investigating what has happened in a specific case.

**Kenneth Mathieson:** I realise that.

**The Convener:** If we were doing that, there would presumably be people who had a different point of view. However, it is important to try to understand what the process was.

**Kenneth Mathieson:** I was giving the background.

**The Convener:** I appreciate that. You clearly have very strong feelings about the issue and you are within your rights to express them. However, I just want it recognised that we are trying to draw general conclusions. I invite Michael Russell to come in at this point.

**Michael Russell (Argyll and Bute) (SNP):** Maurice Corry was right to say that it is about the general conclusions that we can draw from the particular case, but Kenneth Mathieson has indicated how strong the feelings are about that particular case. In fact, if we learn something from the particular case of the IJB in Argyll and Bute, I hope that it will lead to what Max Barr indicated, which is an improvement in guidelines and a new set of guidelines. It is the poor performers who require guidance; those who do things properly do not need guidance. The IJB in Argyll and Bute has been an exceptionally poor performer.

There are a number of proposed major changes in Argyll and Bute, including those for Struan Lodge care home and Auchinlee care home in Campbeltown, and other issues. In all those cases, the quality of the consultation has been exceptionally poor. Decisions have been made without consultation and everything has been done to avoid public scrutiny. It is important to note that in some communities, such as Dunoon, there are active groups but that they have just not been listened to. I pay particular tribute to Max Barr, who has done a power of work on alternatives during the past three years—it has almost been a full-time job.

Those who cannot perform to the highest standards for consultation need to be encouraged and driven in that direction. For the Argyll and Bute IJB that means three things, which are perhaps the general lessons. The first thing is that a process must be explained before it is implemented, so that people know what is going on. The agenda on which the decision was made was crowded. It contained a great deal of information, and nobody knew that the decision had been made, including some members of the

board. There should be absolute clarity about the process.

Secondly, there should be clarity that no decisions should be made until consultation has taken place. There should not be consultation after a decision. Doing that is perverse.

09:45

Thirdly, on the nature of the consultation, Kenny Mathieson mentioned the conversation cafe idea. To be blunt—the convener knows that I am often blunt—that is gimmick-ridden nonsense. It is important that people step forward and say, “This is what the board is proposing. Let’s discuss what this means and how we could go about it.” When people are not resistant to change and a proposal has been explained to them, they will participate in making the decision, but if there is an attempt to enforce change by sleight of hand, which is what we have seen, there will undoubtedly be strong public resentment.

I hope that the particulars of these cases can inform a general set of guidelines that will drive poor performers such as the Argyll and Bute IJB into far better performance. It is early days, so there is great disappointment that it has chosen to behave in such a way.

**The Convener:** People are cynical if they go into a process when a decision has already been made. That is deeply frustrating. However, I am interested in the separate question of how we can make big general changes while individuals are, understandably, focused on an individual service. We see that in hospitals or anywhere where it has been proposed to close down something perhaps for the greater good. That is a challenge in specific cases. It would be interesting to know the Scottish Government’s view on how to manage the process of change when individuals are not too concerned about how their issue fits into the bigger picture, but are concerned about the direct impact on their own work situation or their family and those whom they care for.

Do the witnesses want to say anything more?

**Max Barr:** I take your point. The situation is very difficult. We are talking about major changes to different things, and it cannot be easy for any board to decide which things are so important that they have to consult on them.

In the past, the problem seems to have been that processes have been set up and everything has become cosy. People need to find a way of getting to the nub of the problem with the people who understand it. We submitted a strategy document, and we were not even asked about it. We were not asked what we thought should be done. We had a long-term strategy for Struan

Lodge care home that was not just about 24-hour care; it was about the use of the hospital and public assets that were not being used properly. Those things need to be addressed.

**The Convener:** There are very interesting issues, such as a proper understanding of what is a major change and what is a minor change, and the cynicism that occurs when something is defined as a minor change and does not have to be scrutinised elsewhere. The Scottish Government must be wrestling with those matters, as they are very difficult.

Do members want to consider how to take the petition forward?

**Brian Whittle:** We recognise that there is significant strain on the care home sector and that closing any such facility is highly emotive. The convener has already alluded to that. I imagine that it is very difficult for any IJB to speak to such an issue.

On Mr Russell’s point about uniformity of public scrutiny across the board, we can take something out of the petition for sure. The IJBs are a fairly new initiative, and I would be interested in hearing the Government’s view on how it can make public scrutiny uniform.

**The Convener:** We can ask the Scottish Government to reflect on the request in the petition. Should we contact anyone else?

**Maurice Corry:** The issue is to do with rural care homes. That goes back to the question that I asked in the chamber. We can probably draw more from the Scottish Government on its policy on that. It is not sufficient to say that the issue is the responsibility of local government; it is a national issue. I made that very clear in my question. That can be added to the comments from Mr Barr and his team. I am aware of the strategy that the action group drew up two or three years ago, which made valuable comments, but it is a big issue.

**The Convener:** We can agree to write to the Scottish Government in those terms. Perhaps we can also seek NHS Scotland’s views and write to the Scottish health council to ask about its role in the consultation process. I am interested in the lines of accountability when the Scottish Government has devolved responsibility to the health boards, which, along with local government, are now part of the integration joint boards. Has everything become a bit distant? It seems to be much more difficult for people to identify who is directly responsible for a decision. It might also be worth asking COSLA how it thinks that the joint boards are proceeding and whether there is a tension when it comes to accountability.

**Rona Mackay:** We should also ask about monitoring of the delivery of integration, because an eye needs to be kept on how it is working.

**Brian Whittle:** I think that it is important that we speak to the Scottish health council, because Mr Barr has brought to the table the fact that each person is an individual. In such cases, people's individual circumstances and rights must be considered.

**Maurice Corry:** We are now being asked to consider care in the community, which is a fundamental issue. I think that some of the parts of the jigsaw are not there yet, which is why it is important that we approach the Government and NHS Scotland to find out what they are doing to bring everything together.

**The Convener:** A final suggestion is that we contact Audit Scotland to find out how it is monitoring the integration process.

**Michael Russell:** I am afraid that I must leave, convener, because I am giving evidence to another committee, but thank you for your hospitality.

**The Convener:** Far be it from me to keep you away from another committee, where someone will ask you a hard question for a change. Thank you very much.

A substantial number of suggestions have been made. I thank Mr Barr and Mr Mathieson for their attendance and their presentation. We will come back to you once we have received responses to the correspondence that we send out in relation to your petition.

I suspend the meeting briefly to allow for a changeover of witnesses.

09:52

*Meeting suspended.*

09:55

*On resuming—*

### **Ocular Melanoma (MRI Scans) (PE1629)**

**The Convener:** We move on to petition PE1629, which is on magnetic resonance imaging scans for ocular melanoma sufferers. The petition is by Jennifer Lewis, who is here to present evidence to us. She is accompanied by Iain Galloway, who is a member of OcuMel UK, which is a charity that supports sufferers of the condition.

I welcome you both to the meeting, and I invite you to make a brief opening statement of up to five minutes, after which we will move to questions from the committee.

**Jennifer Lewis:** Good morning. I am a 52-year-old sufferer of ocular melanoma. My tumour was identified during a routine eye test at Specsavers. Thankfully, a very good optician noticed it; it is known as choroidal ocular melanoma. I received plaque radiotherapy treatment for it in Gartnavel hospital in 2013. At the point of diagnosis, I was informed that it was a very rare type of cancer that could spread to my liver and that I would have to attend Gartnavel hospital for surveillance scans for the remainder of my life.

I am the Scottish representative of OcuMel UK, which means that I am the point of contact for newly diagnosed patients in Scotland. If someone needs support, they will ring the charity in England and then phone me, because I am the local point of contact. I would never have received support for my form of cancer, which I had never heard of, if it had not been for this small charity in England, and I would never have had the opportunity to meet other sufferers of this rare cancer.

I am here because I would like to bring to the committee's attention the fact that, in Scotland, we are offered abdominal ultrasound scans only to track any metastasis to the liver, whereas fellow sufferers and patients in England are offered MRI scans, which make it possible for the cancer to be detected early and for them to receive appropriate treatments and to be entered into clinical trials. In Scotland, we do not have that opportunity. I am here to urge the NHS in Scotland to change its opinion that the use of ultrasound scans is sufficient.

I have brought with me Iain Galloway, who represents OcuMel UK. He is also a sufferer and his cancer has moved from his eye to his liver.

**Iain Galloway (OcuMel UK):** Hello. I am a stage 4 ocular melanoma sufferer. Seven or eight years ago, I picked up something in my eye. I was given plaque radiotherapy, which involves a radioactive plaque being sewn on to the outside of the eye and being left there for three days. It burns the tumour off. Unfortunately, two years after that, in 2012, the tumour started growing again. My left eye was removed and I now have a prosthetic left eye. Eighteen months after that—while I was receiving six-monthly diffusion-weighted MRI scans—it was, thankfully, picked up that I had metastases in my liver, which is where the disease spreads 90 per cent of the time.

Fifty per cent of all sufferers get metastases. With this form of cancer, that is common—half of sufferers get such spread over time. Thankfully, because the metastasis was picked up quite early in me, I was able to have the cancer removed.

That was in 2013. To date, my scans have been clear. I live a full life, I have a young family and a young son and I work full time.

10:00

Without exception, all the people who I meet who have survived the metastatic stage of the disease for any number of years had MRI screening. That screening picks up the disease at a point where it can be treated. With ultrasound, because the disease often appears in lots of different lumps and not just as one discrete nodule or lesion, by the time that it is spotted there are dozens of a similar size and it is too late to do anything. That seems to be the case around the globe.

We have collated a set of patient stories for the committee—I gave them to the clerk to hand out; if he has not done so yet, we will get them to you—that summarises our position.

I am here with Jenny Lewis because I work on behalf of OcuMel UK. I also run the pan-European rare melanoma group. I spoke at the American Society of Clinical Oncology's annual meeting in Chicago. We talked about patient involvement in screening and patient-directed research.

**The Convener:** Thank you very much. We will circulate the evidence that you have brought with you and we look forward to reading it.

As with many of the issues that come before the committee, our first experience is through the petition. I thank you for lodging the petition, because it has brought to our attention and, more broadly, to the Scottish Parliament's attention a condition that many of us have probably never heard of.

The first part of your petition summary calls for NHS Scotland to recognise patients with ocular melanoma. The background information says that GPs do not understand the condition. Why might that be? How might understanding be improved?

**Jennifer Lewis:** The condition is rare, and the number of people in Scotland who present to their GP is minimal.

**The Convener:** You have said that there is more awareness in the rest of the United Kingdom. What has allowed that difference to arise?

**Iain Galloway:** My perspective, and certainly that of those who I have met, is that doctors are not aware of the condition. The cancer is very rare—I think that it affects six or seven people in 1 million. Sometimes, a GP may say that they have only ever seen the condition once or that they have never seen it before. Often, a person relies on being referred to a specialist centre.

Key to identifying the condition has been referral to a specialist centre, such as Moorfields eye hospital in London, or to hospitals in Sheffield and Liverpool. At that point, the patient is given leaflets

and information, because those hospitals have specialist ocular oncologists.

Usually, making progress involves a patient's GP acknowledging that they do not know much about a rare cancer—GPs cannot know everything. My GP was proactive and did research, but that is not the case for everyone. I was escalated to a local eye centre, where it was recognised that I had a lump in my eye. At that point, I was seen at a specialist centre. The more rapidly that a person can be referred to a specialist centre—not just to a local consultant in secondary care but to a tertiary care centre—the better. There are three such centres in England, where more information about the disease can be imparted to patients. That is not possible at the lowest primary care level, because the condition is so rare.

**Maurice Corry:** That is most interesting and eye-opening. Is there a link between any lack of understanding of the condition and the absence of the provision of MRI scans?

**Iain Galloway:** Most certainly. With this cancer—and with breast cancer and so on—screening regimes operate subsequent to the primary disease having been resolved. Because the cancer is rare, not much is in place, and there is little understanding of the disease.

In 90 per cent of the cases when the cancer metastasises, as happens in about 50 per cent of all cases, it will do so to the liver, which will appear peppered or be dotted throughout—what is called miliary—so it cannot be cut out. If there are 100 patients with eye cancer, 30 of them will, within five years, have unresectable metastases in the liver and a further 20 per cent will present with metastases elsewhere—in the lung, in the spine and so on. By and large, we know where to look for the metastases. With ocular melanoma, we get that on a plate; we can MRI scan the patients, look at their livers and pick up 30 with whom we can then do something.

That is not the case with ultrasound, which often picks up the disease too late to be able to do anything about it. I mentioned the disease's diffuse nature, with dozens of lesions of 1cm in size. By the time there is 25 to 50 per cent liver involvement, it is too late. However, if the disease gets picked up through MRI scanning, one of the many new treatments that have come out in the past two to three years can be used, and they are keeping people alive for a long time with a high quality of life. Indeed, in some cases, the treatments are curative.

In direct answer to your question, I think that the cause is a lack of understanding of the disease and its metastatic presentation.

**Jennifer Lewis:** My experience of being sent for ultrasound scans is that Gartnavel tends to push people out to local hospitals instead of doing scans itself. The local hospitals do not have the ultrasound-scan sonographers with the expertise to know what type of lesion they are looking for; indeed, they have admitted to me, “I’ve never heard of your condition, and I don’t know what type of lesion I’m looking for.”

I ended up having an MRI scan by default after the ultrasound scan came back inconclusive, because the sonographer admitted that she would not be able to recognise the lesions. As a result, Gartnavel pushed me off to another hospital for an MRI scan. The only reason that I got one was the fear that something was wrong.

I do not trust ultrasound scans, because I know that they do not work for us. Someone might get a scan once every six months and then go home still anxious. I do not trust the scans or the results that they produce, and I worry that the operator is not competent. After speaking to Scottish patients, I know that everyone feels exactly the same. Ultrasound scans are not beneficial to our mental health and anxiety levels.

**Brian Whittle:** Good morning. The petition calls for enhanced MRI scans in an attempt to detect early metastatic disease; you call them “vital” and say that they would allow you to have

“life prolonging treatments and to plan for the future”.

You also say that the scans are being provided in England. Without going into too much detail, can you give us any information on the success of the scans south of the border?

**Iain Galloway:** On how this pans out with the medical community, there is no dispute that the enhanced MRI scan provides the ability to spot the disease. The contrast agent that is used allows active areas to be spotted, and diffusion weighting is used; it gives a better—indeed, the best possible—picture.

There is no dispute that the scan allows the disease to be seen earlier but, when people are pressed, those who do not support the scans often say, “It doesn’t make any difference, because you’re going to die anyway.” I have come across that several times; people have said, “Irrespective of whether the disease is spotted now, in six months or a year down the line when it’s big enough to be picked up by ultrasound, you’re going to die anyway.” However, evidence shows that there are life-saving treatments that treat the whole liver. As I have mentioned, most people cannot have the cancer cut out; it is peppered all over the place, so the size makes no difference.

As I have said, treatments are available. One is called chemosaturation—or CHEMOSAT—in

which the liver is isolated and 100 times the usual systemic dose of chemo agent that might be given for another disease is given just to the liver for half an hour. The blood flow is controlled, the agent is removed from the bloodstream via a filtering mechanism and the patient goes home after a day in the intensive care unit.

Many patients who have had that treatment—it is offered by a company called Delcath—are surviving three or four years later with very good quality of life. They might have had repeated treatments. That calls into question the contention that ultrasound and MRI scans make no difference because people are going to die anyway. With that new treatment, which was presented at several medical conferences last year, we can save people if the condition is detected early. I think that, in a couple of months, there will be a big reveal of new data that will show the treatment in an even better light, because the technique improves as things such as the filtering mechanism are improved.

New treatments are available. Another one is the Sirtex system, but I will not go into too much detail on it. I have referred to the treatments in the handout that I submitted. We now know that early detection enables intervention that will save someone’s life or give them several years of high-quality life during which they will be working. We know that just from the UK, and I dare say that the results are similar elsewhere in the world.

**Brian Whittle:** I understand that all Scottish cases are sent to the specialist unit at Gartnavel. Is that true?

**Jennifer Lewis:** The diagnosis normally happens at local hospitals, and then everybody is sent to Gartnavel. I know some patients who have gone down to Liverpool for proton beam treatment, because it is carried out there and not in Gartnavel, but most patients are treated with plaque radiotherapy in Gartnavel.

**Brian Whittle:** Do you contend that, because the condition is so rare, there are not enough consultants with enough knowledge of it?

**Jennifer Lewis:** I do not think that there should be only one specialist unit. At times, I get confused and angry, because Gartnavel sits right beside the Beatson cancer centre, but the two facilities do not work together. The Beatson has technology that runs all through the night for Scottish cancer patients. I do not understand why the medical oncologists and the ocular oncologists do not work together, because they are next door to each other.

I attended Gartnavel in January and I have now been discharged. I cannot fault the treatment of my eye. However, when I asked the ocular oncologist in January who I should see for scans



of my liver, the answer was that my local hospital would send for me in a year. That will be next January, which is worrying me because, by next January, it will have been 18 months since my liver was surveyed by ultrasound or MRI scan. I am in limbo because I do not know what is happening. The cancer travels through the blood, but I do not know what is happening in my liver, and I will not know until January.

I have spoken to my GP about the issue and she seems unconcerned. To give her credit, she has said that she does not understand the condition and that she follows the direction of Gartnavel. I do not think that ocular melanoma patients in Scotland are offered the same support and treatments as those with other cancers are offered.

**Rona Mackay:** Have you or patients you know asked for MRI scans after diagnosis and been refused? If you or they were refused, what was the explanation?

**Jennifer Lewis:** I have asked for MRI scans, and there is a gentleman in the public gallery who has also asked for them. Most of the people I speak to about the issue have asked for scans. The answer that I got—you might find this shocking, because I did at the time—was, “If you come to my private clinic in Glasgow and pay me, you can have an MRI scan.” My ocular oncologist said that. They said, “We do not offer MRI scans because, when the disease travels through the liver, nothing can be done anyway.”

**Rona Mackay:** But if you had had a scan earlier, that could have been picked up and you could have been treated before it happened.

**Jennifer Lewis:** Yes, but that was the answer that I got when I asked. I have constantly been asking Gartnavel hospital, and I keep getting told that it does not do them.

10:15

**Rona Mackay:** As far as you are aware, is that what other patients are being told?

**Jennifer Lewis:** Yes. I know a lady who attended Gartnavel last week who is a newly diagnosed patient. She has made history, in my eyes, because she was given a scan. However, the only reason she got one was because her liver was sitting too high in her body for the ultrasound to get a good picture of it.

**Rona Mackay:** That is interesting. Thank you.

**Maurice Corry:** You state in your petition that you have also written to past and present health secretaries. The paper that has been prepared for us today quotes the Scottish Government's answer to a written question. It says:

“Current guidance suggests that there is currently insufficient evidence on the benefits of the use of MRI scanning for the detection and treatment of metastatic disease in people with ocular melanoma.”—[*Written Answers*, 22 November 2016; S5W-04917.]

What is your response to that?

**Iain Galloway:** That information is a little out of date. As Jenny Lewis just said, she spoke to a consultant who told her that it does not matter if they find something in the liver, because there is nothing that they can do anyway. Unfortunately, there is a bit of a lag in the medical community, given the rapid development in the field of ocular melanoma and others besides. We are going through a renaissance in cancer treatment—you read about it all the time. I am on immunotherapy drugs at the moment. More than two and a half years ago, I had a lump on my face, because the cancer had spread outside the liver again. Within two months of the treatment beginning, it had shrunk to nothing—my oncologist could not believe it.

Of course, all that is possible only through early scanning. At the moment, to try to collate the evidence to indicate that there is a benefit in early scanning, and thus that there are effective treatments, we have collated the patient stories of people who have benefited from the new treatments. I will use CHEMOSAT as an example, although there are other treatments. Medical papers have been published within the past year—so I am talking about recent developments—that demonstrate the efficacy of CHEMOSAT in the treatment of ocular melanoma metastases. We know that the treatment is effective only at relatively low tumour burden—some of the early trials were just trying it on all and sundry, and they found that it was much more effective when the cancer was caught early and patients therefore had a much lower tumour burden.

I would challenge the contention in the Government's answer that you read out. I think that it was probably true in the light of the data that was available at the time, but more up-to-date information is available, and more is coming, too. We see it regularly. I think that there is just a time lag.

**Maurice Corry:** Does Jenny Lewis want to come in on that?

**Jennifer Lewis:** No—Iain Galloway can explain the scientific stuff a lot better than I can.

**Maurice Corry:** I am interested in what I have just heard. Are you saying that what is available on the NHS at Gartnavel is out of date—yes or no?

**Iain Galloway:** Yes. There are doubtless cost implications with the new treatments and so on, and it is worth noting that many of them are now

available on trials. I have got my next set of three-monthly scans tomorrow, and I will find out my results—fingers crossed, touch wood—on Tuesday. However, I know what I am going to do if anything goes wrong—you have a plan B if you need it. There are a number of trials throughout Europe for the latest treatments. I have mentioned the Delcath system, and there is another one called IMCgp100, which is produced by an American company called Immunocore, which has been running a base in Oxford—that trial has shown great promise. Some of the treatments are not available on the NHS in Scotland or the rest of the UK, because they are quite new, but people can get them if they join the trials. People are surviving because of drug trials. That is useful for hospitals, in some respects, because it comes at little cost to them.

**Maurice Corry:** People are also paying privately.

**Iain Galloway:** Yes. However, the Delcath system costs £35,000 privately. I know someone who has survived longer than I have with the disease, even though he has a more aggressive form of it. He has had seven of those treatments, but he has the most incredible cover through BUPA, and it has paid for them. Some people have had to pay out of their own pockets. Things are different in the USA, but I know of people there who have sold their houses to pay for the treatment. Crucially, however, they are still alive and are able to watch their kids grow up.

The treatments and so on at Gartnavel and in other places are out of date, but the bottom line is that the opportunity to take advantage of those trials, to pay privately for the treatments or to treat the disease by another means is only possible if the disease is picked up early enough.

**Angus MacDonald:** Good morning. You have given us a general idea of the number of sufferers. You referred to ocular melanoma as an orphan cancer and said that there are only a few sufferers in Scotland. However, do you know the exact number of sufferers in Scotland?

**Jennifer Lewis:** We have the numbers up to 2014, when there were only 59 sufferers in Scotland.

**Iain Galloway:** It is about seven per million. The numbers are slightly higher in certain northern climates. For example, in Scandinavia, the figure is eight or nine per million. Scotland has a population of 5 million or 6 million, so we would expect between 40 and 50 new cases a year. I think that the figure of 59 sufferers in Scotland dropped to 47. That is how many people are diagnosed each year, and half of them go on to get metastatic disease. At the moment, nearly all of them will die, unless an individual is very lucky

or pays privately for MRI scans, gets the disease picked up and then has one of the new treatments. Those are broadly the numbers involved, although they will vary from year to year. Between 40 and 50 people in Scotland will be diagnosed each year with ocular melanoma, which will metastasise for half of them.

**The Convener:** The other side to the point that is made that attention is not paid to orphan diseases because there are so few sufferers is that, because there are so few, there is not a massive cost implication involved in dealing with those cases.

**Iain Galloway:** Absolutely.

**Jennifer Lewis:** Yes.

**The Convener:** Jennifer Lewis presented with the disease in England. Are sufferers like Jennifer routinely offered MRI scans in England?

**Iain Galloway:** It depends which centre people go to, but it is certainly not universal throughout the UK. However, there are specialist centres in London, Liverpool and Sheffield, for example. Once my eye was treated, I went to Birmingham's Queen Elizabeth hospital, because it is well regarded and has, ironically, one of the top liver departments in the world. I thought that it would therefore be an opportune place to go, and the hospital gave me routine MRI scans. Southampton university hospital is probably the leading hospital in the world for dealing with ocular melanoma metastases. The hospital has taken a particular interest in the disease and its specialists have done very well. The hospital will routinely provide screening via MRIs post-primary.

Not every hospital will provide MRIs in that way. Again, if there is not the level of specialism in the hospital, people will not know about the disease, which is the issue that we discussed earlier. However, the specialist centres recognise what can be done. As long as people go to one of those hospitals, they will be given MRIs—as I was.

**The Convener:** I suppose that we would expect specialisms anywhere in the NHS, but it is about informing people that there is the specialism to which you refer and that people can at least be directed to it and learn best practice from it.

**Iain Galloway:** Exactly. OcuMel UK tries to funnel people into the specialist route through, for example, leaflets that show what they should be getting, which means that they are more informed when they go to the specialist centres. We have to funnel people into them somehow, and that is just one way.

**The Convener:** But the issue is that the view might be taken at consultant level or GP level that that does not matter because they are doing something else. It is about how we ensure that the

medical or clinical community in Scotland is aware of the specialisms and draws on them.

**Rona Mackay:** On that point, I was concerned about Jennifer Lewis's statement that her GP did not know anything about her condition. Do you know of other patients who have had the same experience? Is there more awareness of the condition south of the border than there is up here? The awareness might relate to the number of cases. Is the lack of knowledge about the condition among medical professionals widespread?

**Jennifer Lewis:** I honestly think that it is widespread. The Scottish Government's strategy was set out in the document "Beating Cancer: Action and Ambition", where we read about pushing awareness of the "big four" cancers. However, I think that for the sake of the education of all of us—GPs, hospital staff and the general public—there should be greater awareness about eye health. I went to the optician just because I fancied a new pair of glasses—I had no symptoms—and I ended up being told that I had ocular melanoma. That could happen to any of us: it is a matter of, "There but for the grace of God go I."

**Rona Mackay:** Opticians should be praised for picking up those things. It is important that people get regular eye checks, but it is concerning that, when the matter goes from opticians to some in the medical profession or some GPs, they do not know what it is about.

**Jennifer Lewis:** I will tell members what they might think is a funny story. My GP said, "This isn't a life sentence. Go home and watch 'Breaking Bad'." I did not even know what "Breaking Bad" was. I went home, asked what it was, found out, and was not too enamoured by that comment. That showed me that he had no knowledge of my condition. I gave him an ocular melanoma leaflet and pleaded with him to look up the site to give him a little bit of information about why I was so worried. When I went back next time, he had not done so.

I was at my GP two weeks ago, as I was concerned about when my next liver scan will be. She said, "Och, it'll be in a year." They do not get how anxious the condition makes all of us.

**Rona Mackay:** That is very concerning.

**The Convener:** One might not necessarily expect a GP to be fully informed about everything, but they should receive information. There is also a concern that there seems to be a gap between what happens in Scotland and what happens elsewhere at the next level up.

Do you want to make any final comments? We will distribute the handouts that you have brought with you.

**Jennifer Lewis:** Chapter 5 of "Beating Cancer: Ambition and Action" is all about early detection and diagnosis. That is what we are asking for. Eye cancer is not in that policy. Could that be included in that policy for early detection and diagnosis, please? That is what we need.

**The Convener:** Can we have suggestions about how to take the petition forward?

**Brian Whittle:** The obvious suggestion is to go back to the Scottish Government and ask for an updated view, given that there seems to be a lot of new evidence to bring to the table.

**Rona Mackay:** I agree entirely. We could also get the views of some of the cancer support charities, such as Macmillan Cancer Support, Cancer Research UK and OcuMel UK on everything that we have talked about today.

**The Convener:** Is there a case for contacting the opticians' professional bodies, as they develop a lot of policies in the area? This is about identification and recognition. How do they do that? How supported are they? The connection between what happens to a person's eye and their liver seems to be missing now. The witnesses have certainly made a compelling case for MRI scans to be routinely offered. It would be useful to know the views of the opticians' professional bodies, as well.

**Maurice Corry:** Maybe the Royal College of General Practitioners in Scotland when we are asking why this message is not getting across. Jennifer Lewis has been very explicit about that.

**Jennifer Lewis:** From the stories that I get from a lot of patients, they tend to think that Gartnavel hospital concentrates on the eyes and is happy once the eyes have been treated.

**Iain Galloway:** Very much so.

**Jennifer Lewis:** It does not move on to the medical side of things.

**The Convener:** It might be worth while making contact with the specialist units in England that Iain Galloway has identified. We could try to establish what has triggered the position. There seems to be an understanding that is different from ours.

**Iain Galloway:** Southampton would be a good place to start, as the hospital there specialises in the area.

MRI doubtless has cost implications, but people are receiving ultrasounds anyway, and they cost a couple of hundred quid. An MRI costs £500 or £600. Probably £500 or £600 a year is saved by

not giving a person an MRI, but a huge proportion of metastatic patients are picked up by them, as many cancers spread to the liver within five years. It is very sad that so many do. There can be a high hit rate of positive finds, all of which there are options to do things with. We would know where to look. We could point an arrow at the liver and say, "Look here in the next five years." There would be finds in lots of people.

**The Convener:** There are certainly a number of very useful actions that we can take.

I am very conscious that we have found the issue compelling, but you are living with it and, at a personal, wellbeing level, you are anxious about what treatment you are getting. That must take its toll.

I thank you very much for coming to the meeting and wish you all the very best as your treatment progresses. We will come back to you with our findings, and the issue will come back to the committee. Once we have received responses from the various bodies, we will consider the issue again. You will certainly have the opportunity to comment on the responses that we receive.

10:30

*Meeting suspended.*

10:34

*On resuming—*

### **Nursery Provision (Funding) (PE1630)**

**The Convener:** We move to those new petitions on which we are not taking evidence. PE1630, by Fiona Webb, is on nursery funding for three-year-olds and calls on the Scottish Parliament to urge the Scottish Government to revise its criteria for children becoming eligible for part-time funded nursery places following a child's third birthday. Members have a copy of the petition and the Scottish Parliament information centre briefing. The background information on the petition explains that many three-year-olds are missing out on part-time funded nursery places as a result of the way in which the current criteria have been drafted. Do members have any comments or suggestions for action?

**Brian Whittle:** Nursery provision has been debated quite a lot in the chamber—it is a hot topic at present. It seems on the face of it that the way in which it is administrated is a bit discriminatory, if that is the right way to put it. It is significant that a three-year-old may miss out on three months or more of nursery care. We should seek some opinions from outside the Parliament—from parenting groups, for example—so that we can get some apolitical views on the issue.

**The Convener:** We can perhaps get some non-party-political views.

**Brian Whittle:** Aye, that too.

**Rona Mackay:** We have to accept that there must be criteria for when children can access nursery provision, but it seems to be a bit of a postcode lottery. A number of local authorities are starting children from their third birthday or the month after, while others take a different view, which is confusing. Perhaps we could get some clarification on that. It is definitely an issue, and we should seek views from the Scottish Government, from third sector children's charities and from COSLA.

**Maurice Corry:** We need to ask why the criteria for nursery provision are not in sync with primary school criteria.

**The Convener:** The point that I drew from reading the petition is that, if someone is entitled to two years' provision, it does not really matter how the provision is delivered because it is about funding the place as opposed to the place itself. I may be missing the point, however. If a child turns three and is entitled to two years' provision, would they not just get that, or is the issue about how that connects with the point at which they go to primary school?

**Brian Whittle:** That is a good point—some kids are going to primary school before they are five.

**Rona Mackay:** We need clarification on that—I do not know.

**The Convener:** This is an entirely personal view, but I sometimes wonder whether parents may feel that their child is not yet qualified to go to primary school but they are facing financial pressure to send them anyway. If the child was entitled to two years' funding and would therefore get funding to stay in nursery beyond five, they would stay in. I do not know whether that is the case. Sometimes, there may be pressure on families to send a child to school very early. If there was no financial pressure, those parents might say—as some parents currently do—that the child would not go to primary school at four and a half but would wait until they were slightly older.

**Brian Whittle:** We can look at it that way rather than going back the way. What you say about pressure is true.

**The Convener:** How the resources are managed comes down to an arbitrary decision around birthdays. I am not sure—

**Brian Whittle:** You have made it more confusing—thank you, convener. [*Laughter.*]

**The Convener:** That is my role in life.

**Rona Mackay:** It is very confusing.

**Maurice Corry:** If I remember rightly, there was a question around comparison with the European system, and the idea of children going to primary school slightly later. I do not know whether that is in the mix at the moment or whether we are just sticking to the old system. We have to seek views and ask further questions.

**The Convener:** It would be interesting to find out about people's direct experiences. At a later stage, we might want to bring in people who have direct experience of the system and find out exactly what their concerns are. How do those concerns fit in with the Scottish Government's broader proposals for childcare provision to be much more flexible and its support for people to access childcare places? Are the criteria pretty random in their consequences for individuals, so that people are not necessarily getting the full entitlement? That seems to be the petitioner's view. The petition states:

"The Scottish Government claim that 'You are entitled to a funded part-time place for your child, broadly speaking, from the beginning of the school term starting after their third birthday.' However, as my husband and I have found out, this is not entirely accurate"

because of birthday cut-off points. It would be useful to get more information on that.

We have already identified a need to seek views from the Scottish Government, COSLA and a range of organisations. The clerk's note suggests that we seek views from Working Families, the parenting across Scotland partnership, Fathers Network Scotland, One Parent Families Scotland, Voice the union, Reform Scotland and Children in Scotland. It would be useful to hear about the experiences of unions that are involved in supporting childcare workers, and of other organisations that work in the field of childcare specifically.

**Brian Whittle:** I am interested in the issue of development. A few months is a long time in the development of a three-year-old. I would be interested to know whom we might ask about issues to do with development and non-development in children of that age.

**The Convener:** The reality for a lot of families is that their child will have a childcare place but it will not be funded. I understand that there are cut-off points that suit the organisations, but if the issue is only about the funding, it does not feel logical to have cut-off points. We might want to explore that further with the Scottish Government.

We might want simply to recognise that the petitioner has submitted an interesting petition and brought to our attention an issue that we want to look at further. Are there any further suggestions

for what we might do? There is quite a lot there to start with.

**Rona Mackay:** As a first step, what you have described is good.

**The Convener:** As there are no further suggestions, I close the meeting to the public at this point and we will move into private session.

10:41

*Meeting continued in private until 10:57.*



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