OFFICIAL REPORT
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Public Petitions Committee

Thursday 24 January 2019

Session 5

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Thursday 24 January 2019

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PUBLIC PETITIONS COMMITTEE

2nd Meeting 2019, Session 5

CONVENER

*Johann Lamont (Glasgow) (Lab)

DEPUTY CONVENER

*Angus MacDonald (Falkirk East) (SNP)

COMMITTEE MEMBERS

Rachael Hamilton (Ettrick, Roxburgh and Berwickshire) (Con)
*David Torrance (Kirkcaldy) (SNP)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Dr Catherine Calderwood (Scottish Government)
Maurice Corry (West Scotland) (Con) (Committee Substitute)
Jeane Freeman (Cabinet Secretary for Health and Sport)
Emma Harper (South Scotland) (SNP)
Mark Ruskell (Mid Scotland and Fife) (Green)
Elizabeth Sadler (Scottish Government)

CLERK TO THE COMMITTEE

Sarah Robertson

LOCATION

The Mary Fairfax Somerville Room (CR2)

Scottish Parliament

Public Petitions Committee

Thursday 24 January 2019

[The Convener opened the meeting at 09:00]

Continued Petitions

The Convener (Johann Lamont): Welcome to the second meeting in 2019 of the Public Petitions Committee. We have received apologies from Rachael Hamilton. I welcome Maurice Corry, who is attending as a committee substitute.

We have one item on the agenda, which is consideration of three continued petitions; we will hear evidence on each petition from the Cabinet Secretary for Health and Sport. I welcome Emma Harper MSP, who is attending for the consideration of the first petition.

Diabetes (Continuous Glucose Monitoring Sensors) (PE1619)

The Convener: The first petition is PE1619, by Stuart Knox, on access to glucose monitoring. The petition calls for glucose monitoring sensors to be made available under prescription to all patients with type 1 diabetes. When the petition was last considered, which was in June 2018, issues were raised relating to the SIGN—Scottish intercollegiate guidelines network—guidelines for type 1 diabetes management and the VAT element of Scottish Government funding for additional insulin pumps as well as continuous glucose monitoring devices. Responses have been received concerning those issues from the Scottish Government and the Cabinet Secretary for Health and Sport.

For consideration of the petition, the cabinet secretary is accompanied by Dr Catherine Calderwood, who is the chief medical officer, and Elizabeth Sadler, who is the deputy director for planning and quality. I welcome the cabinet secretary and the officials to the meeting, and I invite her to provide a brief opening statement of no more than five minutes, after which we will move to questions.

The Cabinet Secretary for Health and Sport (Jeane Freeman): Good morning. I am grateful to Dr Calderwood for attending with me, given all the other pressures on her diary. I am grateful, too, to the committee for inviting me to give evidence on the petition.

As you will be aware from my letter of 8 August, the Scottish health technologies group published its advice statement on the flash glucose monitoring device FreeStyle Libre on 13 July 2018. My letter stated that the national health service boards that had not yet included FreeStyle Libre in their local formularies were considering how to implement the advice to best effect. To update the committee, all NHS boards in Scotland have included FreeStyle Libre in their local formularies and are making it available on prescription. I expect all boards to make FreeStyle Libre available to patients in line with clinical guidelines and in a phased and controlled manner to ensure that appropriate education is delivered prior to initiation and in recognition of the challenges for the manufacturer in matching demand. That move will benefit many individuals across Scotland, and I hope that it will reassure the committee that the spirit of the petitioner's concerns in relation to FreeStyle Libre has now been met.

At the committee's meeting on 28 June last year, my officials clarified that FreeStyle Libre is not a continuous glucose monitor. As more clinical evidence becomes available, FreeStyle Libre is showing positive effects in improving quality of life by reducing the number of finger-prick tests that patients need to carry out to self-manage their diabetes. However, FreeStyle Libre is not suitable for some patients, particularly for those who have limited or no hypoglycaemic awareness. There is strong clinical evidence to demonstrate that CGMs have a positive impact for a small cohort of patients with frequent or severe hypoglycaemia and that they improve glycaemic control and reduce hypoglycaemic episodes and emergency hospital admissions. We will continue to provide NHS boards with additional funding specifically for continuous glucose monitors so that the boards will increase the number available to diabetes patients where that is clinically indicated.

As the committee will be aware, diabetes remains a clinical priority for the Scottish Government. I reassure members that I am committed to ensuring that our health service continues to deliver care and treatment of the highest quality.

I am of course happy to answer any questions that members may have.

The Convener: Thank you. Committee members will recognise that the statement is very positive about the petition. You indicated that there are issues around training and the time for this to work through the system. Do you have a sense, if not a target, about when people across Scotland who would benefit will be able to routinely access FreeStyle Libre?

Jeane Freeman: I do not have a target time; I am sure that committee members will understand that. Dr Calderwood may want to say more on that. Clinical judgment is needed about the

appropriateness of FreeStyle Libre for a particular patient, and then there needs to be a bit of initiation and education with that patient. That has to happen at the secondary care level, but once it has been undertaken the prescription will come from an individual's primary care giver.

The introduction will be phased, and it will be led by the number of individuals for whom this would be appropriate and by doing the necessary two steps before we get into regular prescribing for an individual. I do not know how that may pan out.

Dr Catherine Calderwood (Scottish Government): We know that some of our health boards have come on stream very recently with availability of FreeStyle Libre. For a group of patients, the device will very obviously be the best choice and they may have been looking forward to the opportunity to use it. There will be a period of training for patients and their family members, who will need to attend and ensure that they are able to use the device. Once that has been undertaken, the prescription can go ahead. There is then a group of patients for whom there might be some additional work on whether it might be the right thing for them, and they might need a longer time until they move forward to using FreeStyle Libre.

The device is now available across Scotland in all our health boards and there will be clinical differences in the length of time for people to change over. It is not for everybody, but there is now no impediment to its use by those patients for whom it is the right way to monitor their glucose levels.

Angus MacDonald (Falkirk East) (SNP): Good morning, cabinet secretary. I welcome the announcement, having been approached by a number of constituents about FreeStyle Libre. On our committee visit to Dumfries and Galloway some time ago, its benefits were brought to our attention.

You mentioned the clinical guidelines. The committee has previously heard evidence that the SIGN guidelines for type 1 diabetes management are out of date, because they have not kept up to date with technology. The committee understands that the guidelines will be withdrawn in 2020, rather than reviewed or updated. We are keen to hear your response on that point.

Evidence received by the committee has confirmed that proposals are in the pipeline to begin to update guidelines for type 2 diabetes this year. Why are there no similar plans or proposals to update the SIGN guidance for the management of type 1 diabetes?

Jeane Freeman: As you indicated, the technology is moving so fast that by the time the guidelines are updated, they are potentially out of date. What is being looked at is more rapid technical assessment, such as for glycaemic control in type 2. Professor Jason Leitch offered an explanation about that in his letter to the committee. What needs to be looked at is the system that would keep pace with technology while still offering the right guidance to clinicians. Dr Calderwood would like to add to that.

Dr Calderwood: The SIGN guidelines committee has changed its approach, and it is not specific to this particular diabetes guideline. The SIGN guidelines were being updated for everything every three years. Sometimes there was no change because there had been no more research, but sometimes there had been so much change that the guidelines were out of date.

The guidelines committee has therefore undertaken a complete change in the way that it will do the guidelines. The older guidelines will be retired and there has been a call for much more focused guidelines, rather than something that would take years to produce. With the new technology, we would be looking for the Scottish diabetes group to make a proposal to SIGN that has a very narrow focus. The new SIGN procedures mean that the proposal would be turned round very rapidly. SIGN might request a Scottish health technologies group assessment of the technology and then SIGN would look to quickly produce guidelines that are clinically relevant at that time.

In this new world in which we have FreeStyle Libre, it is for the Scottish diabetes group to make proposals to SIGN. SIGN has said that it will take on X pieces of work per year, which will be produced much more rapidly and which, I would argue in agreement with SIGN, will be much more clinically relevant than something that takes three or four years to produce.

Angus MacDonald: Thank you for the clarification, which is helpful.

The Convener: That point would apply to anything to do with modern technologies. Presumably, modern technology now applies across the medical landscape. Are you saying that, in the medium term, the SIGN guidelines will not be relevant?

Jeane Freeman: No. I do not think that that is what Dr Calderwood or the guidelines committee is saying. This does not apply to everything, but there are areas in which technology is very relevant and it is moving quickly. The guidelines committee has therefore recognised that and has said that it needs to alter the way in which it undertakes its work, so that it can keep pace with that technology. In the past, taking two or three years to update guidelines was adequate but, in some instances, that is now too long. The guidelines would end up being out of date and

would, in effect, be a significant waste of effort. Where it is appropriate, the guidelines committee will undertake a much more focused piece of work that tries to keep pace with the speed of technological developments in medicine and is clinically relevant, and which produces guidelines that add value for the clinicians in respect of the decisions that they have to take.

The Convener: In the meantime, there will be no SIGN guidelines for type 1 diabetes. How is a decision made about which areas across the board are subject to fast technology, and which areas are not? Presumably, there is a rational way of doing so. Obviously, the petitioner felt the need to lodge a petition in order to get health boards to catch up with technology. What reassurance can people be given that there is a rational process when such decisions are made?

Dr Calderwood: The original SIGN guidelines that we are talking about were written in 2010, so we are looking at something that needed to move on. As I described, we would expect the Scottish diabetes group to feed into SIGN. In the meantime, because we have the new technology, we will work with health boards, through the Scottish diabetes group, to make sure that, when patients should receive the technology, they have access to it. We will also monitor the use and uptake of the technology and whether there are any problems.

In respect of the prioritisation that SIGN is looking at, it has a workstream over a number of years but I could not tell you exactly what pieces of work are coming forward, or in what order. However, in Scotland, the idea is that we do not rely on guidance that is years out of date and that we do not have a situation in which the new research that is behind the guidance is not looked at. In common with the way in which guidelines are produced across the rest of the UK, that is a much more rapid process. The Scottish diabetes group is key in that.

09:15

The Convener: That does not necessarily address my point of concern, which is whether, across the board, we will have SIGN guidelines and whether they matter any more. What happens in other parts of the system? I apologise for digressing a wee bit. On the diabetes issues, there is another means by which folk are guaranteed that modern technology is being recognised and their access to the appropriate support is available. Perhaps we can come back to that digression.

Jeane Freeman: It is an important digression. If it would be helpful, we will pull together the information on how the guidelines committee is going about its work, and send it to the committee in direct response to the issues that you raise, convener.

However, for the record, it is important to be clear that neither SIGN nor the committee has said that SIGN guidelines are no longer relevant. The guidelines continue to be relevant, but the guidelines committee has looked to change and improve the way in which it goes about producing them, in order to match the pace at which things are moving forward.

We will pull something together on that and ensure that it is provided to the committee.

The Convener: That would be helpful, thank you. If someone with type 1 diabetes is looking at it from the outside and the guidelines are no longer available, they might think that their issues are being deprioritised.

Brian Whittle (South Scotland) (Con): We recognise that, since the petition was lodged, there has been advancement in CGM and knowledge has been brought to the fore about what it can do for those who have type 1 and maybe even type 2 diabetes. In July 2018, the Scottish health technologies group published an advance statement on FreeStyle Libre flash glucose monitoring, recommending its use among adults who manage their condition with multiple daily insulin injections or insulin pump therapy, and the group concluded that it is good value for money.

Based on those findings, what is the cabinet secretary's view as to the current level of Scottish Government funding that is available to health boards for the technology?

Jeane Freeman: The funding that is available to health boards is adequate for the demand that they have. As they shift to FreeStyle Libre where that is clinically appropriate, they will have resources from other things, such as finger-prick testing kits, that they will no longer need to use for certain individuals. They will be able to manage their resource by balancing what has been available up to now and the introduction of the new technology.

As I said in my statement, the Government has also provided additional funds, and we will continue to provide those.

Brian Whittle: The public will be looking for consistency of application and an understanding of how we will reach that. I heard this morning that, in the Highlands, only four units are available and they are being given out to and being used by the youngest patients. That seems to go against what the Scottish health technologies group recommends. How can we reach a point where those who suffer from type 1 diabetes understand

their position in relation to accessing the technology? There does not seem to be consistent application across all health boards.

Jeane Freeman: I will ask Ms Sadler to respond to some of what you have said. However, I note that NHS Highland was the last board to come on stream, so it is later than other boards in going through the phased introduction that Dr Calderwood explained. Some work needs to be done to ensure that NHS Highland catches up in relation to the availability of the technology to patients for whom it is appropriate.

Ms Sadler may want to give some additional information on that.

Elizabeth Sadler (Scottish Government): FreeStyle Libre and continuous glucose monitoring are two separate tools, but they produce similar things. FreeStyle Libre is now available on prescription across Scotland, with NHS Highland coming on board for that earlier this week. Whether FreeStyle Libre is a suitable technology for an individual is a clinical decision that will be taken by the individual and the clinician.

A continuous glucose monitor is a more invasive device—a person wears it and it goes into their body. A CGM is particularly suitable for people who have very poor glycaemic control and, in particular, people who have no awareness that they are about to have a hypo or a hypo episode, where it happens very suddenly. A CGM alerts the person that that is about to happen.

Over the past few years, the Scottish Government has provided additional funding of £2 million a year to support boards to increase the number of insulin pumps and CGMs, and that money is allocated on the basis of need and clinical decision making. According to the numbers that I have, nine over-18s in Highland have CGMs. I do not have a number for under-18s. Continuous glucose monitoring is being rolled out in conjunction with individuals and their clinicians. Some people are now choosing to have FreeStyle Libre rather than a pump because FreeStyle Libre is a less invasive procedure and it helps them to understand what is happening with their sugar controls.

Brian Whittle: Presumably, given that health boards are not all adopting the technologies at the same time, health boards will be able to share what they have learned from early adoption.

Elizabeth Sadler: Absolutely. We understand that about 250 people across Scotland have continuous glucose monitors, and that number will increase over time. We think that we are reaching roughly 50 per cent of the people who would potentially benefit from a monitor. Some people who would benefit from a monitor may decide, in conjunction with their clinician, that they do not want one. We are making good progress, though, and we are committed to giving more money in 2019-20. We have just written to the boards to ask them about the progress that they have made in 2018-19, and we will then take decisions on the allocation of funding for next year.

The Convener: That is funding from April this year.

Elizabeth Sadler: Yes—for continuous glucose monitors and insulin pumps. FreeStyle Libre will be distributed by boards via prescription.

The Convener: We do not yet know what the allocation will be for decisions in April.

Jeane Freeman: We do not, but the funding is in the draft budget. Boards will tell us what their particular needs are and we will meet those needs by allocating that funding to the boards. It may vary depending on where boards have got to with provision in the current financial year and what more they need to do in the next financial year.

The Convener: Okay, so they have to bid in.

Jeane Freeman: It is not a bid; boards simply have to advise us of their need, show us evidence of their progress so far and tell us whether their need for the coming year looks like X or Y. We will then allocate funds from the pot that is already in the draft budget.

Maurice Corry (West Scotland) (Con): We are hearing good news this morning. However, the Scottish health technologies group advises that further research is needed into the long-term use of CGM and its use with children and young people. Bearing in mind what the cabinet secretary said about how quickly the technology is moving, how will the Scottish Government respond to those findings and how does it intend to explore the issue further?

Jeane Freeman: Mr Corry and I have corresponded on the issue in relation to a constituent case. I hope that what we have said this morning is helpful.

Maurice Corry: It is certainly helpful.

Jeane Freeman: I ask Dr Calderwood to pick up on the point about research.

Dr Calderwood: We must try to ensure that all patients who would benefit from the new technologies get them. There is caution at first, which is why there are some restrictions. At the moment, FreeStyle Libre is recommended for people who are over 18 but not for pregnant women or people who are on dialysis, for example. However, we know that it would be the right thing to use for many people who are under 18.

The chief scientist office in the Scottish Government is under my jurisdiction. We are the envy of the rest of the United Kingdom for our ability to turn grant applications around and have funding available. We have a 30-day turnaround from submission to a decision on whether money will be given. If we have a particular interest in something—having whole-country coverage on this matter is new for Scotland—such a study is absolutely the right thing to propose.

Anyone can come forward, but we will approach the Scottish diabetes group, which has contacts with our researchers across Scotland and beyond, and people with an interest, such as Dr Brian Kennon, who is my specialty adviser on diabetes and has been to speak to the committee previously. We will introduce proposals so that research takes place as the coverage comes on board, with a view to spreading the availability of FreeStyle Libre to other patient groups if that is thought to be appropriate.

Maurice Corry: Are you finding the results of the research useful in giving you leads and steers in how we deal with younger people with diabetes?

Dr Calderwood: Not many, if any, younger people are using FreeStyle Libre, because at the moment it is not recommended. It would be provided on an individual basis on the advice of a clinician who knows the young person very well. We need to look at its use on a case-by-case basis. However, as the technology is spread not only in Scotland but across the UK and beyond, numbers will come forward, and when we begin to have an evidence base that allows us to say that the technology is safe and effective to use with other groups of people, we will, of course, use it.

Maurice Corry: Has the cabinet secretary built funding for such projects into her draft budget proposal?

Jeane Freeman: The chief scientist office has an allocation in the draft budget, and it is for that office to determine how it uses that allocation based on the research proposals that come forward. Quite rightly, such decisions will be made by people with scientific and medical expertise and not by people such as me. I will ensure that there is the appropriate allocation for the health portfolio in the overall draft budget to allow the chief scientist office to undertake the work. The office will then deal with its allocation according to its assessment of the various research proposals that come forward.

If I am correct, we are saying that use of FreeStyle Libre for under-18-year-olds is possible but it is decided on a case-by-case basis by clinicians based on their knowledge and understanding of and relationship with the individual, as Dr Calderwood said. In a way, the approach is not so different from the peer-approved clinical system approach to drug prescribing. Parallel to that, the Scottish diabetes group and the chief scientist office will consider research proposals that look to build on the evidence globally. We will look at the research base on which a decision to widen access to include under-18-year-olds might be taken.

David Torrance (Kirkcaldy) (SNP): NHS boards have been asked to accurately record the introduction of all diabetes devices in the Scottish care information diabetes collaboration system. Can you confirm that the data is being recorded by all NHS boards? Are there any potential challenges for NHS boards in doing that?

Jeane Freeman: I am not aware of any potential challenges for NHS boards; none has been raised with me. I understand that the boards are undertaking that work. If the committee would find it helpful, I would be happy for us to have a quick look round all the boards and get them to advise us as to where they are with that piece of work, so that the committee has that additional assurance.

David Torrance: Thank you.

09:30

The Convener: You said that you will deliver the devices. May I ask about costs? There was an issue to do with health boards being given an allocation but no funding for the associated VAT costs. We had an explanation about average prices and all that stuff, which—to be frank—was less than compelling. Can we get a commitment or a recognition that if you say, “We will deliver X number of devices”, you must will the means for that to happen, and that the issue to do with VAT will be addressed?

Jeane Freeman: You have that commitment from me. I see no point in embracing improved technologies where they are clinically appropriate but not making sure that, as far as we can, we allocate the resources to enable the improved technologies to be delivered to patients for whom they are appropriate.

Professor Leitch responded on the VAT issue in his letter, to which you referred. I have nothing to add to what he said about how the matter is approached. I assure the committee that boards are never slow in coming to me if they feel that they have not been given the adequate resource for a specific piece of work. If that happens as we progress through this work, we will look at the issue, as we always do.

The Convener: Do you accept the general principle that the cost of something includes what

it will cost a health board to get it so, if you are not funding the VAT element, you are reducing the number?

Jeane Freeman: No. I do not accept that, because, as we tried to explain earlier, boards have an overall allocation for prescribing and, as more and more individuals switch from, for example, finger-prick test kits to FreeStyle Libre, there will be a shift in how the resource is used, away from one and towards the other. I am happy to offer further written explanation of that, but our view is that, overall, that will enable boards to continue to manage the resource within the allocations that they have in the draft budget.

As boards go through the next financial year—if we assume that the draft budget will become the budget and the allocation will therefore remain as is planned—if they think that they are having difficulties meeting all the demands within their overall prescribing budgets, they will raise that directly with us, and we will look with them at what more can be done to assist them.

Emma Harper (South Scotland) (SNP): I thank the committee for keeping me up to date on the petition. I declare an interest as a co-convener of the cross-party group on diabetes. I am also a type 1 diabetes pump user and a FreeStyle Libre user.

I clarify that routine finger-prick testing is still required when people use FreeStyle Libre and that there can be variability in the results because FreeStyle Libre uses interstitial glucose monitoring and not blood glucose monitoring. I wanted to clarify that finger-stick readings are still required to make sure that there is accuracy.

The use of interstitial glucose monitoring raises issues to do with assessing competence to drive. What work has been done with the Driver and Vehicle Licensing Agency on accepting FreeStyle Libre or continuous glucose monitoring, given that they involve interstitial testing? I think that, currently, blood glucose testing is required.

My other point is about children. The cabinet secretary said that children with type 1 diabetes who might be unaware of hypo and have seizure activity at night might benefit from FreeStyle Libre but they would work with their GP or specialist doctor on that, and a person-centred approach will be taken for kids. That point has been raised with me at the cross-party group as well as by constituents.

Jeane Freeman: I ask Dr Calderwood to respond on children.

Dr Calderwood: You are absolutely right. It is about the individual. As you will be aware from the cross-party group, continuous glucose monitoring might be more appropriate than FreeStyle Libre for a child. At the moment, as with many new technologies and medications, the initial body of evidence is from adults. Because of individuals, we then creep, if you like, into expanding the indications. The important point is that those individuals are well known to their clinicians and their conditions are well known. The risks and benefits of any new treatment that does not have a body of evidence for an age group need to be considered so that the safety aspects are covered.

We know that continuous glucose monitoring, the flash glucose monitoring that FreeStyle Libre affords and insulin pumps are of great benefit to children for all the reasons that you will know. At the moment, we do not have the numbers to be able to point to big studies that say that this is the right thing to do, but that will come in time in Scotland and we can learn from the literature across the world.

Jeane Freeman: The DVLA requires sufficient evidence that glucose levels are sufficiently controlled, and it requires that evidence at the United Kingdom level. We are at a relatively early stage of being able to produce that evidence for the DVLA but, as it becomes available, it will be submitted and the DVLA will be asked to consider its approach in the light of that.

Emma Harper: Currently, people need to provide evidence of adequate blood glucose management using finger-stick devices because we are not yet at a point at which the DVLA will accept FreeStyle Libre or CGM results.

Jeane Freeman: Exactly.

Brian Whittle: I should have declared that I am also a co-convener of the cross-party group on diabetes. I apologise for not doing that earlier.

We heard in evidence that a compelling argument for the technology is that it has potential to help children with their sleep patterns because they would not have to be woken up to do finger-prick testing. That has been raised time and again in the cross-party group as an area of concern—and hope, I think—for a lot of people who have children with the condition.

Has any work been done on potential long-term savings to the budget from the introduction of the technology? I am asking about not just savings from not using the current kit, but longer-term savings from our being able to prevent those with the condition from sliding into the need for other, more costly treatments. That is where we want to be with the preventative health agenda. Has there been any long-term consideration of the budget?

Jeane Freeman: That is an important point, Mr Whittle, and I appreciate your asking about it. Where we can access the resources of economic analysts, I am keen that, in a number of areas

across our work, we look to begin to develop that cost benefit approach and link it to the preventative agenda. I think that the preventative agenda needs a reinforcement of that type. I am sure that all of us in this room understand the importance of preventative work, but elsewhere it can feel like something that is nice to have if we can manage it and people can think, "Let's just deal with what's immediately in front of us." There needs to be a stronger base, if you like, for the case.

I have begun some discussions about where we might look to initiate and have that work, which will not necessarily always be from inside the Scottish Government. A number of our major academic institutions have a keen interest in health areas and a lot of expertise in doing that economic analysis, and we are considering how we might identify the areas where we want some joint work to be done to move that forward. As we progress those discussions, I will be happy to ensure that certainly Mr Whittle, but also the committee more widely if members are interested, is informed of how we are doing.

Brian Whittle: Thank you.

The Convener: I call Emma Harper. Be brief, please.

Emma Harper: I will be brief. At the cross-party group on diabetes, we heard from a gentleman who had lost seven stone in weight with FreeStyle Libre, which he had self-funded through social prescribing, family support and so on, and he has now reached the point where he takes no medication for his type 2 diabetes. The likes of FreeStyle Libre can have an application if people so choose, and we would encourage those people to look at different approaches such as social prescribing and family support. Is any research being done on this type of monitoring for those with type 2?

Dr Calderwood: Because the technology has been introduced in the first instance for people with type 1 diabetes, the numbers are just not there for those with type 2. I suspect that people like the gentleman to whom you referred are dotted around the United Kingdom, but the difficulty is getting the numbers to do statistically effective research.

However, I absolutely agree that using all sorts of different methods, as that gentleman has done, is the right approach. It will probably take quite some time before there is enough interest in researching this particular area, but we are starting with something that shows a lot of promise and which will bring us benefits, including the economic benefits that Mr Whittle has referred to. Inevitably, given the numbers of people with type 2 diabetes, the use of these technologies will spread as we get more information about the safety aspects and the benefits.

Jeane Freeman: Ms Sadler can give you additional information about our overall investment in work to help people with their diet and nutrition.

Elizabeth Sadler: We will be investing around £42 million over the next five years to support the implementation of the type 2 diabetes prevention framework that we published last year. It is aimed at supporting people who have been recently diagnosed with or who are at high risk of type 2 diabetes in losing weight or changing to a healthier lifestyle, to see whether it is possible to reverse their diabetes or to reduce the rate at which the complications from their diabetes arise, which will obviously keep people healthier for longer.

Emma Harper: Thank you.

The Convener: I want to ask a final brief question. The committee understands that NHS boards are being supported by a part-time continuous glucose monitoring diabetes specialist nurse. Can you confirm the remit and scope of that role and describe how its impact is being measured? Would you like to see it developed?

Elizabeth Sadler: The purpose of the role is to work with boards and provide support to teams in identifying the most appropriate people with regard to the technologies, and supporting the learning and education that those people will need before they can be prescribed a pump, CGM or FreeStyle Libre. It is a relatively new post, and at the moment, it will last three years. I am not aware of our having done any formal evaluation of it, but I know that it is proving very helpful in supporting boards and that the boards have welcomed the additional help and support that they are getting from the specialist nurse.

The Convener: Given the quite significant statement that has been made about access to the technology, the recognition that it needs to be rolled out and, indeed, the commitment that the Scottish Government has made in that respect, do you think that a part-time post for the whole of Scotland is sufficient to do the groundwork to liberate access to the technology?

Jeane Freeman: Of course, boards already have clinically skilled and professionally expert teams working in this area of diabetes, and the nurse is, in effect, providing additional support in that respect.

We must not allow anyone to think that all that is happening is that a part-time resource is being provided. I cannot recall which member asked about the sharing of good practice—it might have been Mr Whittle. The role also entails involvement in the sharing of good practice between those boards that brought FreeStyle Libre into their local

formularies earlier than others, to help other boards to benefit from that early learning.

At this point, we have had no indication from boards that they require a resource in addition to that three-year commitment. There has been a lot of feedback from boards that the role is proving very helpful to them.

09:45

The Convener: I presume that, in the normal run of things, the Government would look at whether that was the best use of that resource, given the cabinet secretary's suggestion that such work is being done anyway, and at what added value the specialist nurse provides.

Jeane Freeman: No—I apologise if what I said led to that misunderstanding. I did not say that such work is being done anyway. I said that individual boards already have groups of people who are clinically and professionally expert in the area of diabetes and in working with patients with type 1 diabetes and those with type 2 diabetes. The specialist nurse is an additional resource for helping the boards with the new technologies.

As Ms Sadler said, it is early days in the three-year timespan. Evaluation work will be done on whether more is needed beyond the three years, but we are talking about a resource to help boards with the new technologies that is additional to the board-based expertise that they already have.

The Convener: Thank you for that useful clarification. I think that we have finished our questions. Thank you very much for a very positive contribution, cabinet secretary.

In terms of what the petitioner is looking for, we might want to reflect on the evidence. We could give the petitioner and others the opportunity to respond to what they have heard, after which we can draw a final conclusion. Would that be fair?

Members *indicated agreement.*

The Convener: Therefore, we will reflect on the very positive evidence that we have heard today and those with an interest in the petition will be able to make further submissions. At that point, we can come to conclusions on the petition. I thank the cabinet secretary for answering our questions.

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. The petition calls for ocular melanoma sufferers to receive MRI scans of their liver to detect the early onset of metastatic disease of the liver.

The petitioner and Iain Galloway, from whom we have previously taken evidence, have been consistent in outlining what they consider to be the advantages of people receiving MRI scans with colour contrast, rather than a straightforward ultrasound scan. Members have a copy of the most recent submission from Iain Galloway, which expands on his concerns.

Once again, the cabinet secretary is accompanied by the chief medical officer and Elizabeth Sadler. I invite the cabinet secretary to make a brief opening statement.

Jeane Freeman: Thank you very much, convener. I am grateful to the committee for the opportunity to give evidence on the petition, which I know has been open for some time.

Although ocular melanoma is a rare cancer, it is important that those with the disease are treated with equal importance as those who have more common cancers. The disease is managed through our National Services Scotland division at the national specialist Scottish ophthalmic oncology service at Gartnavel general hospital in Glasgow under the direction of two clinical oncologists, Dr Paul Cauchi and Dr Vikas Chadha. Both have advised Scottish Government ministers and officials throughout the committee's consideration of the petition.

I understand that, when they lodged the petition, the petitioners were concerned that people with the condition in England were offered MRI liver scans, but that those in Scotland were not. I am advised that there has never been a difference between England and Scotland in that regard. However, the clinical community recognises that there is variation between NHS regions and departments across the UK in whether MRI scans are offered. The current situation across the UK, including in Scotland, is to follow the Melanoma Focus guidelines, which were approved by the National Institute for Health and Care Excellence in January 2015 and which advise that anyone with ocular melanoma should be offered six-monthly screening of the liver using non-ionising radiation. The most appropriate and commonly used imaging method in such cases is ultrasound.

My understanding is that anyone living in Scotland who is diagnosed with an ocular melanoma will initially be treated by an ophthalmology specialist at Gartnavel hospital—Dr Cauchi or Dr Chadha. Follow-up is provided under the direction of those specialists at local centres and is planned in consultation with the patient. During follow-up, those who are assessed as being at lower risk of developing metastatic disease are offered ultrasound scans, usually at their local hospital, with any abnormalities being followed up using MRI.

At UK and Scottish level, there is no clinical consensus for those at high risk. For all, imaging is

undertaken. For those at high risk, additional imaging, including MRI, is undertaken as clinically indicated. Should a metastatic disease be found, care is transferred back to an oncologist specialising in that particular organ for the delivery of systemic therapy. MRI is not routinely used for all people, and the primary reason for that is patient safety. MRI delivers a dose of radiation and therefore regular imaging can in itself be a risk. The second reason is that the guidelines do not specifically state that MRI should be used and, as I said, there is no clinical consensus across the UK on the use of MRI.

To address the issue of variation across the UK, Dr Cauchi has made great efforts to convene a UK-wide group to update the guidelines and develop a consistent approach. When the chief medical officer wrote to the committee on 17 May 2017, there was intent to convene a UK-wide consensus group. However, since then, the other centres outside NHS Scotland have not been willing to engage in the process. Subsequent correspondence to the committee from officials mentions a Scottish guidelines group, which has been put together by Dr Cauchi, who is actively pursuing the development of Scottish guidelines in the absence of UK-wide consensus. Dr Cauchi has convened a group of clinical imaging and patient representatives, which I understand is looking to report by June this year. I am grateful to Dr Cauchi for pursuing that important work, and I look forward to receiving the group's report in the summer.

I hope that the information that has been provided today will clarify to the committee that people in Scotland with ocular melanoma are recognised by the Scottish Government and NHS Scotland, which is why we have commissioned the national specialist service at Gartnavel. Anyone in Scotland with the disease can have an MRI scan if it is considered clinically appropriate and, thanks to Dr Cauchi, work is under way to try to ensure a degree of clinical consistency in the approach.

I am grateful for the opportunity to make that brief statement and I am happy to answer any questions that the committee has.

The Convener: Thank you. The centre of the issue, which we want to explore, is that the petitioners' experience is that they do not have access to MRI scans. The caveat about the scans being deemed to be clinically appropriate will be the challenge for us all. You mentioned the Scottish guidelines group, which the petitioner and Iain Galloway referred to in their written submission of September 2018. Can you update us on the group? When did you say it will report by?

Jeane Freeman: June.

The Convener: What is the membership and who are the patient representatives? Will they include a patient with experience of what the petitioner refers to as

"the rarity, complex issues and scanning modalities for Ocular Melanoma"?

The petitioners feel that, because the condition is so rare, there is a lack of understanding and their direct experience of it would be relevant.

Jeane Freeman: I am happy to provide the committee with the names of those on the group, which is convened by Dr Cauchi. I understand that it has the relevant clinical specialisms, imaging expertise and a patient with experience of the disease.

Angus MacDonald: The cabinet secretary will be aware that the petitioner and Mr Galloway have also previously highlighted concerns about the experience of ultrasonographers, particularly in terms of interpretation and identifying metastatic spread to the liver from uveal melanoma. How would you respond to those concerns?

Dr Calderwood: The convener has already mentioned the rarity of the condition. We know that there are around five cases of this ocular melanoma per million of the population. In Scotland, that would be around 25 people per year. If we were to look at one of the most common cancers—breast cancer—we would see that one in 12 women will develop breast cancer over their lifetime. That is 80,000 people per million.

We are looking at a disease that is really rare. Most doctors of any specialty and most general practitioners will never see a case in their experience and most of the staff dealing with people with ocular melanoma, other than at the specialist centre, will never before have seen a case. We understand that people who have the disease and have a great understanding of it themselves will find that others do not have that understanding and do not have the detailed knowledge.

It is clear when I look across the various guidelines that there is not clinical consensus on recommendations. In part, that is because of the small number of patients. Even across the UK, the number is small. Also, the research has not confirmed what the best modality of follow-up is and whether, in fact, one type of imaging is of greater value in ensuring that we detect metastatic disease early and, crucially, whether that makes any difference to survival.

We know that for 90 per cent of people with metastatic disease, it will be in the liver, so the right thing to do is to image the liver. Ultrasound imaging would, in routine practice, be the first port

of call. Ultrasound is completely safe; it is non-ionising radiation, so it carries no further risks to the patient. If we are looking at a frequency of every six months, that is a very large number of scans over a person's lifetime. There is not clinical consensus on whether ultrasound alone should be the modality or whether ultrasound, as a very safe procedure, followed by MRI, is the right thing to do. MRI in itself, with quite a significant dose of ionising radiation, carries with it risks, in particular if there are multiple scans over a patient's lifetime.

Angus MacDonald: Thank you for that explanation.

Brian Whittle: In his most recent submission, Mr Galloway states that, because

"Ultrasound scans are not recorded",

the results of those scans are only open to interpretation at the time, whereas MRI scans are much clearer and are available for a second opinion because others can look at them. Do you have an opinion on Mr Galloway's concerns?

Dr Calderwood: I suppose I am considering the use of ultrasound in general terms. The routine of an ultrasound scan is that still images are taken during the scan and those would be recorded and kept as part of a clinical record, so pictures would be available. Obviously, if an abnormality was found, a picture would be taken. Also, if you are looking in particular areas, metastatic disease can be seen in some areas of the liver earlier than in others. That is to do with the way that it spreads. There would then be pictures of clear areas of the liver to put in the patient's record.

A report is written but, if a second opinion is needed, still images are always taken of ultrasounds, which form part of the patient's record. I do not think that there would be video, because it is not a dynamic scan. In my specialty, which is obstetrics, we can take a video of the ultrasound to be saved and looked at again. However, it is not the case that there are no records after an ultrasound or that somebody cannot go back and look at images.

10:00

Brian Whittle: I am not particularly expert in this, so I ask for clarity about what I think Mr Galloway is saying. If people are scanned every six months, are ultrasound stills comparable? Would being able to compare one six-month scan with the next be adequate to highlight any abnormality? Would an MRI scan not necessarily add any complexity?

Dr Calderwood: This is not my expert area, so I have been reading and taking advice from experts. I understand that the view is that, in cases where ultrasound is performed, it would pick up metastatic disease. The clinical consensus is that, if there are abnormalities or in groups of patients who are seen to be at high risk, there is not agreement across the country about whether to move directly to MRI scanning in every case. Everyone in Scotland will have direct access to ultrasound scans, and those people who are at high risk—there are various clinical criteria that will put people into a high-risk category, such as age and certain appearances of the melanoma—will have an ultrasound scan that progresses to an MRI, or an MRI scan directly.

At the moment, we do not have the evidence as to whether one approach will clinically change the outcome for people over a different approach. We do know that the significant dose of ionising radiation that would be given in the course of regular six-monthly MRIs has the potential to cause harm. Just to be clear, that harm would mean the risk of incidence of some of the blood cancers being significantly increased over a patient's lifetime. That risk is not insignificant. A large dose of ionising radiation at very regular intervals carries that risk.

The Convener: One would have thought, then, that there would be a clinical consensus not to do it.

Dr Calderwood: It is always a balance of risk.

The Convener: We received a submission from Neil Pearce and Professor Christian Ottensmeier from the University of Southampton, who are cancer specialists, and they say:

"we tend to do an US first because it is cheap ... not because it is ... better".

They also say that MRI is

"not harmful to patients."

That seems to directly contradict your justification for not recognising, for something that is very rare, the request in the petition that we have MRI rather than ultrasound.

Jeane Freeman: Convener, I think that it is an unfair characterisation of what we are saying to say that we do not recognise that. We are working on the basis that there is no clinical consensus here.

The Convener: With respect, Catherine Calderwood said that you recommend not using MRI because of increased risk. The evidence that we have is that it is not about risk, but about cost.

Jeane Freeman: No. I am sure that Dr Calderwood is very able to speak for herself, but what she said was that there are risks associated with frequent MRI scans with regard to increased incidence of blood cancers. There are different clinical views as to whether that risk is balanced by reducing risk in terms of identifying metastatic

spread into the liver with MRI. There is a balance of risk here.

I hope we all understand that, in almost every area of health and medicine, we ask our clinicians to constantly balance risks, and we work from how they balance those risks. That is precisely what Dr Cauchi is trying to resolve. He is trying to find a clinical consensus so that there can be greater consistency. However, I refute absolutely the suggestion that what lies behind that is any consideration of cost. Of course those who provided evidence to the committee are entitled to their view, but I disagree with that view. It is not about cost. It is about my being led, as cabinet secretary, by clinical opinion and clinical decision making—as I should be. The current difficulty is around the absence of clinical consensus, and I am grateful to Dr Cauchi for trying to help us to resolve that.

The Convener: Of course, but do you accept that part of the problem is that there are so few people who have the condition and that, although you are doing research and trying to establish the balance of probabilities and risk, there is no body of evidence, and if you wait for that body of evidence, those people may be denied the treatment that they need?

You talk about the balance of risks, but Professor Ottensmeier is explicit in saying that MRI is "not harmful to patients." In the context of the risk that patients may be facing in not being given an MRI scan, do you accept that the general view that you have expressed about MRI bringing its own risk should be recognised and balanced against the experience of the patients?

Jeane Freeman: Convener, you have encapsulated exactly what the clinicians, led by Dr Cauchi, are trying to resolve. I do not think that it is accurate to say that we are waiting for a body of research. We have a group that is actively engaged—in the absence of being able to secure UK-wide participation—in trying to resolve the issue at a Scottish level and reach a level of clinical consensus, which would address many of the issues that the petitioner and members of the committee are raising.

It is not about long-term research. It is about actively working to see whether it is possible to reach greater clinical consensus to guide the work, and the group will report soon, in June. Although there is, as you said, a clinician who believes that MRI scans do not carry risk, there are clinicians who would come forward and say that they do. That is the heart of the matter, and—

The Convener: It is a balance of risk—

Jeane Freeman: Absolutely.

The Convener: It is a balance of risk that the patients say they are being denied, and if they lived in other parts of the country they would not be denied it. I am sure you can appreciate that, for them, this is not a theoretical argument about a balance of risks. It is about their sense that they are not having access to treatment on the basis of an argument, which is being propounded by Catherine Calderwood, that is not agreed with by everyone in the medical profession. I presume that not everyone agrees with it, or people with the condition would not be routinely given MRI scans in other parts of the United Kingdom.

Jeane Freeman: As I understand it from what Dr Calderwood has said and what I have read, in those circumstances, it is possible that there are areas in Scotland where people will move to the MRI scan rather than ultrasound, because there is a difference of view between clinicians about what is the most appropriate next step. I am absolutely not dealing with this as some theoretical debate. I am very conscious of the impact on individual patients. However, it is not for me as the cabinet secretary to overrule clinical experts in the area. Rather, I am grateful to Dr Cauchi for the work that he is doing. I look forward to his report and his recommendation on how he and his fellow clinicians should proceed.

The Convener: I appreciate that. Nobody is suggesting that you should overrule clinical evidence. The problem arises, and the petitioners repeat this point, because their condition is so rare. It is not that it is being overlooked, but it is not properly understood and there is not a body of evidence on it. Therefore, they feel that they are further punished, in the sense of the way in which the condition affects them, because there is not enough evidence on it.

I will bring in Maurice Corry at this point.

Maurice Corry: There are also concerns that there is a large proportion of patients in Scotland whose risk status is unknown. In Mr Galloway's report, he suggests that that is a consequence of many issues including some missing biopsies and metastatic spread of the disease being picked up too late. How do you answer the point that is made by the petitioner and Mr Galloway that ocular melanoma patients should be treated as being at high risk?

Dr Calderwood: The petitioner must be congratulated on bringing the issue of this rare condition to the committee and, in doing so, highlighting—as I said in answer to Mr MacDonald's question—a condition that is so rare that most healthcare practitioners will not have heard of it, let alone come across it in a lifetime of practice.

On the convener's point, the highlighting of the condition has led the two experts in Gartnavel hospital to go back and look at the evidence that we can get from the small number of cases in Scotland. I understand that an audit is being performed of the cases in Scotland—cases from the past, and looking forward. The audit aims to tie up the gaps in the data that you and the petitioner have pointed out, so that, where there is consensus, our guidelines could state that, for example, biopsies or certain tests needed to be done or a certain amount of follow-up was needed over particular periods of time, and the specialist centre would co-ordinate all of that. From the audit—I do not know its publication date—we will have more knowledge of the disease across Scotland in the people whom we have audited, and we will know where the gaps are.

As with many rare conditions, people obviously want to receive at least some of their treatments closer to home. For example, if someone lives far away from Gartnavel, they can have an ultrasound at their local hospital. Importantly, the audit will pick up whether those people are receiving the treatments that they should receive as if they were being treated in the specialist centre. We want to know whether we are giving the right treatment at specialist level whether that is delivered locally or at Gartnavel. We would not want a situation where patients who lived locally to Gartnavel or were able to travel there were getting a specialised service while others received services locally that did not tie up or co-ordinate with that.

I hope that the audit will highlight any gaps that exist with a view to improvements in relation to some of the data issues that you and the petitioner have highlighted.

Maurice Corry: Will the report, which we hope will be published in June, also look at the determining of risk?

Jeane Freeman: Yes. The updated guidelines that come from the work that is being done by clinicians and imaging experts—and which involves patients—will consider new evidence on genetic risk, which will inform the definition of high risk.

Maurice Corry: Okay. Will the audit draw on the evidence from England? My very close friend's son has this problem. Fortunately, it was caught by having an MRI scan and he is now in the six-month scan situation. He is a runner and he is leading a normal life, but he had to be medically discharged from the Army—from the special forces—so it is a tragic situation. The systems in Hereford and London picked it up and, so far, he is clear. Will the authors of the audit draw on the English results, too?

Dr Calderwood: I understand that they are reviewing all the evidence that is available. The plan is that, using that evidence and what we have from the small numbers in Scotland, we will pull together a consensus with much more standardised guidance for use around Scotland.

Maurice Corry: I realise that, in England, things are better in some patches than in others—Liverpool and Southampton, for example, are extremely good, and I understand that Sheffield is coming up behind them. It is important that we look beyond the borders of Scotland.

10:15

David Torrance: The petitioner has consistently made the point that ocular melanoma patients are referred only to ocular oncologists and should be seen by medical oncologists who have experience in liver disease. What is your opinion on that, cabinet secretary?

Jeane Freeman: My understanding is that, for the treatment of ocular melanoma, patients are seen by the ocular specialist, but if the cancer is detected as having spread to another organ, the oncology specialist in that organ will pick up on the treatment.

The Convener: The petitioner and Mr Galloway presented further arguments about the benefits of MRI as opposed to ultrasound. Access to MRI is often arranged in some places in England through a process of identifying and explaining the risks, but that option appears to have been closed down for patients in Scotland. Moreover, the option of joining clinical trials that offer new and promising therapies is denied to patients who have not had an MRI scan.

Apart from the point that was made about risk, which is obviously a matter of dispute, are there particular barriers or challenges about which the committee has not yet been informed that prevent ocular melanoma patients from accessing MRI scans?

Jeane Freeman: On the latter part of your question, my understanding is that there are no other factors in the way; it is about the absence of consensus on the balance of the risks. As I said, Dr Cauchi is trying to move us forward by looking at all the evidence that is available and considering imaging expertise, patient experience and so on. I do not know of additional barriers.

The Convener: If someone does not get an MRI scan, they cannot get into a clinical trial that might help their condition. You can see that, from the patient's point of view, there is an incentive to have an MRI scan rather than ultrasound.

Jeane Freeman: Yes, I understand what the petitioner is saying.

The Convener: Does that not change your view on what should happen?

Jeane Freeman: In truth, convener, given that I am a non-medically qualified cabinet secretary, it should not change my view. What should change my view is the work that is coming from clinicians and imaging experts, including work on patient experience, which I expect to receive in June. I think that the petitioner and other people would be reassured to know that it is not an unqualified politician who is changing their view and reorientating how clinical care is delivered—that is for the clinicians to do.

The Convener: It is clear to the petitioner that there are clinicians who think that the approach that is being taken is not the right one. It is not that there is no clinical evidence; it is about which clinical evidence you respond to, or the balance of the clinical evidence. Can I ask—

Jeane Freeman: Sorry, convener, but I must say that I do not believe that that is the case. I am not responding to one set of clinical views over another; I am looking for clinicians to find a way of reaching a degree of consensus that allows us to move forward and that is based on all available evidence. That is exactly what I am doing.

The Convener: Will you at least concede that the committee has been given evidence by some clinicians that the approach in Scotland is disadvantaging patients because they are not routinely getting MRI scans and that, to go back to David Torrance's question, the fact that they go to an ocular oncologist rather than someone with broader expertise in the liver might mean that there are delays that cause problems?

I have another question. I appreciate the amount of time that you are giving to the petition. In the context of our consideration of the petition, there appears to be some difference of opinion about the merit of peer-reviewed evidence. The Scottish Government has indicated that a Scottish guidelines group will review articles. Has that been done? Are you aware of recent developments in that regard?

Jeane Freeman: Dr Calderwood will respond initially to the latter part of your question, and I might add some comments. First, however, I say for the record that I absolutely appreciate the fact that the committee has heard from clinicians who believe that MRI scans should be the first port of call here. What I am saying is that other clinicians who are equally expert in the field would come before the committee and present the opposite view. That is the crux of the matter and the issue that we are trying to resolve.

I ask Dr Calderwood—

The Convener: Are you saying that there are clinicians who believe that people ought not to get MRI scans?

Jeane Freeman: Sorry?

The Convener: You said that there are people who would present an absolutely opposite view. Which clinicians believe that there ought not to be an MRI scan for those who have the condition?

Jeane Freeman: No, that is not what I am saying. The issue is that there are clinicians who believe that the risk that is posed by frequent MRI scans outweighs the benefits of having them, and there are others who take a different view.

The Convener: There are clinicians who have explicitly said that they believe that there is too much risk involved in giving people with this very rare condition an MRI scan. However, that is not the opposite of what Professor Ottensmeier is saying.

Jeane Freeman: No. What I think I was trying to say to you was that you will get different views on the matter depending on the clinicians who give evidence to the committee. I do not think that that is disputed.

The Convener: With respect, cabinet secretary, you talked about clinicians presenting the "opposite view". We have not received any evidence that puts forward an opposite view to the fact that these patients would benefit from an MRI scan for their condition. You are saying that there are people who are cautious with regard to the general implications of using MRI, but that does not address the specific issue of what is a very rare condition. We have not had clinicians saying the opposite of what Professor Ottensmeier has said. They might be reluctant to express a complete view on the matter but, although their general view is that there might be a risk attached to MRI, they are not saying that, as far as this condition is concerned, there is too much risk in having an MRI scan.

Jeane Freeman: No—the issue is not with there being an MRI scan, as you have said. I apologise if I used the wrong words, but there is a view among clinicians that the frequency of MRI scans that is required poses the risk that Dr Calderwood has outlined.

The Convener: With some conditions, there will always be some risk—indeed, you have referred to the balance of risk—but, to be clear, I say again that the committee has not received any evidence from clinicians that, as far as this condition is concerned, there is too much risk attached to a routine MRI scan. To be kind, I would say that the jury is out on the question, and you have said that you hope to have an answer to it by June.

Jeane Freeman: What I am hoping to have by June is the report from Dr Cauchi's group, if it can make progress on the matter.

I think that Dr Calderwood wanted to provide some information with regard to the other part of your question.

Dr Calderwood: On the Scottish guideline group that is looking at peer-reviewed evidence, I can provide the committee with a note to confirm whether that has been done.

The Convener: I do not know whether committee members have any more questions, but I have a final one. What do you expect to happen once Dr Cauchi reports? Will further time or a delay be required while standardised guidelines are developed? We might want to write to Dr Cauchi, asking him to give evidence, because, as the cabinet secretary has said and as we recognise, work is clearly being carried out on the matter. Indeed, we are not suggesting otherwise. What will be the next stage once he reports?

Jeane Freeman: The work that is being led by Dr Cauchi is about developing Scottish guidelines on liver surveillance, and his report will, I expect, include those revised and agreed—or introduced and agreed—guidelines. As I have said, they will consider new evidence on genetic risk to inform the definition of "high risk" and will advise on the best approaches for long-term follow-up, including continuing to offer local services along the lines that Dr Calderwood has mentioned, to ensure greater consistency of approach and access to those services.

Dr Calderwood: An advantage is that the two doctors who are involved are the specialists for Scotland, so they see every patient with the diagnosis as well as seeing them for regular follow-ups.

In contrast with some of the more common cancers, in respect of which there are lots of clinicians to communicate with, we will have guidance that has been produced by the group. The group involves the two specialists who see all patients and who make sure that there is an appropriate follow-up, which may be done locally. The specialists also follow up with the patients in person at Gartnavel on a regular basis. The implementation of, or any thought about, delay is removed because the two individuals are involved with every patient.

The Convener: If the report comes in June, will the guidelines be implemented from June?

Dr Calderwood: Yes, if the report has been written in the form of guidelines that need to be implemented. The specialists are writing the guidelines for themselves and not for other people. The guidelines will guide the scanning and so on that we are discussing. The people who are pulling together the evidence are the people who will implement the guidance.

Maurice Corry: Dr Calderwood, have you seen the terms of reference that Dr Cauchi is proceeding with at the moment?

Dr Calderwood: I have not seen them as written terms of reference.

Maurice Corry: You have not seen the terms of reference of what the report is, we hope, going to produce.

Dr Calderwood: I have seen a summary of them, which the cabinet secretary has read.

Maurice Corry: The terms of reference are in black and white.

Dr Calderwood: I have not seen them written as formal terms of reference, but I have seen—

Maurice Corry: Have you signed them off as being appropriate?

Dr Calderwood: I do not sign them off. That would not be appropriate, as I am not an expert in the field.

Maurice Corry: Let us go back to the convener's comment about the risk of MRI scans. Will there be a section in the report that addresses the scientific evidence of the risk element of multiple MRI scans? Will there be anything about that specifically?

Dr Calderwood: I understand that the evidence is being pulled together in order to give guidance on the routine management of imaging for follow-up for such patients.

Maurice Corry: Do the terms of reference clearly refer to scientific evidence?

Dr Calderwood: We will need to gather what evidence there is in order to produce standardised guidance, as we would in any—

Maurice Corry: So, you cannot say here today that that is actually clear in the terms of reference?

Dr Calderwood: Sorry—we are talking about two different things. I understand that guidance will be produced on the imaging that will be recommended in the follow-up for those patients. Beyond that, I do not know exactly what has been committed to, although I could ask to see the terms of reference.

Because there is such a small volume of scientific evidence, which relates to some rare conditions, there might have to be other ways of coming to a consensus. That might be done by having a shared decision-making conversation with the patient or achieving a consensus among experts rather than basing a decision purely on

scientific evidence if it does not exist in any great volume.

I am now talking about detail that I have not discussed with the chair of the group. I can get the terms of reference for the committee, if that would be helpful.

Maurice Corry: That would be good, because, as the convener says, there is a question about the scientific evidence. We have to be clear about where we are with MRIs. I visited a nuclear power station recently, and there are very clear guidelines on such visits, which are written by scientists. In this case, the users of science are the clinicians—are you with me?—and we need those scientists to give clear evidence. I am very surprised that you do not have a very clear view of the terms of reference in respect of that specific area.

Dr Calderwood: I would not routinely see such detail, Mr Corry. Given the situation that we are in, the scientific evidence must not come down very clearly on one side or another, or we would not be here.

Maurice Corry: Granted.

The Convener: That is a circular argument that the petitioner would find difficult to break into.

I will finish with a quote from Iain Galloway's submission. You may not be able to respond to it, but he makes this point, which I think is a powerful one that you may want to reflect on. He says:

"around 50% of all ocular melanoma patients have the disease return, and in those 90% or so in the liver. This same huge figure (which is considerably higher than many other cancers) of 50% will be the proportion of those whose risk is indeterminate whose cancer will return. That's a significant proportion of our patients at risk who aren't being appropriately scanned."

We should also note that

"pharmaceutical companies and those sponsoring clinical trials will simply not permit ultrasound scans as sufficient evidence of disease spread (which is why they demand MRI) and we consequently deny this opportunity to our 'indeterminate risk' cohort too."

Do you understand why that has become such a significant issue for the petitioner and those supporting her?

Jeane Freeman: Yes, I do. Our specialists at Gartnavel also understand that, which is why they have initiated and are leading work to address some of the issues that the petitioner raises.

The Convener: That brings us to the end of our consideration of the petition. It has been very useful to try to tease out the issues that have driven the petitioner to lodge the petition with the committee and those issues that arise from the evidence given by Mr Galloway.

We have said that we might like to hear from Dr Cauchi about the work that he is doing. As the cabinet secretary noted, the clinicians who are working in the field have a great deal more expertise than us. We would also want to hear from the petitioner and Mr Galloway, as well as from others who have an interest in responding to the evidence that we have heard.

Brian Whittle: I agree. It is important that we at least link up the concerns raised by the petition to the current evidence gathering that is being carried out by the clinical experts, so that they are aware of those concerns.

Maurice Corry: I would like to hear more about the scientific evidence of the risk of MRI, too.

The Convener: Okay. We can pursue that, too.

I thank the cabinet secretary for her evidence on the petition. To be charitable to us all, I suggest that we take a short break.

10:31

Meeting suspended.

10:40

On resuming—

Myalgic Encephalomyelitis (Treatment) (PE1690)

The Convener: The final petition for consideration is PE1690, which was lodged by Emma Shorter, on behalf of #MEAction Scotland, on the review of treatment of people with myalgic encephalomyelitis in Scotland. I welcome back Emma Harper MSP and Mark Ruskell MSP for consideration of the petition.

In previous written and oral evidence, we have heard concerns about the consistency of treatment for ME sufferers across health boards, about the training and education materials, about the efficacy of cognitive behavioural therapy and graded exercise therapy, and about the level of investment in biomedical research that the Scottish Government announced recently.

Recent written submissions have been included in our meeting papers, and a further submission that has been received from #MEAction Scotland has been provided for members for this morning's meeting. The Cabinet Secretary for Health and Sport is accompanied by the chief medical officer and Elizabeth Sadler.

I invite the cabinet secretary to make a brief opening statement before we move to questions.

Jeane Freeman: Thank you very much, convener. I am grateful for the opportunity to

contribute to the committee's consideration of the petition on ME.

Our written submission of 12 July last year sets out in comprehensive terms our response to each of the points that have been raised by the petitioner. I am happy to answer any questions that the committee might have on the matter.

I start by making a fairly fundamental but important point to people who live with ME, which is that I believe you. I believe that ME is a disease that limits the quality of your life, I hear what you are saying to us, and your experience matters to me, as the cabinet secretary.

Yesterday, I was pleased to meet the petitioner, Emma Shorter, and her mother, Janet Sylvester, to hear at first hand the impact that ME has on Emma's life and on the life of her mother, as her carer. Although we had limited time in the meeting, it was very helpful to me and I assure the committee that I want to make progress and to make life better for people such as Emma who live with the condition.

However, in order to make progress, we must recognise the position from which we are starting. There is clearly a lack of evidence about what causes ME and, from that, how to treat ME. We need more research into the condition. The only way to build an evidence base that can inform treatment options and the development of service is by enhancing the research base. The Government does not initiate research, but we can and will work with the ME community to try to enhance the research base.

Over the past 18 months, we have been developing Scotland's first national action plan on neurological conditions in co-production with partners and stakeholders, including people who live with neurological conditions, their carers and their families. The five-year plan is wide ranging and has been welcomed by Scotland's neurological community. We have engaged with the ME community and feedback has been considered by our national advisory committee during the draft plan's development. Given that the plan is broad and aims to make improvements for everyone who lives with a neurological condition, it does not include condition-specific measures. However, we will continue to take on board any feedback that we receive through the consultation process. The consultation is open until 8 February, and I encourage people to continue to participate in shaping the final plan.

We will continue to work closely with others, including the third sector, to support the work that they do for people who live with ME. In recent years, we have invested just under £0.5 million in funding towards that purpose.

I look forward to taking questions from the committee on the three main areas of the petition.

10:45

The Convener: Thank you very much, cabinet secretary. I am sure that the petitioner very much appreciated the opportunity to speak to you directly. Members of the committee have had representations from people who have ME. My sense is that they have a very strong feeling of not being believed and, as a consequence, being given treatments that make things worse and compound the already challenging circumstances in which they find themselves.

You mentioned the national action plan that was recently published by the national advisory committee for neurological conditions but, as the petitioners note, there is no data on the current prevalence of ME in Scotland. Do you believe that the national action plan can be relevant to people with ME, given that there is such a lack of data and a lack of understanding of the illness among neurologists?

Jeane Freeman: I think that the current draft action plan could be enhanced by the contribution that #MEAction and people who live with ME could make to the consultation, which would help us to understand better what those individuals need from the action plan. I completely take their point about the absence of data and research on the subject, but the action plan is not designed to be specific to any particular neurological condition. It aims to identify a common set of actions that should be taken that would assist people who live with a neurological condition, regardless of what the condition is.

As the action plan is developed, I would expect people who live with ME to say, "That set of actions is fine and it works for us, but you've missed these other needs that are specific to us." We would want to look at that and to work with them to see what more we need to do.

As the petitioner and I recognise, there is an absence of research. We might want to look at what more the Government could do in that regard. The absence of data means that it is right that we should work on the basis of the lived experience of ME sufferers. That is why, in addition to the very brief meeting that I had yesterday and further such discussions, I need to hear from ME sufferers so that they can input into the consultation on the draft action plan.

Ms Sadler has a couple of points to add.

Elizabeth Sadler: The data on the number of people with neurological conditions that is included in the draft action plan was taken from Information Services Division data, and we absolutely

recognise that it is not complete and does not include people with ME. There is a specific commitment in the plan that is about improving the range and depth of data on the number of people affected.

From other sources, we estimate that there are around 20,000 to 21,000 people in Scotland with ME, so it is a disease that is prevalent across the country. The ME community has been very active in engaging with the development of the plan. For instance, we did some work on a lived experience survey with the Health and Social Care Alliance Scotland, and 33 per cent of the responses to that survey were from people with ME. We are seeking people's views and we are committed to improving the data on the number of sufferers, which could potentially be followed up by research.

The Convener: We are talking about a condition that I was aware of 30 years ago. There was a lot of scepticism and a lot of unhelpful commentary on it in the 1980s. I worked with a colleague who had the condition, and it was evident to me that it was a significant problem. Why is it the case that, 30 years on, ME sufferers are almost still at the point of proving that they exist, because they do not appear in the data?

Dr Calderwood: Like the convener, I first came across people with ME a long time ago—in my case, as a junior doctor in Glasgow, when I did a regular clinic at Ruchill hospital in Maryhill. It was very clear to me then that ME was a condition that was highly debilitating.

ME is a very complex condition. The World Health Organization defines it as a neurological condition, but it is a diagnosis of exclusion. People come forward with a wide range of symptoms including nausea and dizziness. Extreme fatigue is always present, which is not helped by any amount of sleep or rest. People can experience muscle pain, and in extreme cases people do not have enough energy to get out of the house. The range of effects on the person's life is also wide. In the most severe cases, people can be bed bound, have extreme sensitivity to light and noise and have an extremely poor quality of life. Others are able to work and manage their illness.

In scientific terms, ME is somewhat unusual in that there is no test, because there are no biological markers. We cannot do a blood test or an imaging test that will come back with a report saying, "This person has ME," and therein lies much of the issue. I think that that is why, in the many years since the convener and I first had contact with people with this very real and very debilitating condition, things have not moved on.

We have no means of diagnosing ME except by exclusion, and we have no cure. We do not have a mechanism by which we can create medication or find a treatment through the usual modality in medicine. Because we do not know the cause, we do not have a way of researching how a cure could best be found. The literature across the world shows that that is being struggled with. In Australia, a committee is grappling with similar issues to the ones that the petitioner describes. In the US and other countries, the issue that the convener mentioned is prevalent—the fact that there seems not to be recognition of the condition.

We are talking about something that we have been aware of for many decades without, it would appear, making much progress. I hope that, given the issues that the petitioner has highlighted, we in Scotland may be able to start to move forward rather than saying that this is something that cannot be done.

The Convener: Thank you. That is very useful.

Maurice Corry: Cabinet secretary, will you ensure that adequate resources are made available to the information gathering group so that we get as much data as possible on the prevalence of ME in Scotland and to ensure that no stone is left unturned?

Jeane Freeman: Yes, we will. As Ms Sadler said, the draft action plan contains a commitment to improve data collection and the sources of data. When the draft action plan becomes a plan, the commitments in it will be resourced.

Maurice Corry: So that will follow on from the draft plan. You will make that commitment to make sure that it gives the end results that we are looking for.

Jeane Freeman: Well, to make sure that it produces improved data.

Maurice Corry: Yes—sorry.

Angus MacDonald: My question is also about resources and your plan to enhance the research base. Will the Scottish Government provide funding for a patient-led national ME strategy to address the issues that have been raised in the petition and in the evidence that we have seen to date?

Jeane Freeman: There are a number of factors. First, as I understand the issues that the petitioner raises, and from the brief opportunity that I had yesterday to have the personal conversation that I mentioned, there are issues to do with what can be done to enhance the research base.

I will pick up on Dr Calderwood's point about ME being a diagnosis of exclusion. We must ask what research can be done to move away from that and see whether there are other ways of reaching a diagnosis and treating the condition. Along with Dr Calderwood and the chief scientist office, which, as we heard, is part of her locus in the Scottish

Government, I am very committed to looking at how we might enhance the existing research base, which must include reaching beyond Scotland. As Dr Calderwood has said, other countries are grappling with similar issues, so we need to connect with where they are and what they are discovering so that we can enhance what we have.

However, along with the people who are living with ME, we also need to look at the care and support that they require. We should not wait until we have a better research base and greater clarity on what treatment options might be appropriate. People are living with ME right now, so we need to look at the work that needs to be done to increase awareness and understanding of the condition and, from that, the care and support that sufferers need. We want to work with #MEAction Scotland and others to understand better what needs to be done and then to put it in place.

I am not sure whether that completely answers your question, Mr MacDonald. I guess that I am saying that I need to know what we need to do, and then we will bring to bear the resources to ensure that it happens.

Angus MacDonald: You are not ruling out funding for a patient-led national ME strategy.

Jeane Freeman: No, I am not. I hope that committee members know that I am very committed to the importance of lived experience in contributing to our thinking, policy development and understanding across a range of issues that we need to look at. It is not exclusive, but it is a very important element in this area, in which we have a significant body of patient-led experience to work from.

Brian Whittle: The petitioner has expressed concern that some health boards continue to offer graded exercise therapy and cognitive behavioural therapy as treatments for people with ME, despite there being little evidence that CBT is effective for it. You said that there is an absence of data and that you are having to rely on lived experience. With that in mind, would you consider requesting that such treatments be withdrawn from the published material prior to any review of the NICE guidelines?

Dr Calderwood: From my experience in clinics looking after people with ME, it is clear that the illness affects people in a wide range of ways. We have also heard that from the petitioners and we can read about it. I have said that we know that there is not a cure. Perhaps the issue is that some treatments have been deemed to be "the treatment" and therefore suitable for all. Clearly, in some cases such treatment has been continued with despite the patient not finding it to be beneficial or, worse, finding it to be detrimental.

Previously, you and I have talked about realistic medicine. Two of my fundamental principles on that are shared decision making and a personalised approach to care. Let us look at the issue of continuance of any kind of treatment when the patient is telling the practitioner that it is not beneficial and, in fact, is detrimental to them. Why would we continue with that and push somebody into something that clearly, from their experience, is not right for them?

11:00

However, we know from the work of the pilot in Lothian that some of those therapies have been beneficial for some people. That is where I would bring in shared decision making and a personalised approach to care. What is right for one person may not be right for someone in a different situation, so we have to discuss the treatment with people. We would not continue a treatment if it is not right—although I know that that has happened, which is a matter of regret—but some treatments might be helpful for some people, as long as they share in that decision. Therefore, we need to be cautious about withdrawing a particular treatment but, on the other hand, we must not continue with a treatment when it is clearly not right for the individual.

Jeane Freeman: As I am sure members know, we have the Scottish good practice statement on ME. The guidelines in that statement recognise that some treatments are controversial and they are clear that nobody should be required to have a treatment that they do not want, although, like Dr Calderwood, I recognise that that has not been the case in every circumstance.

That goes back to the earlier point about the need for awareness raising and education among our clinical community to ensure that people know about the Scottish good practice statement on ME, which says clearly that, with ME, as with other matters, treatment decisions should involve the patient, and that patients should not feel compelled to undergo a treatment that they do not want. That is the route that we should pursue. Given the evidence that those controversial treatments produce a benefit for some, rather than withdraw those treatments, we should assert that people should be actively involved in decisions on their treatments and on whether to engage in those treatments.

Brian Whittle: Given the lack of data on and understanding of ME generally across the medical profession, on which we have heard evidence, how can you cascade that approach? We have heard a lot of evidence that some medical practitioners still deny the existence of ME, which must be a terrible experience for an ME sufferer. How do we cascade that approach into front-line

services? For me, that has always seemed to be one of the key elements in relation to this issue.

Jeane Freeman: I will say two things in response to that, and Dr Calderwood may want to add to them.

As there is a lack of sufficient evidence and research, it would not be especially helpful to get involved in an argument between clinicians who recognise ME and those who do not. Considering how we can enhance the research base will assist us in resolving that question. The absence of sufficient research can be used as a reasonable ground for individuals to pursue different arguments in relation to whether they accept that ME exists. I completely understand that people must feel more than frustration if they have the condition but it is not accepted or recognised as a medical condition.

On how we enhance the research base, I have asked the chief medical officer to consult the chief scientist about what more the Scottish Government might do to assist our academic communities to increase the level of research. We have provided initial funding to support a PhD student to begin some work, but we might be able to do more in that regard.

How do we make sure that the good practice statement is more widely understood? With our networks in the clinical community, through the chief medical officer, and with the health board community, through my locus, we need to look at how—alongside the statement of good practice—we increase awareness and understanding in order to reduce the incidence of individuals who feel that they are being compelled to take a treatment that they do not want.

Brian Whittle: Surely, given the length of time that we have been aware of ME, nobody should now deny the existence of the condition. Surely, we cannot accept medical practitioners taking the opposite view. That has to be tackled—it could be tackled right now.

Jeane Freeman: I ask Dr Calderwood to pick that up.

Dr Calderwood: As a result of the petition, and because the statistics show that such a large number of the medical profession—I think that it is up to 50 per cent of general practitioners—do not accept ME as a condition, we undertook to write to Sir Peter Rubin, who is the chair of the board for academic medicine. He has distributed the letter to the deans of Scotland's medical schools with information highlighting the condition and some of the detail that I gave earlier, so that that is incorporated into the schools' curriculum. We cannot dictate what they put in their curriculum, but—this is not an immediate solution—teaching our medical students, who are our future doctors, about the condition will change attitudes. That approach has not previously been focused on.

Brian Whittle: For the avoidance of doubt, there is no way that we can say that ME does not exist as a condition; there is no way that we can deny that. If that is the case, surely there must be a way to cascade to front-line staff that it will no longer be acceptable to deny the existence of ME.

Dr Calderwood: I confirm that the WHO has a definition of ME/chronic fatigue syndrome; it is a World Health Organization-defined disease.

Brian Whittle: I am sorry to push you on this but, therefore, we cannot accept any of our medical practitioners denying its existence and denying access to treatment.

Jeane Freeman: This Government absolutely accepts the World Health Organization definition, so we say to practitioners, "The World Health Organization, this Government and NHS Scotland accept that this condition exists, therefore, we expect you, in carrying out your clinical practice, to operate on that basis." There is no reason why we would not make that crystal clear, and I am very happy to make that crystal clear.

However, as frustrating as it is, we nonetheless all have to accept that it is right that a clinician's decision—this applies to their views, decision making and how they work with an individual patient across the whole spectrum of medical conditions—cannot be countermanded by me. I cannot instruct them in that regard. I can say what the position is of NHS Scotland and the Government and, therefore, what I expect, but I am not in every clinical situation and consultation.

I can make sure that clinicians are aware of and understand what the statement of good practice says, and that they are aware of our expectation that they will work to that statement of good practice. We will then look at how we can support individual patients, including when they express their rights not to undergo treatment that they do not wish to undergo.

There are a number of ways of going about this, but I cannot issue an instruction to clinicians.

Brian Whittle: I am sorry to push you again. I absolutely accept that you would never countermand any medical diagnosis or treatment, but I am making the point that we cannot have medical practitioners who, before treatment, deny the existence of ME. That is what I am getting at, and I want to ensure that we can do something positive about that.

Dr Calderwood: Regardless of what a medical practitioner believes, if somebody presents with those symptoms, they need treatment and help with those symptoms. We would be able to say that the list of symptoms that I have discussed are

symptoms that need to be treated. Some of the frustration that petitioners and medical practitioners feel comes about because the range of treatment options is limited and their knowledge of the treatment options that might be best is limited. If they then want to access some treatment, they find that it is available in some places and not in others.

Regardless of that practitioner's opinion, if I can put it that way, about a WHO-defined disease, the people who are suffering from the illness need help, and we need to get to the point at which appropriate help that is individualised to them as a patient in their situation is made available to them. It is clear that that is not the case in Scotland at the moment.

The Convener: Cabinet secretary, you said that people should not be compelled to undergo treatment, and that is entirely fair. Is there an issue to do with people being judged when they say that they do not want that treatment? We took evidence from Professor Jonathan Edwards and, although I do not want to put words in his mouth, my reading of what he said is that there is almost a false correlation—because people benefit from the treatment, the implication is that ME patients benefit from the treatment, but ME patients are saying that the nature of treatment offered has nothing to do with their condition, and their being compelled, or feeling obliged or under pressure to take CBT or GET action is making things worse. Do you accept that there is an issue to do with people being judged? You might say that they are free to refuse treatment, but that can bring accusations that they would not engage and that they are being reluctant or difficult, and that feeds into that narrative.

Jeane Freeman: It is credible to me that that situation can arise and, from what I have been advised by those who suffer from ME, it has arisen. That speaks to a lack of awareness and understanding of the condition. You said it yourself, convener: 30 years ago, individuals who suffered from the condition were unfairly characterised, and it is fair to say that some of that unfair characterisation persists.

That relates to one of the areas that the petitioner highlighted—and I accept that we need to do more work on it—about the need to raise awareness and understanding in order to minimise the number of people, be they clinicians or otherwise, who do not believe that there is such a condition, and act on that belief in a way that is unfair and debilitating for the individuals who suffer from the condition.

Although we look to change such attitudes and views, another important point is that, as Dr Calderwood said, when someone with symptoms comes to a clinician, the clinician's job—regardless of their view on whether ME exists—is to deal with those symptoms, treat the individual and provide that person with whatever care and support they can.

11:15

David Torrance: Some of the evidence that has been presented to the committee focuses on the investment that the Scottish Government recently announced. The petitioner notes that an investment of £15,000 per year over the next three years equates to 70p per patient. How do you respond to such concerns? Do you consider such investment sufficient to build research capacity?

Jeane Freeman: That is the support that we have given a PhD student to begin work on how we might enhance the research base. I believe that #MEAction approached us for that support, which we have given. That does not preclude what I have touched on, which is my request for the chief medical officer and, through her, the chief scientist, to look at how we might further support an enhancement of the research base.

I hope that that investment will not be the only thing that we do. We responded to a request from #MEAction to support the PhD student to do that work, along with Professor Ponting, but that is not the end of the story.

Brian Whittle: Following up our earlier discussion, we agree that there is evidence of a lack of understanding of ME among healthcare professionals, which was identified in the National Advisory Committee on Neurological Conditions report on the lived experience survey. Given that, how will you ensure that NHS Education for Scotland provides effective education and training based on the most up-to-date biomedical research?

Elizabeth Sadler: We have given Action for ME money to support the provision of information for health professionals. Its website now hosts a series of materials on good practice, and the organisation provides webinars for shared learning, local models of care and good practice. Action for ME has also worked with NHS inform to put information about ME on the NHS inform website.

NES is developing a training module for GPs to raise awareness and support them. That will be in NES's next iteration of work, in the next financial year.

Brian Whittle: How do we ensure a positive uptake of training such as webinars and modules?

Jeane Freeman: I understand that, when NES considered the issue, it did work through the GP group that it works with on how a training module would be responded to, and the response from

GPs was positive—GPs would like that to be available to them. NES is now working on that.

On the basis of the initial positive response that GPs would like such additional training, we expect uptake to be good. However, we always look at how positive any uptake is and what more we might do to encourage GPs to undertake additional training.

The Convener: I am conscious of the time—we need to wrap up by 25 to 12 and we must stop by 20 to 12—so I ask our two colleagues who are not committee members to contribute now, as I am keen to allow them to participate. If there is time left after that, the committee can raise a number of other questions.

Mark Ruskell (Mid Scotland and Fife) (Green): Comments have been made about enhancing research. To what extent can the provision of specialist support on the ground help develop the research and fill the gaps in effective support and treatment for people with ME? In Fife, a popular support service has been put in place, but it has become very overstretched. Moreover, those kinds of support services are not being offered across Scotland. How can the roll-out of particular approaches to supporting people with ME enhance the growing knowledge and understanding of how we effectively treat and support people with the condition, as part of a package of research?

Jeane Freeman: I will ask Dr Calderwood to answer that question, but before I do, I just want to say that I appreciate the convener's point about timing. I need to be in the chamber to answer general questions at 20 to 12—I think that I am first up—so I would appreciate it if I could leave soon.

The Convener: Let us try to finish by half past 11. We might have a few more questions to direct to you, but we can send them on to you. I think that that is only fair—-you have more than earned your corn this morning, cabinet secretary. It is a pity that you have to answer the first question at general questions—you are not going to have a rest.

I will take Emma Harper's questions, then the committee will come to its conclusions instead of asking its final few questions. We will just send them to you.

Jeane Freeman: Thank you, convener. I appreciate that.

Dr Calderwood: Again, I congratulate the petitioner on bringing to the fore this illness, the existence of which has been denied and ignored. It has received neither the provision for treatment nor, as I said in response to David Torrance's question, the funding for research that other neurological conditions have received. When we pull together what the petitioner has bravely brought forward—I think that some of the people involved are here today—we see that in Scotland we need a co-ordinated approach to tackling the illness of ME.

We therefore propose the creation of a working group to look at the provision of services and consider the good practice in NHS Fife that Mark Ruskell mentioned. We will need to scope out what the asks of the group will be. We know that up to 21,000 people in Scotland have ME, which means that, on average, each GP practice has about 20 patients with the illness. We will also look at the pilot in NHS Lothian, which involved some effective interventions and treatment, and we will bring into the ME working group people who have been involved in good practice in Scotland.

There will be a series of pieces of work, and I can see the scope including the education and awareness raising that Brian Whittle mentioned, the availability and provision of treatment and so on. As I have said, we do not have a cure at the moment. There are some treatments that work, and there are some that clearly do not work for everyone.

As well as all the work that is going on in the background, there will be the enhanced research that I have mentioned. On the research front, we in Scotland will need to join up with others, perhaps on a global scale, given that other countries are struggling with many of the issues that the petitioner has highlighted and are in the same position as we are in. I would not want us to set off on something that is then delayed, because people are suffering. While we wait for the evidence—including the NICE guidance, which is due to be published in 2020—we in Scotland can set up the working group to tackle what issues we can tackle, and that can be done by looking at the good practice that we know works in places such as NHS Fife.

Emma Harper: I am aware that, in the House of Commons today, there will be a debate led by Scottish National Party MP Carol Monaghan, calling for more funding for biomedical research. Funding from the Westminster and Scottish Governments would be welcome. I will follow that debate and send on any questions later.

The Convener: I thank the cabinet secretary and her colleagues for attending the meeting and for the seriousness with which they have addressed the petitions. We will now consider this particular petition. If the witnesses need to leave, they have permission to do so—if they need it—and I suspend the meeting very briefly to allow that to happen.

11:24

Meeting suspended.

11:25

On resuming—

The Convener: We will now reflect on the evidence that we have heard. I should have said at the beginning of the meeting that I thank all those who provided submissions to the committee. A significant number of people with an interest in the petition responded, and that has helped the committee's consideration. We will invite the petitioner to respond to today's evidence from the cabinet secretary and her colleagues, and other people with an interest might want to respond to what they have heard, too.

Do members have any comments or suggestions for actions that they would like the committee to take?

Brian Whittle: First, I would just say that this petition shows the importance of bringing petitions to the committee. As has been very evident today, they raise awareness of such issues, and that, in itself, is helpful.

There are two issues for me: first, how we ensure that research on the treatment of ME continues, and secondly—this is where we could probably have the most impact on right here, right now—how we get over the hurdle of medical practitioners denying the existence of ME. The Government could take some specific actions to address that issue, and we need to look at how the committee can help facilitate that or push such action along.

Emma Harper: The Royal College of General Practitioners has an online training programme for chronic fatigue syndrome and ME, and it would be interesting to know its uptake by GPs.

Mark Ruskell: To pick up on Brian Whittle's point, I think that it is a matter of concern that 80 per cent of neurologists still do not consider ME a physical condition. There is a mismatch between what is happening on the ground with regard to treatment and the commitment to research that we have heard from the cabinet secretary and others this morning.

The Convener: The issue of research is significant. An area that we did not focus on is the role of clinical nurse specialists; although the Government describes that role as "pivotal", there is only one clinical nurse specialist for people with ME in Scotland and none of the additional investment has gone towards nurses for people with ME. We will want to ask the Government about that, but we are conscious of the pressures on the cabinet secretary's time.

We will ask for a response from the petitioner and anyone else who is interested in the matter. Specifically, we will ask about the GP uptake of the online programme as well as the role of the specialist nurses and whether there is a sufficient number of them. It would also be interesting to know, as Mark Ruskell suggested, about the level of support other than clinical support in the system.

I thank everyone for attending, particularly our visitors Emma Harper and Mark Ruskell. Again, I put on record our appreciation to the Cabinet Secretary for Health and Sport for spending such a significant amount of time with us on these very important petitions, even though that they are a small part of her broad remit.

Thank you all very much. I now close the meeting.

Meeting closed at 11:28.

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