

MEETING OF THE PARLIAMENT

Wednesday 1 October 2008

Session 3

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Scottish Parliament

Wednesday 1 October 2008

[THE DEPUTY PRESIDING OFFICER *opened the meeting at 14:15*]

Time for Reflection

The Deputy Presiding Officer (Alasdair Morgan): Good afternoon. The first item of business is time for reflection. Our time for reflection leader is the Rev Robert Pickles, from Orwell and Portmoak parish church.

The Rev Robert Pickles (Orwell and Portmoak Parish Church): Good afternoon.

We all need cohesion in the soul. I am not going to give you some false truths about how great and wonderful you are, or the positivism that says that you must love yourselves, which we all buy into—and the resulting guilt that it brings. That does not give us the freedom that we desire as we meet ourselves in the boiling cauldron of public service, whether we are a member of the Scottish Parliament, a minister or a minister of religion.

We are chosen by the unwilling to do the impossible—especially at the moment. We face costly decisions with small resources. We are asked to fulfil the agendas of others, simply to empower them and not to solve the problem.

How can integrity be maintained in the midst of all this? What is love in all this? This afternoon, I want to give you a definition of love that has freedom for the tired person written all through it. This is not the love that is so sweet that it will make your teeth fall out. This love is simply the decision to act for the wellbeing of another, whether you like them or not.

Let the implications of that extend your thoughts. Maybe some of you are realising at this point that you still love your partner in life, because you do not wish him or her harm but seek their wellbeing—even after 20 years. You may—shockingly—understand that you care deeply about that difficult constituency member, who is more than intolerably unpleasant and needs to get a life. You may be realising that you love your country because you want its wellbeing.

You may choose to apply that thinking to things that you do not like about yourself as you look in the mirror. I know that you, with other politicians, abound in the belief that you are marvellous and can do anything—or that is what we must believe about you. I want to address the true you, who is there when you are alone.

If you want your own wellbeing, you may truly love yourself and absolve the disagreeable parts of you, without the stress of sweet-hearted American psychology.

May the peace of the earth be with you
The peace of valleys too
May the peace of the oceans be with you
The peace of the rivers too
Deep peace falling over you
God's peace growing in you.

Question Time

SCOTTISH PARLIAMENTARY CORPORATE BODY

14:19

Energy Performance of Buildings

1. Margo MacDonald (Lothians) (Ind): Presiding Officer, you will forgive me if I speak very slowly to fill up the time, given that this is the only question—

The Deputy Presiding Officer (Alasdair Morgan): Simply read the question, please.

Margo MacDonald: To ask the Scottish Parliamentary Corporate Body whether it will provide an update on what progress it has made towards compliance with European Union energy performance of buildings directive (2002/91/EC), which came into force on 4 January 2006. (S3O-4573)

Alex Johnstone (Scottish Parliamentary Corporate Body): The Energy Performance of Buildings (Scotland) Regulations 2008 were signed by the Minister for Transport, Infrastructure and Climate Change on 16 September, and bring into force the requirement in the EU energy performance of buildings directive for the energy performance rating of buildings that meet certain criteria to be calculated and displayed by 4 January 2009. That has enabled us to go ahead with procuring professional services to meet that requirement.

Margo MacDonald: Can the member of the corporate body outline further what other services need to be purchased in order to comply with the directive? Could those possibly have something to do with the fact that the directive requires that the energy certificate

“is placed in a prominent place clearly visible to the public”?

The current corporate body, like the previous one, is aware of the fact that the rating that is given to the Scottish Parliament might not be altogether too impressive and might fall below what would be considered a reasonable standard, given the amount of money that was spent on the building.

Alex Johnstone: I can tell the member that, at this moment, I am unaware of any additional services that require to be procured in order to fulfil the requirement.

As far as the likely rating is concerned, early in September, officials consulted the relevant Scottish Government office—formerly known as the Scottish Building Standards Agency—which advised of the approach to be taken for the

building certificate. That approach will be followed. Until the exercise is completed, the rating will not be known, and I will not speculate about what it might be.

John Scott (Ayr) (Con): Given the need to keep energy within the building, the integrity of the roof structure of the chamber is a matter of great concern. Can the member tell us who was ultimately found to be liable for the strut failure that occurred above my head? In addition—

The Deputy Presiding Officer: Mr Scott, that is not a supplementary to the question.

We must move on to the next item of business.

Crofting

The Deputy Presiding Officer (Alasdair Morgan): The next item of business is a statement by Michael Russell on the Scottish Government's response to the report of the committee of inquiry on crofting. The minister will take questions at the end of his statement, so there should be no interventions or interruptions.

14:22

The Minister for Environment (Michael Russell): When we last met to debate crofting, on 15 May, there was a near unanimous welcome for the final report of the committee of inquiry on crofting. Following a period of reflection on the committee's recommendations, I am pleased to announce today the publication of the Government's response to the report.

Crofting is a distinctly Scottish phenomenon that the Government is determined to nurture and sustain. Consequently, we will support those who choose to croft. We do so not because crofting is unique, but because of its outcomes. Crofting is an engine of sustainable economic growth, which is the Government's central purpose, and is needed more than ever in the present difficult times.

Crofting brings social, economic, environmental and agricultural benefit to remote parts of Scotland. It contributes to the provision of local food, helps to retain livestock on the hills and underpins many fragile and remote communities. Without crofting and the hard work of individual crofters, the whole of Scotland would be poorer. We should, as a Parliament, say that loud and often. Of course, we must also match words with deeds.

The purpose of the Shucksmith inquiry was to modernise crofting in order that it might continue to provide those benefits in the 21st century. Since the publication of the committee's report, there has been considerable debate about its recommendations' merits, with opinion ranging from outright rejection to ringing endorsement.

Let me make it clear that I believe that Mark Shucksmith and his colleagues did exactly what they were asked to do, and I remain grateful to them. The committee of inquiry consulted extensively and reached its conclusions after hearing the views of around 2,500 people in written evidence and at a series of public meetings. I remain very positive about the committee's recommendations.

Since the report's publication, the Government has carefully reviewed the recommendations and listened to the comments that have been made. I spoke to many crofters during the summer and

attended a range of formal and informal meetings, but crofting is about more than reports and structures, so I was keen at those meetings—and I am keen now—to discuss a range of positive measures that will help individual crofters to continue with their work and attract new people into crofting.

It would be fair to say that we support the main thrust of the committee of inquiry's recommendations, which promote localism and community. However, we have not accepted all the recommendations. I start with governance. We have not agreed to the abolition of the Crofters Commission and its replacement with a federation of locally elected crofting boards. I agree with my friend John Farquhar Munro that the commission has a wealth of experience and knowledge that needs to be preserved. It will be. However, the commission could do much better. In particular, I want it to be more democratic and accountable. We therefore propose to reconstitute the commission as a small and focused central body working through a limited number of area committees that will have an elected component, which should ensure that policies and decisions better reflect regional circumstances.

We have agreed to separate the functions of the Crofters Commission as recommended, and to the Registers of Scotland being responsible for creating and maintaining a new register of crofts. Lead responsibility for the development of crofting communities will go to Highlands and Islands Enterprise, and the management of crofting agricultural grant schemes will go to the rural payments and inspections directorate of the Scottish Government. That is because we strongly believe that the proper role for a regulator is regulation, and that more effective regulation is needed for crofting.

The equally important task of developing crofting communities, as opposed to focusing on individuals, should be the responsibility of the body that has been charged with a strategic development function in the Highlands and Islands, and that body is HIE. It is developing the exciting new growth at the edge approach, which will provide crofting communities with the assistance that they need to develop their futures. We will streamline resources to put more effort into fragile areas to accelerate growth. HIE will achieve that by engaging with crofting communities and local authorities, so that it can better understand the communities' ambitions, develop plans and work with the communities to grow their populations, their economies and the many opportunities that are needed. Grazings committees will also have a part in that. Those that are inclusive and imaginative will encourage the development of new life, and we will encourage them.

I turn to the bull hire scheme. On support for livestock improvement, the Government accepts the committee's view that there are better ways than the centralised bull stud facility to maintain cattle operations in the crofting counties. The fact is that last year, from approximately 13,000 crofters, the bull hire scheme was used by just over 100 groups, involving approximately 430 individuals. Accordingly, the cost to crofters—£500 at present—would have to rise to around £1,250, which clearly is unrealistic, so the Government proposes to close the central state-owned stud facility by the summer of 2009.

Nonetheless, we will continue to support livestock quality and numbers in remote areas. We propose to put in place new arrangements through the Scotland rural development programme to mitigate the costs of private bull hire. As a transitional measure, we plan to offer stud farm bulls for acquisition at modest cost to the crofting communities that have used the hire scheme in recent years.

Many members have made representations to me about a range of matters in the Shucksmith report, and many went out of their way to consult their local crofters during the summer. I am grateful to them. One recommendation above all others has caused substantial concern. Most people can see the reason for the committee recommending that an occupancy burden should be placed on housing on land in crofting tenure. For many years, there has been real worry about speculation in land and housing, and the insidious effects of perpetual absenteeism. However, as my colleagues Alasdair Allan and Rob Gibson have rightly pointed out, the recommendation ran the risk of creating a two-tier housing market within the Highlands and Islands, and it might have weighed unfairly and too heavily on some individuals. Accordingly, after a great deal of thought, I have rejected it.

We still need to take action to dampen croft land speculation for the purpose of building houses that will be used as second homes, not least because the effect of such speculation puts the price of crofts beyond what local and young people can afford, thus preventing new entrants and the infusion of new blood. We do not wish to prevent decrofting per se, because it is important that new houses continue to be built in order to meet local community housing demand. Often, the only available land for housing development in remote communities is a small part of croft land. However, croft land should be used only to meet demand from people who are willing to live in those fragile communities permanently. We therefore propose to consult further, with local authorities in particular, on the utility of applying some form of occupancy condition at the point of decrofting, and

only at that point, and on the best way to implement such a condition. [*Interruption.*]

The Deputy Presiding Officer: I wonder whether the minister has an electronic device near his microphone.

Michael Russell: I am unaware of that. My pacemaker is working perfectly at present.

On land in crofting tenure, better enforcement of existing legislation that requires crofts to be put to purposeful use and crofters to live within 10 miles of their crofts will address absenteeism and the neglect of crofts. We will review the existing legislation to enable the regulator to take more effective action and we will consider the provision of renewed direction to the Crofters Commission—even in the short term—to achieve that aim.

The Government's response accepts the committee's recommendations for creating stronger rural economies and agrees to review the support for croft housing. Many of the recommendations that the committee made in the land and environment section of its report on support for crofting agriculture and rural development are already the subject of reviews and consultation, and we will provide a fuller response to those recommendations once the outcome of the consultations is known. However, as we have said before, the committee's concerns about and desire for positive action in such areas mirror our concerns and views as a Government.

The key principles that underpin our response need to be set out. First, the Government will endeavour to maintain the amount of land that is held in crofting tenure, because it is important to continue to secure the economic, social and environmental benefits that crofting delivers. I am sure that all members were pleased to note the Crofters Commission's recent approval of six new crofts on the island of Jura. That is just the type of innovation that we should seek. I am also encouraging public bodies that own land in the crofting areas to review their holdings to establish what land could be freed up for crofting, particularly for new entrants, and I am pressing Forestry Commission Scotland for early implementation of its mechanism for creating forest crofts.

Secondly, we believe that land in crofting tenure must be put to productive use. Land is our most basic natural resource, and it must always be used, whether for producing food, for delivering environmental benefits, for creating business premises or for providing housing. Of course, the definition of land in productive use should be drawn widely to allow croft land to be used for a variety of purposes but, overall, we must make it clear that Government and crofters need to stimulate the creative and productive use of land.

Our third guiding principle compels us to ensure that housing in crofting communities makes a full contribution to the local economy. The fact that an adequate supply of housing is vital to maintaining and increasing the population of any area makes it central to securing economic growth in the remote rural areas of Scotland. Moreover, occupation of such housing is essential to providing a resident population. We must try to ensure that more housing in the crofting counties is lived in and contributes fully to the economic and social life of those communities.

We must also give more power to local people to determine their own futures. A key component of successful rural development is the local mobilisation of individuals and communities, with the support of appropriate agencies, to take control of their futures. By devolving power, we enable communities to plan their own futures and take decisions that are appropriate to their needs and circumstances. However, with power comes responsibility, and it is important to ensure that the people who take decisions are representative and accountable.

Our final principle is that we must look to the future and find a way to help young people and older new entrants into crofting, because without them crofting will not survive. I am sure that the debate on the future of crofting will continue, and I look forward to hearing the views of individuals and communities on what I have said and what is being published today.

It is obvious that the status quo is not an option, but it is equally obvious that only consensus will drive us forward. The Government will now proceed to draw up a draft bill for consultation on the legislative changes that are needed, and we hope thereafter to be in a position to introduce a crofting bill in the Parliament. I should also tell members that the Government has accepted the Shucksmith committee's recommendation on the simplification of crofting law, and that a separate crofting consolidation bill will be drawn up for introduction at some future date, perhaps in the next parliamentary session. However, there are things that we can do without legislation. For example, we can reform support for croft housing, reform the crofting development function and modernise support for crofting livestock quality improvement. We will continue to work on those areas with vigour.

Crofting provides people with the opportunity to be part of strong communities, to enjoy a rich culture and to live in one of the most spectacular environments in the world. In other words, crofting has everything going for it. That is why people choose to croft and will continue to croft, and it is why many people want to remain crofters. Crofters must work together and with other people in the

community to build a strong and secure future. Government must do what we can to support them. Through that partnership between crofters and Government, I believe that crofting can be, and will continue to be, an activity that more and more people want to do. It will also be a model for effective rural, social, economic and agricultural development.

The Deputy Presiding Officer: The minister will now take questions on issues raised in his statement. I intend to allow around 30 minutes for questions, after which we will move to the next item of business.

Sarah Boyack (Edinburgh Central) (Lab): I thank the Minister for Environment for the courtesy of advance sight of his statement. Labour members very much welcome the minister's change of heart on the abolition of the Crofters Commission, and we welcome his statement about the release of land for more crofting. We welcome, too, the direction to the commission to deal with the worst cases of dereliction. Finally, I welcome the minister's commitment on the completion of a register, although I would be keen to know the completion date.

The statement raises many issues. In particular, how will making the Crofters Commission more cumbersome, bureaucratic and time consuming, with lengthier decision making, help crofters? Will the minister confirm that he is pushing the most difficult decisions to new sub-committees, meaning that individual crofters will be required to regulate their neighbours? Will he provide details of how his proposed 80-odd commissioners will be funded, how the appointments will be made and how they will operate in practice? That is not clear in the statement or in the accompanying documentation. Does the minister not recognise that crofters are worried about how they will survive economically, not how many people are in the pie of individual decision making?

I ask the minister to think again about his suggestion that we centralise the crofting counties agricultural grant scheme in Edinburgh. Is there not a better argument for integrated practical financial support for crofters? Finally, we want to study the minister's detailed response before we come to a view, particularly on the issue of burdens, and we will want to consult crofters further.

I hope that the minister takes on board our request for full consultation before he introduces his proposals in a draft bill. The devil is in the detail, and it is vital that we get the detail right. While we welcome elements of the minister's statement, many big questions remain that need proper discussion and debate before we get to the stage of a draft bill.

Michael Russell: Let me try to accentuate the positive. I am glad that Sarah Boyack welcomes some of our proposals. There has been no change of heart. We never responded to Shucksmith's committee to start with. What we did, properly, was listen to the committee and, over the summer, listen to the vast range of opinion. However, I am disappointed that Ms Boyack does not see the virtue of accountability and the involvement in decision making of elected individuals within communities.

At the end of my statement, I stressed the importance of empowerment. Unfortunately, if Sarah Boyack is still on the side of the unelected, the disenfranchised and those who want decisions to be made distantly, she does not understand what rural development is about in general, and she certainly does not understand the importance of ensuring that crofters are enabled to make decisions about crofting. That was the solid theme of Mark Shucksmith's recommendations, and it should be the solid theme of all our rural activity. We have to put power into the hands of communities. Indeed, that was a solid theme of the Organisation for Economic Co-operation and Development's review of Scottish rural policy, which commented favourably on the previous Government's work on decentralisation. Far from reconsidering, we will pursue the issues in consultation with communities, which will help communities to make decisions about themselves.

On consultation and timescales, the Shucksmith committee consulted 2,500 people. There was considerable debate in the summer. I have been more than willing to attend meetings, to listen at events, to receive correspondence and to talk to people. I will remain open in every way to the discussion, but we have to move on. We will draft a bill and it will be put out for consultation. We will have another opportunity to debate the issues and then, I hope, we will have legislation. If we continue to delay, crofting will continue to decline. That may be what Sarah Boyack wants, but I am not on the side of a continued decline in crofting.

John Scott (Ayr) (Con): I, too, thank the minister for the advance copy of his statement, which the Conservatives cautiously welcome.

We support the need to keep vibrant and dynamic communities in our crofting counties and the release of more land for crofting. I welcome the fact that the rural payments division will take responsibility for the CCAGS.

The minister proposed two new bills, one of which will not be delivered until after the next election. Does he accept that crofters have been waiting for years for successive Administrations here to introduce legislation to address their concerns? To say the least, it is regrettable that crofters will still not have adequate legislation until

at least 12 years after the creation of this Parliament.

Finally, what level of funding will be available to encourage new entrants into crofting? Will the funding be adequate, bearing in mind the legitimate concerns over the lack of funding for the Government's new entrants scheme for farming?

Michael Russell: I am caught between two opposing forces: one thinks that I am going too fast, and the other thinks that I am going too slow. Perhaps that means that the speed at which we are going is just about right.

I agree that priority should have been given to pushing crofting legislation. We are moving as fast as we can. Mr Scott should not be too worried about the second bill, which will codify and consolidate all the existing crofting legislation. What we are trying to do—

Sarah Boyack: It will never happen.

Michael Russell: From a sedentary position, Ms Boyack says that it will never happen. It will happen if this Administration is re-elected in 2011, so clearly there is no commitment from Ms Boyack's side. We therefore already know whom to vote for in 2011.

We have two steps to take. One is to make the necessary immediate changes. In my statement, I said repeatedly that it is not all about legislation, and that there are other actions that we can take. We are going to do so.

The second step is to consolidate the entire—I was going to say mess, but I should say mass of crofting legislation. We have to make it understandable so that people can work their way through it. That is the right thing to do. As Mr Peacock said at an early stage, it would have been virtually impossible to take on the consolidation task with the other proposals. I think that we are doing things in the right order, and we are making progress.

Liam McArthur (Orkney) (LD): I offer my apologies to the chamber for my slightly delayed arrival. I was at a meeting with constituents and the Cabinet Secretary for Rural Affairs and the Environment. I add my gratitude to the minister for the advance copy of his statement.

In July, I attended a meeting in my constituency, hosted by the Scottish Crofting Foundation, to consider the Shucksmith report. The feeling that was expressed was very much that the report offered some excellent recommendations, but that some recommendations would not command support among crofters in the northern isles or, indeed, in the other crofting counties.

Given the complex issues involved, I am not surprised that the minister has taken rather longer

than expected to prepare his response. However, like Shucksmith himself, the minister has offered elements that are welcome. I certainly have little problem with the principles that he articulated towards the end of his statement.

Will the minister comment on the aspects that did not feature in his statement? Why, for example, has he chosen to ignore Shucksmith's recommendations on the various crofting grant schemes? The report aroused its fair share of controversy, so why has the minister decided to do nothing about the elements of the report that were welcomed across the crofting counties and across the political spectrum?

I encourage Mr Russell to read the evidence that was provided by Hughie Donaldson of the SCF to the Rural Affairs and Environment Committee on 24 September. House building across Scotland is in crisis, and Mr Donaldson showed how the crofters building grants and loans scheme and the croft house grant scheme had delivered significant returns for relatively limited investment. Will the minister agree to consider that evidence and to consider what scope there would be for reintroducing a system of loans to support and stimulate house building in the crofting counties—especially in light of the planned reduction in crofting assistance from £6.4 million to £5.6 million?

Finally, does the minister accept that the decision to hand responsibility for the “strategic development” of crofting to HIE will be greeted at best with suspicion by many crofters? Given last year's decision by the Government to slash HIE's budget, that suspicion may yet give way to incredulity.

Michael Russell: I am glad that Mr McArthur welcomes some aspects of the report—although he did not actually mention any of the aspects that he welcomes, which was a pity. Let me make it clear to him that I have not ignored any of the issues. The Presiding Officer would not have allowed me to read out the Government's complete and detailed response, but I have it here. In that response, which was published today at the same time as my statement and is available in the chamber, we have responded to every recommendation. None has been ignored.

I mentioned in passing that we are taking forward an immediate review of the croft house grant scheme and two other rural house grant schemes—the rural home ownership grant and the rural empty properties grant. The review will specifically consider the detailed recommendations that were made by the Shucksmith committee of inquiry, which I take very seriously.

Liam McArthur knows the great importance of the croft house grant scheme, as does anybody with experience of the crofting areas. We entirely accept that we must continue to emphasise its importance.

With regard to HIE, I ask Mr McArthur to undertake a Coleridgean willing suspension of disbelief. We have to make progress on this issue. If it is accepted—and the report makes cogent arguments for it—that the proper role of a regulator is regulation, it follows that development is the proper role of the body that is charged with strategic development in the Highlands and Islands, which is HIE. We must ensure that HIE attracts and develops the confidence of the crofting communities in undertaking that task. I indicated in outline—although I had only a brief time in which to do so—some of the ways in which that will happen, and I am happy to sit down with Mr McArthur and any other member to discuss the ways in which we can ensure that HIE fulfils those functions. I am sure that Mr Mather, as the minister with responsibility, will also take part in those discussions.

The Deputy Presiding Officer: A fair number of back benchers want to ask questions, so I ask members to keep their questions brief.

Alasdair Allan (Western Isles) (SNP): I welcome the attention that the minister has given to two issues that have been raised by me and by many others—burdens, and the structure of the Crofters Commission.

What will the minister do to reassure crofters who have used the bull hire scheme in the past, especially in areas where commercial alternatives are not readily available? Will the money for that be kept inside the crofting system? Will the Government be able to direct crofters to any source of assistance towards the high costs of wintering a bull?

Michael Russell: I know that there will be concern about that. However, last year, at the Scottish Crofting Foundation conference, I made it clear that I was asking Mark Shucksmith and his colleagues specifically to consider the issue. They have come back with some clear information. I repeat the information that I used in my statement.

Last year, the bull hire scheme was used by just over 100 groups involving 430 individuals out of some 13,000 crofters. However, we recognise that some people will be disadvantaged by our decision. So, yes, the resources will remain within crofting—I made that clear last year. Secondly, we have structures that will support commercial bull hire, including applications to the Scottish rural development programme. Those are immediately available and will continue to be available.

In addition, as a transitional measure, we plan to offer stud farm bulls for acquisition at modest cost to crofting communities who used the hire scheme in recent years. It would be an unconventional Christmas present, but perhaps not an unwelcome one, were someone to give a community a bull. Those bulls will be available. I suspect that there will also be grant aid available under the SRDP for the costs arising from the creation of wintering quarters for bulls.

In all regards, we are covering the demand that exists within the available resources and in a way that will continue our concern with maintaining the quality of cattle in the crofting areas.

Elaine Murray (Dumfries) (Lab): I note, from the minister's statement, that the responsibility for developing crofting communities will be transferred from the Crofters Commission to Highlands and Islands Enterprise at a time when HIE's funding and staffing are being substantially reduced. Will additional resource be transferred to HIE along with that responsibility? How will the growth at the edge initiative contribute to crofting as a whole? GATE is targeted on fragile and remote areas—that definition would exclude some crofting areas in Scotland.

Michael Russell: I welcome Elaine Murray to her new post. I think that it is the first time that we have crossed swords, so to speak, and I am sure that it will not be the last. I look forward to those exchanges.

I will not enter into a debate about resources in the context of the work of HIE. I disagree profoundly with what Dr Murray says, but I will not enter into debate about it. Of course, the resources that are presently applied to crofting development will be transferred from the Crofters Commission to HIE. What resources are being used will be transferred—that is absolutely clear.

The GATE initiative is a little narrow and may exclude some of the crofting areas, especially if there is an expansion of the crofting areas—we may discuss that matter later. In such circumstances, we will consider the ways in which HIE can operate in those other areas. I repeat the offer that I have just made to Liam McArthur. We have work to do to ensure that the policy operates properly and I want to do that work; therefore, I will sit down with representatives of the crofting communities, with individual crofters, with party spokespersons and with members who have a constituency interest in the matter, so that we can work things out properly.

I have a strong commitment to the development of crofting. It is very important that new people are allowed to enter crofting, and—I did not mention this in my response to John Scott—we have specific schemes for new entrants. I want to

ensure that the work is done effectively, and HIE will take on the task of doing it effectively.

Roseanna Cunningham (Perth) (SNP): The minister has agreed to review the support for croft housing. I want to pick up on an issue that was referred to by Liam McArthur, which is of interest to the Rural Affairs and Environment Committee because of our inquiry into rural housing.

As the minister is aware, 20 years ago Government support covered 82 per cent of house building cost, but now it covers only 14 per cent. He is also aware that the loan element of support was removed in 2004, on the grounds that ordinary mortgages were easily and cheaply available. Now that we know that that is not likely to be the case in the foreseeable future, will restoration of the loan element be specifically included in any review that the minister undertakes? As far as I can see, that is not mentioned specifically in the Government response document.

Michael Russell: I would not rule out the inclusion of all and every consideration, although I think that it would be difficult to overcome the worldwide difficulty in the obtaining of loan finance specifically for the crofting community and in relation to only one small area of concern.

Roseanna Cunningham is right to say that the proportion of Government support changed in the way that she describes. One of the reasons for that is that commercial finance became available more easily and more cheaply. It would have been wrong to continue with a scheme that was more expensive to crofters. Those circumstances might be changing, and we might need to reconsider the position. I give Roseanna Cunningham the commitment that the review will be thorough and comprehensive and will, I hope, be informed by the work that her committee is doing on rural housing. I would welcome the committee's assistance in our thinking on those matters.

Peter Peacock (Highlands and Islands) (Lab): The minister talked about seeking to consult local authorities about what he has called an occupancy condition. Is he still seeking a real occupancy burden, as Shucksmith described it? The minister also talked about area committees, which will comprise 72 members overall. Will those committees displace the much-respected assessors network that exists at present?

Michael Russell: I would not wish to be misrepresented and I am sure that Mr Peacock would not wish to misrepresent me. Therefore, let me make it absolutely clear that there is no intention to impose a burden. We have not accepted that recommendation. I would not like reporting of this matter to be accompanied—even inadvertently—by quotations from people who say

that the situation involves something that is a burden by any other name. The burden will not be imposed.

We are consulting on whether there should be an occupancy condition at the point of decrofting. That would have the effect, were it necessary, of retaining occupancy in houses. It would not be a title burden. We have rejected the title burden. I am happy to express that in as many different languages as the member wishes, just to make it absolutely and utterly clear.

On the area committees and the assessors, I am surprised that, once again, a Labour member opposes democracy. Labour has suffered rather badly because of democracy in the past 18 months, but I would have thought that Labour would want to see a democratic element in the decision making on crofting matters. It strikes me as axiomatic that those who know about something and are engaged in it through the sweat of their labour—in this case, crofters—should be involved in the decisions that govern that activity. If the Labour Party wishes to resist that type of progressive thought, I think that it will pay the price.

Jamie McGrigor (Highlands and Islands) (Con): I welcome the Scottish Government's plans to improve the Crofters Commission and make it more democratic. Can the minister give more details on how big that democratic element will be and on how the elections will be held?

The minister will have anticipated that I would be unhappy about the decision to abolish the bull hire scheme. I believe that that is a retrograde step that will be opposed by many crofters. What guarantees can the minister give us that crofters will be able to utilise private bull hire through the SRDP? What will happen to the Government farms where those bulls have been bred? Could they be used, for example, to help fatten crofters' lambs?

The minister talked about the importance of housing to the future of crofting. I agree with him, but he did not give many details. Does he plan to introduce an enhanced croft house grant and loan scheme and, if so, when will it be introduced?

Michael Russell: I feel like referring the member to the answers that I gave a moment ago, as I have answered all his questions. However, I will address two of them.

I regret the fact that some people will be adversely affected by our decision on the bull hire scheme. However, the number of people is not nearly as great as Jamie McGrigor has indicated—last year, the scheme was used by about 430 people. Further, the inevitable increase from this year's cost of £500 to almost £1,250 would create state-aid issues. The SRDP alternative is a good

one. In addition, I repeat my earlier offer—I have never previously been in the position of being able to say twice in one day, "I'd be happy to give you a bull"—and say that crofting communities that have the potential to acquire one of the bulls from the stud have the opportunity to get one. There is a great deal of potential in that course of action.

The member asked about the elected element. We are trying to ensure that crofters are involved in making decisions about crofting. That principle is made clear in Mark Shucksmith's report, and I endorse it, as most members have done. Worries have been expressed that such a system would work on too narrow or too small a level. It was feared at one stage—Peter Peacock and I addressed a meeting in Skye at which this fear was mentioned—that grazings committees would, like some sort of small-district soviets, make decisions about every regulatory issue in their area. That was never proposed. However, there is an optimum size and an area structure within the existing Crofters Commission. We have examined that and tried to work out the optimum size for locally based decision making within a much more focused commission structure.

That principle is important and it will work; in addition, it will appeal to crofting communities in which decisions are made by people who know what they are talking about in all the relevant circumstances. We can then consider the right method of election—I have mentioned one or two methods in the document—and the way in which we can make the system work. I ask the member not to try to exclude decision making by people who know what they are talking about.

John Farquhar Munro (Ross, Skye and Inverness West) (LD): The minister said that the last time that crofting was debated in the Parliament, there was almost unanimous approval. I question that statement very much indeed. However, we have moved on, and months later we are having another debate on the issue. If there had been unanimous approval during the previous debate, we would not be having the debate today, but that is another story.

The Deputy Presiding Officer: I ask the member to get to the point.

John Farquhar Munro: I am just coming to the point.

I welcome the decision on the Crofters Commission—I campaigned for that, and the minister has responded—but I find much that is in the document that has been presented to us today difficult to accept in its current form.

The Deputy Presiding Officer: Order. The member should ask a question now.

John Farquhar Munro: I hope that we will have a debate in the months ahead. However, will the minister end the uncertainty and decide that—aside from the statements that he has made in the chamber today—we will forget the rest of Shucksmith’s proposals and put the report in the bin?

Michael Russell: I am sure that very few people have ever described John Farquhar Munro as an extremist, but he is taking an extremist position on this matter. It is contrary to the position that he has previously taken in the chamber and which he took at the meeting that we addressed in Skye. At that meeting, John Farquhar Munro said twice that his main objective was to ensure that the Crofters Commission was not abolished. I would have thought that he would be skipping with delight today—a concept that I am sure we can all imagine—as he was content with the issue, and that he would work with the rest of us to ensure that the best recommendations were taken forward as legislation.

I do not think that John Farquhar Munro believes that everything must remain the same—indeed, he made the opposite point at the meeting in Skye. He should not find himself stuck behind the debate; he should be within it to welcome the real potential for change that will produce real benefits for his crofting constituents. I have listened to him—I hope that he will now listen to me.

Kenneth Gibson (Cunninghame North) (SNP): I welcome whole-heartedly the minister’s statement and the two visits that he has made to my constituency to discuss the inquiry with local people. Does he agree that the exclusion of Arran and the Cumbraes in my constituency when the crofting counties were established has brought about an unfortunate anomaly? When will the Scottish Government right that historic wrong?

Michael Russell: As the member says, I have twice addressed meetings on the island of Arran to speak about the issue. There has been a consultation process, the results of which I intend to announce next week. I hope that the member will not be disappointed by them.

Rhoda Grant (Highlands and Islands) (Lab): Does the minister agree that crofting will not survive unless it is economically viable? As other members have said, the statement does not deal with Shucksmith’s recommendation on financial support. The minister says in his response to the inquiry that he does not propose to introduce a loan element to the croft house grant scheme. Given that it was difficult to get mortgages prior to the credit crunch, how will he now ensure that crofting will survive?

Michael Russell: To hold me responsible for the credit crunch would be taking things a little far.

Rhoda Grant is a member of a party that was in government and made a *bùrach*—if I may use a Gaelic word, Presiding Officer—of the Crofting Reform etc Act 2007 and now proceeds to lecture us on how to legislate for crofting. We have reacted strongly and positively to a range of recommendations and we have taken principled positions on others. We have indicated where we want to continue consultations and to look at the recommendations to provide more help to the crofting counties.

We should all be involved in that process and we should all be focused on the benefit of crofting. I would greatly regret it if a narrow partisan view were to develop in this debate instead of a view that benefits crofting. The party that takes such a position will have to answer not only to the chamber, but to the crofters who want consensual change and who want real debate about change. It is regrettable that I have not as yet heard such an approach from the Labour Party.

Dave Thompson (Highlands and Islands) (SNP): I welcome the minister’s statement, which outlined a positive approach. I, too, was at the meeting on Skye. Some criticism was made of the consultation process up until that point, which I think was unjustified.

I welcome the minister’s announcement that there will be two bills to deal with crofting. What will the timetable be for the consultation process on the first bill? Will the minister elaborate on the process in general?

Michael Russell: Often, people who say that they were not consulted just do not like the outcome of the consultation. I am determined that we should continue to debate and discuss all the issues. Until now we have had 18 months of consultation. The Shucksmith committee was very detailed in its work: it went right round the country, took a great deal of evidence and listened to many people. When its report was published, there was strong unanimity of support for it; members will see that if they read the *Official Report*. We continued to have debate and discussion during the summer. I attended a variety of meetings and listened to a range of people—that included sitting on the games field at Durness listening to a group of people who have a website called “Bin Shucksmith”.

I have had those discussions and we now have a response that indicates how we can take the matter forward. There will be a formal consultation period when we publish a draft bill in the spring. Between now and then, I am happy to have creative and constructive debate—not negative debate along the lines that we should throw away the whole thing and start again. We will publish a draft bill, on which we will have a formal consultation, and we will then move to legislation.

We cannot go on talking for ever. We should accept that there are problems in crofting and that we need to set them right; some of those problems can be solved by administrative action, but the rest must be addressed by legislation. I want the legislation to be debated and passed in the Parliament and to see crofting benefit from it.

Jamie Stone (Caithness, Sutherland and Easter Ross) (LD): I acknowledge the dialogue that the minister and I had on the games field in Durness during the summer. I also acknowledge the significant gives that he has offered us today, on the Crofters Commission and on burdens.

I acknowledge the minister's position on HIE having a development function. Will he at least undertake to look at and audit what is happening as the policy rolls out? There is concern that HIE's budget has been reduced and that, because it has to tackle issues such as Dounreay and Nigg, the development of crofting may be lost in the process. Will the minister give me that assurance?

Michael Russell: Yes. I am happy to give that assurance. The spirit of those comments is exactly the spirit that I would like to see. I commend Jamie Stone for that. We can work together to ensure that this works. We will put in place a means of assessing the situation and we will ensure that some of the developmental work that we want to see being started starts well before the legislative process. As I said in my statement, there is much that we can get on with now.

Cancer Drug Access

The Deputy Presiding Officer (Alasdair Morgan): The next item of business is a debate on motion S3M-2598, in the name of Frank McAveety, on the Public Petitions Committee report on availability on the national health service of cancer treatment drugs.

15:05

Mr Frank McAveety (Glasgow Shettleston) (Lab): I thank members for being present for this debate on a report of the Public Petitions Committee, which was presented several months ago with a challenging but important petition, which we took firmly on board, on access to cancer drug treatment in the health service. I thank all those who made submissions, which we took forward as part of our inquiry. I also recognise the hard work that was done behind the scenes by the clerks to the committee and the many others who were involved in the development of the petition.

Most important, I put on record Parliament's appreciation of the work done by the petitioner, Tina McGeever, who has been in a very difficult personal situation, and by her late husband, Michael Gray. They took the time to lodge the petition in light of Michael's experience of accessing treatment from his local health board. I welcome Tina to the chamber this afternoon.

Margaret Curran (Glasgow Baillieston) (Lab): Many in the chamber will recognise the contribution of Mike Gray, a good friend of mine over many years, and his wife and friends, who have had an enormous impact and have helped us to look at the complex issues of provision and funding of cancer drugs, and indeed the operation of the national health service. There are many telling lessons to learn for all of us who are committed to the national health service.

Many in the Parliament are well aware of Mike Gray's outstanding record of public service in residential child care and housing. Does the member agree that perhaps the best way in which we can pay tribute to Mike Gray's contribution to public service in Scotland is by reaching for the highest possible standards of health care and ensuring that it is accessible to all? That would be a fitting tribute to the lifetime contribution that Mike Gray made to public service in Scotland.

The Deputy Presiding Officer: Interventions, regardless of their content, should be brief. That was not a good example for members to follow.

Mr McAveety: I echo Margaret Curran's comments about Michael Gray's commitment, as well as that of Tina McGeever alongside him.

I welcome to the chamber today a colleague from the House of Representatives in Australia, Julia Irwin, who is convener of the Standing Committee on Petitions. I hope that she will see how the work done by the Public Petitions Committee in Scotland can influence further developments in Australia. Our approach has already been taken on board in the House of Representatives, which modelled its petitions structure on our experience since the establishment of the Scottish Parliament. I hope that we can continue our good dialogue.

The committee had in front of it a difficult issue and members reflected its seriousness in the values that they took into the inquiry. Our extensive inquiry identified several key issues on which we made recommendations. This afternoon, I will go through some of the key areas of concern or deliberation that we raise in the report. We hope that the Cabinet Secretary for Health and Wellbeing, who has responded to the committee's report, will amplify some of those areas in her speech.

We share a commitment to improving matters for everyone involved in the delicate and difficult experience of confronting the challenge that cancer throws up to all patients and their family members. It is important that we nail down some of the key issues that the report identifies. Although I welcome the cabinet secretary's comments this morning and the press release on the subject, there are still points on which to deliberate in the period leading up to the review process of which she spoke today. However, I welcome the fact that the debate has moved on since the petition was lodged and the inquiry report was published.

I am sure that many members have taken time to explore the many issues in the debate. My colleague John Farquhar Munro will touch on some of those in his concluding comments.

The key issues are: defining the roles in relation to the allocation of treatment; guidance; data gathering; availability, which covers the sensitive and difficult issue of exceptional prescribing; and funding, which covers the difficult issue of public-private funding of treatment, or co-payment. It is important that we identify the key issues that were raised.

As we say in our report, we wanted to examine the roles that are being fulfilled by the many different bodies that are involved in undertaking clinical, scientific and cost-effective assessment of the use of cancer treatment drugs and to establish whether there is any duplication of roles.

We wanted to find out about the implementation of guidance across health boards, as evidence indicated that there were contradictory voices.

On the issue of exceptional prescribing, given that we are a relatively small nation, the range of criteria and conditions involved surprised us and struck us as anomalous. That is something that could be addressed by the parliamentary process, by health boards, and by the guidance set out by the cabinet secretary.

We also wanted to establish the reasoning behind the position whereby a person cannot be treated as a private patient and an NHS patient for one condition during a single visit to an NHS organisation.

Those are big issues. I know that the cabinet secretary has been careful to try to address them in her written response and in her comments to date. It would be useful to have further elaboration of that.

I turn to the areas of concern that the report identifies. The first area is data gathering. Eminent health professionals and people who are involved in the assessment of health needs in Scotland said that we need to resolve a number of issues. That is something that the cabinet secretary can take forward. One concern was that we have an inadequate national system of data collection; for example, there are not enough data on how many patients get one drug and how many get another. Concern was also expressed about the implementation of guidance across boards, which is highlighted in paragraph 55 of the report.

We do not know what data are being gathered locally and what data are being gathered nationally. It would be useful to have that clarified at national, health department level and at local health board level. The cabinet secretary said in her response that better data would help all of us who are involved in the process. It is important that we get clarity around what data could be captured nationally, how we capture the data and what we do with that information. That would certainly help us, because much of the debate is centred on the limited resources that are available in the NHS and their effectiveness when the individual requires support.

In its response, the Government identifies areas of development since the report was published and outlines some of the areas in which data are being captured. We would like to hear what further work will be undertaken and to be kept up to date on that. Other members will probably request further clarification on some of the issues to do with the better cancer care plan, which is the overarching strategy.

A number of the cancer care charities that made submissions to our inquiry identified that it is important that key health professionals are involved in discussing what it would be beneficial to gather together in developing a more coherent

strategy. What are the broader views of those health professionals on the action that the Scottish Government can take, alongside them, to address those concerns?

Finally, will the better cancer care plan contain more detail than we have already been given? What issues of data gathering will be further considered and reported on to the Parliament? We seek further clarity on that.

Difficult issues arise with the quality-adjusted life years assessment, which John Farquhar Munro might address in the limited time that we have to address key points in the report.

The availability of drugs was the central point of the petition that Tina McGeever and Michael Gray lodged. In the anguished circumstances that faced Michael, they made a brave submission. Michael believed in the health service's principles and was committed to equity of access—that was the point of Margaret Curran's intervention. Because of his professional and personal circumstances, he happened to have money to obtain privately drugs that were not available on the NHS, but he found that, as a result, the NHS part of his care was not provided. That was outwith his control. The motivation behind the petition was not to drive a coach and horses through the important principles that many of us—if not all—in the Parliament share on equitable access to the health service. The question was whether, when we are in the most difficult circumstances that could face any of us or our families, we can find a more effective way to deal with them.

I am sure that the cabinet secretary agrees that what made the issue even more difficult was the fact that the journey through the assessment of treatment was uneven—that is a euphemism. That threw up many other issues that the cabinet secretary and health boards are responsible for resolving for the future. That is not a criticism of any individual in the process; the structure was not sensitive enough to the petitioners' needs.

Terminology such as “exceptional prescription” is used and the assessment procedure is imposing. Given the way in which the individual who was facing difficulty had to confront senior health professionals locally to justify their request to be considered for drug treatment, even the health board involved has acknowledged that it needs to do much better on that in the future.

What information is available to individuals who are involved in such a process? In response to the committee's report, the cabinet secretary has identified ways in which improvements can be made. It is important that the public, patients and consumers—whatever term we want to use—are centrally involved in shaping developments. We can use the next few months to expedite effective

action on those comments and observations. I would like to hear how more public and patient involvement in the process will be achieved. I am sure that that will influence the better cancer care plan.

What is the cabinet secretary's view on appointing liaison officers in each NHS board to act as a communication link between clinicians, boards and patients, as proposed in paragraph 85 of the report? What information—in leaflets or in other ways—will be given to patients when they confront a diagnosis? When the better cancer care plan is published next month, will it set out clearly how the quality of information on the exceptional prescribing process will be improved and made available early to patients? How will that process be made fair throughout Scotland? What input will the difficult decisions short-life working group have into the process?

I will touch on another concern in the report.

The Deputy Presiding Officer: The member should conclude his speech.

Mr McAveety: My final comment will be on funding; I am sure that other members will deal with other issues. I welcome the cabinet secretary's comments this morning about funding, because the health department's guidance was inconsistent. It would be useful to hear how the cabinet secretary will make that clearer.

We recognise that the issue is difficult. I have not had the time to get anywhere near a wheel of issues, which I hope that other members and the cabinet secretary will address. We are trying to achieve for patients a much better, fairer and clearer system, which minimises trauma such as that which Tina and Michael experienced in their journey through that difficult part of their lives. I await the cabinet secretary's response to the report.

I move,

That the Parliament notes the conclusions contained in the Public Petitions Committee's 3rd Report, 2008 (Session 3): *Availability on the NHS of cancer treatment drugs* (SP Paper 133).

15:20

The Deputy First Minister and Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon): I welcome the opportunity to participate in one of the most important debates that the Parliament has had. There is no doubt that the process that led to the debate has highlighted many of the best features of our Scottish Parliament. The ability of a member of the public to raise issues that are not only fundamental to them but of enormous significance to many in Scotland reflects our collective values

of engagement and inclusion. In turn, the matters that were brought before the Public Petitions Committee received robust, detailed and thorough examination. I pay tribute to the committee for producing a report that I believe will result in a number of positive developments in the system in Scotland for introducing new drugs—a system that the report recognises as having a number of considerable strengths.

At the outset, I take the opportunity of paying tribute to Michael Gray. His strength of character and determination shone through the deliberations on the issue. Richard Lochhead, who is the constituency member for the area in which the family lives, has told me how highly regarded Michael was in his local community. Margaret Curran has also spoken about the broader contribution that Michael made.

I place on record my thanks and appreciation to Michael's wife, Tina McGeever. My thoughts and condolences remain with Michael's family at what I know must be a very difficult time. The support that Michael got from his family and friends was unwavering. It says an enormous amount that they are determined to continue to seek what he sought for the many in Scotland: a system that does not have the faults that necessitated him and his family going through what they did.

I have no doubt that the debate this afternoon will offer all members the opportunity to consider the committee's recommendations in detail. In the time that is available to me, I am unable to go into the detail of all the issues or to answer all the detailed points that Frank McAveety raised. However, in my oral evidence to the committee, and my written response to the report, I made it clear that, where there is scope for improving and developing the existing arrangements, we will take action. I know that the Parliament will continue to pay close attention to the issues. I welcome that.

Peter Peacock (Highlands and Islands) (Lab):

I echo many of the comments that the cabinet secretary has made. However, will she commit to using every power that she has to ensure that no one else has to suffer the kind of degrading and inhumane circumstances to which Michael was subjected in having to plead his own case? Will she give an absolute commitment to finding a better way of doing things in the future?

Nicola Sturgeon: I think that we all agree that we want to deliver improvements to the system, which the committee recognises in its report as being robust in many respects. One expert described it as a "model" for others to follow. In improving the system, we should manage to avoid the kind of circumstances in which Michael Gray and other patients found themselves.

I will begin my substantive comments by underlining some fundamental points. First, and perhaps most obviously, the Government—and, I believe, the whole Parliament—remains absolutely committed to the founding principles of our NHS, which is that treatment is provided free at the point of access and is based on need, not the ability to pay. We all believe in services that are comprehensive and equitable.

In the "Better Health, Better Care" action plan, which we published last year, we made a clear commitment to providing evidence-based clinical care. The arrangements in place in Scotland have never been, and never should be, focused solely on costs or health economics. They must be focused on a wider set of principles, including those of clinical effectiveness and evidence of benefit.

I attach huge importance to all processes being independent of ministers. The arrangements are designed to allow for the consideration of a range of factors and perspectives, including those of clinicians and laypeople, academics and the pharmaceutical industry. That diversity promotes thorough debate before any decisions are reached. In many cases, the decisions will be difficult to take, but it is important that they are based on the right factors. The processes and systems that we have in place assess not only the impact on the NHS but benefits for patients. That is the responsible way in which to do these things in a publicly funded NHS.

As I have said, when we talk about policy issues and complex decisions, we must never forget their impact on individuals and their families. In large part, that is why we are having the debate.

From the committee's recommendations, it is evident that much in the system works well. It ensures that the Scottish Medicines Consortium gives early consideration to all new drugs; that, when appropriate, recommendations from the National Institute for Health and Clinical Excellence are considered swiftly; and that NHS boards ensure that particular drugs or their equivalents that are recommended for use are made available equitably and in line with clinical needs. However, it is also clear from the evidence that was submitted to the inquiry that there needs to be greater clarity and transparency regarding how the arrangements work in practice and how we achieve a greater consistency of approach throughout Scotland.

I have made it clear that the Scottish Government is keen to ensure that it takes appropriate action where there is scope to develop and improve the current system. That is why, in my response to the committee, I outline the work that is under way to improve data gathering, which is essential if we are to assure ourselves on the

points that have been raised, and agree the need to address a number of challenges. Much of what needs to be done will be achieved through existing work programmes—for example, the e-health strategy, the better cancer care plan and the outcome of the recent evaluation of the Scottish Medicines Consortium. I attended the SMC conference to discuss the evaluation, at which there was obvious enthusiasm on the SMC's part to address the challenges too.

However, it is also clear that the various work streams that I have talked about will not be enough in themselves. We need to take other action if some specific recommendations are to be addressed properly. For example, we need to reconsider how patients are supported through the whole process, particularly the exceptional prescribing process. I am more than happy to assure Frank McAveety and the committee that we will consider having liaison officers and better information for patients.

I have also made it clear today and in my response to the committee that the time is right to review the guidance on co-payments. It is important to highlight some of the key principles on that difficult and controversial issue. First, I stress that co-payment must and always will be the exception, not the norm. Under current arrangements, if drugs are shown to be clinically effective, they should be available on the NHS. We must ensure that we focus on ensuring equitable and improving access to clinically effective drugs on the NHS. Tina McGeever made that point powerfully on radio this morning.

Secondly, it is an important principle that the NHS cannot charge patients for treatment that would not otherwise be available to them. In other words, patients cannot and should not be able to pay the NHS to provide care that is not otherwise available; if they could, that would lead to a two-tier system.

However, patients already have the right to access care from the private sector. The question is the extent to which, when they exercise that right for one element of their care, the NHS can still provide other aspects of care. That must be considered case by case. If the treatment that is to be provided privately is so interwoven with NHS treatment that there can be no clear delineation between the two, concurrent treatment might not be appropriate for reasons of clinical governance and patient safety. However, if different elements of care can be separated safely, concurrent care may be possible.

Those are complex judgments, and the purpose of the revised guidance will be to provide clinicians, NHS managers and patients with the right framework for arriving at those difficult decisions. That framework must respect individual

patient rights and protect the principle on which our NHS was founded: care based on need, not the ability to pay.

Mary Scanlon (Highlands and Islands) (Con):

Will that guidance also apply to people who pay privately for treatment in another country? When they come back here, they depend on the NHS for follow-up treatment. Will that situation also be covered in the guidance?

Nicola Sturgeon: We can perhaps have a more substantial discussion about that later. Under those circumstances, the hypothetical patient described by Mary Scanlon would have access to NHS treatment. In many cases already, concurrent treatment would be possible.

I got the strong message from the Public Petitions Committee that there is a need to make the arrangements clearer and more transparent for patients—and indeed for clinicians.

This is an important if difficult debate. In some respects, it is controversial. However, I am determined to listen and to act where necessary. Our approach to introducing new drugs is robust and well regarded, but there is no doubt that it can be improved. I have been pleased to have been personally involved in the Public Petitions Committee's inquiry, and I will continue to ensure that the necessary leadership and commitment are in place to turn the committee's recommendations into a practical reality. I look forward to further debate and to continuing this discussion with members from across the Parliament, and indeed with the wider public.

15:31

Cathy Jamieson (Carrick, Cumnock and Doon Valley) (Lab):

Like other members, I put on record my thanks to Frank McAveety and the Public Petitions Committee for bringing the report to the chamber. This afternoon's discussion is very important, and we will have to return to the issue in the future.

This is my first opportunity to contribute to a debate in the subject area of my new portfolio responsibility and I know that many people have followed the issue—both professionally and as committee members—for much longer than I have. However, one of the useful things about having a fresh eye is that the key themes jump straight out of the piles of submissions and reports that I received from various organisations. I hope to identify some of those themes during my speech.

I pay tribute to Tina McGeever and Mike Gray. As the committee's report indicates, they both went through a harrowing process, but showed a great deal of dignity, strength and determination.

As Frank McAveety and Margaret Curran have acknowledged, Mike Gray's concern was not simply for himself; he sought to ensure that others would benefit from changes made as a result of his experience.

Everyone in the chamber will be touched at some point in their lives by cancer. Some of us will, sadly, have suffered and might suffer in the future. Others have lost, or will lose family and friends. In the face of such circumstances, every one of us would want everything possible to be done to treat the condition and to halt it, when possible, or to improve the quality of life of sufferers when that is not possible. We can all understand the scenario in which patients and their families want to pursue every possible avenue to get the best outcome possible.

At a time when they are at their most vulnerable, patients and their families need as much clarity as possible. They should have a real say in the treatment and care that is provided, and they should have confidence that everything possible is being done. They should be presented with honesty, not false hope. They should be made aware of the circumstances under which decisions are made.

I was struck by something that was highlighted in some of the briefing notes that various organisations supplied. Although the roles of the various bodies involved in decision making—such as the area drug and therapeutics committees, the Scottish Medicines Consortium and NHS Quality Improvement Scotland—might be relatively unambiguous, and although they themselves know what they are about and what they are doing, it is not easy for someone to weave their way through all those organisations and get a positive outcome if they have never come across them before.

People can experience further confusion when they discover that the guidance from the SMC is advisory, and that whether the patient actually gains access to the treatment still depends on whether the ADTC agrees to follow the guidance. As we know, there is no statutory duty to do so in Scotland, unlike elsewhere in the United Kingdom, where NICE guidance is subject to such a duty.

Frank McAveety painted a vivid picture of what Mike Gray found as he tried to make his way through the process at his local health board. Various organisations and patients have raised concerns about the processes for prescribing in exceptional circumstances being different, depending on the health board area. That is not a situation that we want to continue. Cancer Research UK has described the considerable variation in the implementation of SMC guidance, including on the processes for exceptional prescribing and the use of top-up payments. I was struck by that variation, which Cancer Research

UK thinks is unacceptable. I understand that a number of organisations, including the British Medical Association, think that patients should be able to top up, but such an approach raises other issues, as the cabinet secretary said, and would potentially create more problems than it would immediately solve for the NHS.

Suggestions for improvements to the system have been made. There could be more sophisticated appraisal in the context of quality-adjusted life years, and exceptional prescribing panels could be more uniform, streamlined and transparent. Other issues must be considered. It has been pointed out that our spending does not necessarily reach the European average. More work must be done by the pharmaceutical industry with Government.

We should consider the matter from the point of view of patients and their families. Surely it is difficult enough for a person to deal with a diagnosis of cancer or other potentially life-terminating illness without having to worry about whether they have the wherewithal to afford top-up treatment, if that is the only option. Co-payments are the most sensitive issue in the report, and we will need to return to the matter.

I was pleased that the cabinet secretary said that she intends the review to consider change on the basis of the need to safeguard and preserve the fundamental principle of the NHS: equal access to care that is free at the point of use, regardless of ability to pay. I hope that all members will send a strong message of support in that regard. There are concerns that the least well off and the least well educated find it most difficult to negotiate the system. Whatever we do, we should not perpetuate existing inequalities or create new inequalities. If we are not to create a scenario in which two people on the same ward receive different treatment for the same condition, based on their ability to pay, we must resolve the difficult dilemmas that members described.

I ask the cabinet secretary to ensure that the review is based on the founding principles of the NHS and to acknowledge that the funding issues that might well arise will be considered as part of the process, so that we can ensure that the focus is not on finding ways for patients to pay for their treatment, but on ensuring that they receive timely, appropriate and effective treatment.

15:38

Nanette Milne (North East Scotland) (Con): I fully endorse the comments of Frank McAveety and other members about the late Michael Gray and his wife, Tina McGeever. It is fair to say that all members of the Public Petitions Committee were deeply moved by the bravery of the couple,

who, in the final stages of Mr Gray's illness, put so much effort into their petition, which aimed to secure a better experience in future for patients who suffer from terminal cancer and might benefit from drugs that are not approved for the NHS formulary. Mr Gray's evidence was delivered in a straightforward, unemotional way, as indeed was Tina McGeever's evidence when she returned to the committee a few weeks after her husband's death. That made a deep impact on committee members.

A number of important issues for the Government to take forward arose from the inquiry. If the end result is more clarity of procedure, more patient involvement and more support for people who are faced with terminal cancer, that will be a well deserved and fitting legacy for Mr Gray.

All five key areas that the Public Petitions Committee examined led to requests for Government responses. I welcome the cabinet secretary's sensitive and constructive reaction to much of what we put to her. The first area to be explored was that of defining the roles of and interplay between the bodies that are involved in appraising the clinical and cost effectiveness of a licensed cancer treatment drug. Although the committee was struck by the numbers and tiers involved in the process, we were reassured by witnesses that roles are well defined and have minimal overlap and that the system is clearly understood. However, the Patients Association thought that more transparency was needed in the appraisal process, specifically at local level, and the committee wanted to know how Government would improve the system and involve patients more at that level.

In that regard, it is interesting to note that a citizens jury that was set up by Breakthrough Breast Cancer regarded it as vital that all patients receive clear and realistic information on the true benefits, risks and limitations of new treatment so that they can make fully informed decisions on their treatment pathway. We hope that those issues will be addressed in the forthcoming better cancer care plan and that good practice at local level will be rolled out across Scotland.

On the issue of guidance to NHS boards, there is some doubt about whether the guidance is applied consistently and equally across all boards, despite the Scottish Government's expectation that health boards and clinicians should take full account of SMC advice and guidance from NHS QIS in light of any subsequent NICE multiple technology appraisal. The committee believes that more clarity is needed on how the Government monitors its expectation of health board compliance.

We were also concerned by the SMC assertion that it could not assess the uptake of its advice across Scotland because of inadequate data gathering. The current lack of data prevents the identification of areas where difficulties exist and where improvements could be made. All NHS boards would welcome a national data-gathering system. It is encouraging to note that the Government's response to this section of the committee report states that steps are being taken to ensure that appropriate data are gathered, analysed and used to inform decision making. Those roles of definition, guidance and data collection are clearly important in the equitable provision of approved and appropriate cancer drugs throughout the country. It is only right that patients receive the best recommended treatment available from the NHS.

The main focus of the committee's inquiry, in the light of Michael Gray's experience, was on the issue of exceptional prescribing, which comes into play when the SMC and the ADTCs have assessed that a drug should not be made available on the NHS, but the patient's clinician considers that the drug could benefit the patient and should be prescribed. NHS boards should have protocols in place to consider requests for non-formulary treatment, but the evidence that we received suggests that the procedure is not patient friendly and lacks equity and consistency across health boards. At a time when patients and their families are distressed and often bewildered by the realisation that they face a terminal illness, they need clear information, guidance and advice that lays out the options available to them. The patient and the clinician should be involved at every stage in the process of consideration as to whether a non-formulary drug is to be funded.

The committee believes that there should be a more consistent approach to non-formulary prescribing across health boards, with better communication between the board, the patient and the clinician. The process could be helped by the appointment of a liaison officer to guide the patient through the exceptional prescribing process. I welcome the cabinet secretary's commitment to consider that suggestion.

We also need unambiguous guidance on co-payments. For patients such as Michael Gray, who chose to pay for a non-formulary drug, the cost of the drug may be relatively inexpensive but the associated NHS costs can mean that the entire episode of treatment becomes prohibitively expensive. Of course, such issues are complex and involve financial, ethical, moral and clinical factors that need to be considered. Therefore, I very much welcome the cabinet secretary's stated intention to initiate a review of the guidance on co-payments. I also endorse Cathy Jamieson's comments. Co-payments are an issue of

increasing concern, particularly in the treatment of advanced cancer, and are already being looked at south of the border. I hope that the results of the on-going reviews in England will be considered by the cabinet secretary in the course of her review.

In conclusion, the Public Petitions Committee's inquiry has revealed some extremely important and complex issues. If those can be resolved to ensure a smoother pathway of care for people like Michael Gray, the efforts of that brave man and his wife will have made an enormous contribution to terminal care in 21st century Scotland.

15:44

Ross Finnie (West of Scotland) (LD): I welcome Cathy Jamieson to her new role. I also associate myself and my party with the opening remarks of Frank McAveety and of others in recognising the courage, tenacity and dignity of the petitioner, Tina McGeever, and her late husband, Michael Gray.

I congratulate the committee on producing such a comprehensive report on a difficult subject and on finding its way through the maze that is SMC, NHS QIS, NICE, ADTCs and NHS boards.

Since the report was published, we have had a constructive response from the Government, and the findings of the national medicines utilisation unit's evaluation of the SMC's impact on and engagement with stakeholders. The latter added weight to the committee's call for greater consistency in the adoption of approved medicines by recommending that medicines that are accepted for use should be included in formularies, and that by organising themselves regionally, ADTCs might achieve more consistent implementation. Some of the report's recommendations are therefore already being picked up by others who are looking at the subject.

Without a shadow of a doubt, the Government's response accepted the principles enunciated in the report about the evaluation process, and it cited the forthcoming better cancer care plan as a potential vehicle to institute more rigorous monitoring and data gathering to monitor the implementation of advice. In his opening remarks, Frank McAveety elaborated on the need for even more development in that field, and that was broadly acknowledged by the cabinet secretary in her speech.

I have one further point on data gathering. I do not believe that there is any contention about this, but I hope that, as a matter of practical expediency, when the cabinet secretary refers to a particular report on cancer, she accepts that a number of the points made in it are applicable to a range of service delivery in the national health service.

The committee's report acknowledges the fact that, because of its intricate nature, the concept of the quality-adjusted life year was not addressed in full. However, it makes some serious and helpful recommendations about implementing health economic methodologies. I am pleased that the Government is participating in the United Kingdom research to consider methodologies and the QALY process.

There has to be such a process and Liberal Democrats believe that the QALY process plays an important, and often misunderstood, part in the current system. It is sometimes cited as an excuse for people not gaining access to drugs when that is not the purpose of applying the methodology. However, as the committee's report indicates, further research is needed.

There is no question but that the report is helpful in pointing out the range of misunderstandings, inconsistencies, and delays in the granting of exceptional prescribing across health boards. The cabinet secretary has acknowledged that, and work is in process. I thought it helpful that the cabinet secretary added the need to provide support for those who are engaged in that work. That was a key element of the report and I am in no doubt that, if all the questions that the report poses to the Government are comprehensively addressed—there is no suggestion that they will not be, but the cabinet secretary suggested that we do not have time to talk about them this afternoon—that will address the majority of the criticisms of exceptional prescribing.

The Liberal Democrats welcome this morning's statement by the cabinet secretary on co-payments, to the effect that the Government will review the matter and issue new guidelines balancing individual rights, clinical governance, and the need to avoid a two-tier health service.

The committee makes it clear that co-funding arises in only quite exceptional cases, and that has been acknowledged by members of all parties this afternoon. The more effective the system for approving drugs, and the more cost effective the commissioning and use of drugs, the more likely it is that co-funding will remain exceptional.

The Liberal Democrats hope that the cabinet secretary, in conducting a review, will take account of the Richards review that is being conducted in England, and also of the points made by the British Medical Association about the fact that, because co-payments affect a range of clinical decisions, an overarching response to the issue is required.

It is right that the matter should be dealt with on a case-by-case basis and we hope that when the concurrent treatment rule is applied after the review, it will not result in a patient being denied support through the NHS.

The committee's report addressed the critical issue of funding and paid particular attention to pharmaceutical price setting. I draw members' attention to the snappily titled recent report by the SMC, "An evaluation of manufacturers' budget impact estimates with resource use over time in NHSScotland", which revealed significant weaknesses in the quality of the budget impact information that the pharmaceutical industry provides to the SMC. It said that the manifest limitations in the budget impact data meant that meaningful and reliable comparisons with actual expenditure could not be made. It is clear that those findings have implications for budgeting for new drugs and thus for their availability, so I hope that the Government will consider the SMC's report carefully and, if necessary, issue new guidelines to pharmaceutical companies to improve health boards' ability to budget, thereby improving their ability to introduce new drugs.

I hope that that report and the findings that have been discussed in the debate will result in a much better, more transparent and more equitable way of dealing of patients, and that no one will have to experience the circumstances that the petitioner had to go through.

15:51

Ian McKee (Lothians) (SNP): The question of which drugs should be made available on the national health service can seem extremely confusing, so let us try to tease out some of the issues.

As the Public Petitions Committee's report tells us, no drug is allowed to be prescribed unless it has passed the scrutiny of one of the regulatory bodies. For the United Kingdom, that is usually the European Medicines Agency. A new medicine is judged for quality, safety and efficacy, so it seems reasonable for a doctor to prescribe it once it becomes available, but that is not always the case. There is no way of knowing the true safety profile of a medicine until it has been prescribed for a wide range of people, not just for the small pool of volunteers who were recruited for pre-registration trials. Likewise, efficacy becomes truly apparent only once the preparation is on the market and has been prescribed thousands, or even hundreds of thousands, of times. Some drugs have to be withdrawn as a result of unexpected serious side-effects only a year or two after becoming available. Others, which seem initially to convey only marginal benefit, flourish as their true worth slowly becomes apparent.

For those reasons, the wise doctor does not rush to prescribe the latest drug on the market unless there are compelling reasons so to do. Such a reason might be the fact that there is no alternative effective treatment for a particular

illness. He or she considers all the evidence and then advises appropriately. Organisations such as the SMC and NICE provide some of the evidence to facilitate that decision. The SMC provides a snapshot of a medicine that is new to the market. NICE takes a more leisurely look, after the preparation has been widely available for some time. Their work is complementary. Along with area drug and therapeutics committees, many other organisations, such as the Scottish intercollegiate guidelines network, can offer informed advice.

However, we are in danger of allowing the presence of a horde of advisory bodies to obscure what should essentially be a very simple position. I argue—from the safe confines of the back benches—that their function should be to provide top-quality advice to the prescribing doctor, not to act as some sort of rationing institution. In a top-quality health service, prescribing decisions must be left to the doctor who is caring for an individual patient.

We are discussing cancer, and cancer patients vary enormously according to the severity or stage of their illness and the type of people they are. Gaining a few more weeks or months of productive life might be worth any risk of discomfort to one person, but such risk might be totally unacceptable to someone else. If I am ever in that position, I would like my treatment to depend on my personal preference, once I had received full information from a well-informed doctor. The few doctors who might abuse that position of responsibility should be dealt with individually. It is totally inappropriate that a health board or any other outside body should interfere routinely in that process as long as any medicine prescribed as a result is licensed for the purpose. In her evidence to the Public Petitions Committee, Tina McGeever said that it is important that the patient has someone in whom they can trust. I agree, but who better than the patient's own doctor? How sad that we think that that should not be the case.

I draw the line, however, if any proposed treatment has not been shown to be efficacious, particularly if it is wildly expensive and even if it has been given as part of a trial. A trial is to determine whether a medicine is efficacious and safe. If the preparation is shown early on in the trial to be of definite benefit, the trial is halted as it is unethical to deny it to the placebo group. The medicine should then be available for routine prescription. If it has not been shown thus, it seems unreasonable to make it prematurely available on the NHS. The same goes for alternative treatments of dubious worth. Evidence is everything.

Mary Scanlon: As an experienced prescribing doctor, does Ian McKee acknowledge that many medicines and drugs are given out to patients day and daily throughout Scotland that have never been evaluated?

Ian McKee: I agree that many medicines and many treatments have not been evaluated. The challenge for the health service is to go ahead with the evaluation and get rid of some treatments, such as various homoeopathic remedies that are prescribed in the health service, which, to my mind, are totally useless.

Where does this leave us as far as co-payment is concerned? The danger of allowing patients to pay for medication that would not otherwise be available to them, and then to have it administered as part of the NHS, is that it could be the thin end of a wedge leading to a two-tier health service. If a medicine is of proven benefit, and both doctor and patient wish it to be prescribed, it should be allowed. As the cabinet secretary indicated, we must not fall into the situation whereby effective medicine is paid for by some and denied to others because they cannot afford it, but I do not see why a publicly funded health service should spend its time and resources and risk administering treatments that are of no proven benefit, even if the patient is paying. There are plenty of organisations willing to administer quack treatments without the NHS joining them.

My plea is for health boards to take a step back and to trust their professional employees to make the appropriate treatment decisions for individual patients, but—as Mary Scanlon said—to insist on an evidence base to underpin those decisions. Effective cancer drugs should be available to all.

15:58

Duncan McNeil (Greenock and Inverclyde) (Lab): I welcome the opportunity to speak in the debate, and I have enjoyed the speeches so far. We owe some gratitude to the Public Petitions Committee for securing the debate.

In many ways, the debate is just one strand of a wider debate on the future and evolution of the health service. We would all agree that the principle of free health care for all at the point of need is sound. At times, though, our health service can be bureaucratic to the point of being uncaring, as was highlighted by the circumstances of the Public Petitions Committee report. At the NHS's heart, however, are good people who deliver a good service to those who need it.

That said, we all need to accept that our health system is far from perfect. Our shared ambition of equality is not always delivered: we know that many people are already excluded from receiving appropriate services—the services that we would

want them to receive—because of their social circumstances. We know that people who are disadvantaged die younger, and are less likely to go to a GP and will receive less time when they do. They are less likely to be referred to a consultant early and, as a consequence, are more likely to suffer. In my constituency of Greenock and Inverclyde a person can live 11 years longer than someone who lives three miles away.

As politicians and Governments, perhaps we should seek in our manifestos to equality-proof our health policies. We should ask whether cuts in health spending make people's situations better or worse and we should ask whether the mechanism for distributing finance to health boards really focuses on need. We should also ask whether a flat rate for efficiency savings hits urban areas disproportionately because such areas already have significant problems. We should ask—I admit to having been guilty of this—whether our focus on bricks and mortar, and on new hospitals and old hospitals, prevents us from shifting investment to areas in which it might help people to live longer and better lives.

Does reducing the cost of prescriptions really help the poor? Does greater access to general practitioners in the evenings or at weekends make it more likely or less likely that people with multiple problems or complex problems will get sufficient time with their doctors, or does it simply fuel an unrealistic expectation of the service?

Ian McKee: Does Duncan McNeil accept that high prescription charges meant that lots of pharmacists had examples of people who could not afford all their prescriptions and would therefore ask for just one or two of them? Is he not pleased that such situations have now been removed?

Duncan McNeil: It is a question of priorities. When we are spending money, and when our ambition is to put equality at the heart of service delivery, hard decisions have to be made. I do not believe that we are doing enough to end inequality. I know that Ian McKee has some sympathy with that argument.

Inequality exists, and some people are caught in a poverty health trap. However, as we have heard, other people are taking more responsibility for their own health and are taking things into their own hands. They are accessing private health care at home or abroad and are mixing and matching at the dentist. The multimillion pound business of over-the-counter medicines is testament to the culture of self-diagnosis and self-management of our health issues. NHS 24 and community pharmacists are all on hand to offer help and advice with that. In addition, we have the internet and Google.

People are empowered by knowledge and by a greater understanding of their health issues. That has fundamentally changed the relationship between doctor and patient and it is changing the health service as we know it. We cannot blame people for taking such opportunities; they are not always a bad thing. However, a consequence is that we are widening the gap between rich and poor. That prompts a question: What are we doing for those who are left behind? Now that we have lifted people's demands and expectations, we cannot suddenly say when things get serious, "Well, that's nothing to do with you. You can only fix your sore throat or your headache." When things get serious, and when family members are rallying round, we cannot suddenly say to people, "We are putting a cap on your expectations, your influence and your involvement."

In reading the report of the Public Petitions Committee, I felt that no point was put better than the point that was made by a group of terminally ill women who were consulted by Breast Cancer Care. What they said lies at the heart of the matter: they described top-up treatments as "morally wrong", but confirmed that they would remortgage their homes to buy themselves and their families some extra time.

Whatever we do in the light of this debate and the subsequent review, we should consider the wider context. Our aim should be to level people up, not to level people down.

16:04

Jackson Carlaw (West of Scotland) (Con): I begin by adding my thanks to those that have already been offered to the Public Petitions Committee for its report. My speech will principally address co-payments, but I start by saying that the committee has, in setting out the terms of its inquiry and in the clarity of the language that was used, especially in the opening section on defining roles, succeeded in producing a text that will help enormously in informing people who do not deal with such matters regularly, and in mapping a way through the various abridged terms to which Ross Finnie and Ian McKee referred. That section methodically explains a process and reviews it. Although the report accepts that the process can appear relatively complicated, it finds—as the cabinet secretary noted—that it is working well and has key strengths.

Debates about the running and future of the national health service can all too easily become tribal in character in the reality of adversarial politics. The Labour Party, which in government founded the NHS, sometimes stands accused of being prepared to ignore or be too sympathetic to any faults within it, while in turn this side is accused of seeking to identify those problems only

in pursuit of some ephemeral agenda to privatise the service. Analysis and debate of important arguments often fall at that first hurdle.

It is, therefore, to the credit of the Public Petitions Committee that it has been measured in addressing an issue that has created such a sense of unease. It is clear, from the many organised submissions that have been received ahead of the debate, that that unease is deeply challenging. Events and developments in science are producing potentially life-saving treatments, but access to some of them appears to be outwith the NHS and they are not universally available. One can almost touch the very real concern that that creates. Given that it is a matter of life itself, none of the submissions is prepared to say no. However, the issue of co-payments or top-ups invites politicians to stray from the universal principles of the NHS. In her statement the cabinet secretary sought, in careful and appropriate, yet simple and impassioned language, to establish a potential route forward.

The report deals with the issues of availability dispassionately. It makes sensible points about the different approaches of health boards, illustrating that differences in the availability of treatments can often be reasonably explained by geography. What might be appropriate in an urban area with immediate access to a hospital may not be appropriate in a rural area, where the treatment may be quite different. However, that is for reasons of practicality, not reasons of cost.

On the other hand, concerns persist about there being a lottery. Last Wednesday, the BBC aired a programme that examined the availability of five top cancer drugs across the United Kingdom. All were relatively expensive and, at the time of the survey, none had the approval of the guidance bodies. The results showed huge variation of availability in the NHS and, despite the earlier argument about geography, there were many examples of variation between immediately neighbouring communities. All the treatments are refused in London, while all are funded in the north-west. In Wales, Swansea funded 8 per cent, while Pembrokeshire funded 70 per cent. In Glasgow, all the treatments were refused, while in Northern Ireland all were approved. That disparity is undermining public confidence. I agree with the cabinet secretary that our focus must ensure "equitable and improving access" to new drugs.

However, we must all surely share the anxiety that the protocols of our various systems are now found wanting in an environment in which there is such a pace of change. It is not a question of whether someone can jump a place in a queue; it is a challenge to politicians that is more complex, yet basic. Do we have a right, even with a faster approval process and a more generous budget for

cancer drugs—to achieve that will, in itself, be quite a challenge—to say to people who are literally fighting for their lives that, if they accept treatment from outside the NHS, they will be denied further NHS treatment?

As other members have, I say that this is a real issue for my family. An immediate family member, a mother of three, is in the later stages of palliative care for a terminal cancer and has had the very best treatment. At no point has it been suggested that a treatment that is available outside the NHS would have made any difference. However, had that been the case, I would have done all that I could to ensure that it was made available to her. As Cathy Jamieson argued, I doubt that others would act differently. I would have been outraged if, in accessing such treatment outside the NHS, she was denied further NHS treatment. That is the human reaction that is shared by all those who have written to me.

I understand the position that the cabinet secretary outlined regarding the incompatibility of some treatments, which is of real concern. However, it is not understood in the public context of this debate, nor is it the axis around which the debate is growing in the public consciousness. Rightly or wrongly, many people see the issue as one of cost or of dogmatism—put bluntly, that we should all die together rather than reach for life and that, in trying to live, someone may be cast out thereafter from the NHS. I know that that is simplistic, but the current position is not sustainable: in all the measured words of the many submissions that I have read, and in the report itself, that is understood. I therefore welcome the review that the cabinet secretary is to initiate. If public confidence is to be sustained in the face of complex arguments, the review will need to proceed with some urgency.

I have concluded that, from today's unsustainable position, however narrow the initial dispensation, the incidence of co-payments or top-ups is likely to grow rather than to diminish. I do not share Ross Finnie's view that it will become more exceptional—it will not do so while science continues to gather pace and make substantial breakthroughs. I imagine that, in time, it will create its own insurance market, which will be quite distinct from current comprehensive private health care plans. I imagine that co-payment insurance policies will evolve and that premiums for such policies will be minimal by comparison with the comprehensive care model. It would certainly make such an option affordable to millions, rather than a few. I note this in passing not to advocate it but because I think that is how the market will eventually respond. We need only consider the experience of countries such as Denmark, where co-payments are allowed. There, specialised insurance cover has evolved and almost a third of

the population take advantage of it. I accept that some people will balk at that prospect, but I do not.

Meanwhile—even in such an environment, were it to evolve—we need to be able to respond to new treatments quickly within the NHS. We have campaigned all our lives and in everyone's interests, not just the interests of some, to beat cancer and its cruelty. I appreciate the trenchant way in which Duncan McNeil addressed that point in terms of equality.

We might face what will be for many a difficult adjustment in policy, but in view of the gravity of the issue, we cannot allow ourselves to dwell on it as if it were some enigmatic puzzle, and neither should we jump to a judgment. It is important that the change is the subject of widespread agreement. The situation is, however, urgent: lives are being lost and will continue to be lost. The cabinet secretary stands ready to adjust policy guidelines within parameters. Let us establish what they are, and proceed.

16:11

Christopher Harvie (Mid Scotland and Fife) (SNP): We are here today because of a tragedy—the illness and death by cancer of Michael Gray—and his wife's petition, which was founded on that experience.

The issue is an emotional one for me because three and a half years ago my wife, Virginia, was diagnosed with an unusual cancer that had developed between regular scans. It had moved to the liver and become inoperable. I still live out the time that was left to us and those days—there were only days—from the first consultations to the final diagnosis. I remember the kindness of nurses and doctors in the last weeks of the old Middlesex hospital, my wife's courage and composure, and the days of waiting at her bedside for death to come.

It is impossible not to feel for anyone who is facing such a situation, and to hope for some treatment that might reverse symptoms or at least prolong life. For those who know that they have only a short time, even that can be important. Anything that might enable the good death—arranging one's estate, providing for family, seeing projects through—is grasped. Surviving, at 64, I am in a minority among my friends, as many of them have died from cancer.

This issue concerns second opinions and alternatives. I telephoned my friend, Professor Theo Lippert, of the University hospital of Tübingen, who is a gynaecologist and pharmacologist. He delivered my daughter more than 26 years ago. He also lost his Scottish wife, Dr Elsie Lippert, to cancer. His view partly

endorses the flexibility of the approach that is being urged in Tina McGeever's petition, which is to provide a framework for making cancer-treatment drugs available in medically justified cases to the relatively few who apply—the recent BBC availability study counted only 30 applications in Scotland in the past year—and making sure that the postcode lottery does not determine who can or cannot have access to drugs or other treatment. I agree with both aims.

Second opinions are important, and should not be sidelined due to cost or administrative considerations. However, the subject is opaque and drugs are not the only consideration. In a recent case, a constituent of mine was offered for prostate cancer a hormone treatment that would have extended his life for two to three years, but with a poor prognosis. He opted for surgery, which was not covered by the NHS. It was successful, but he had to negotiate it for himself, and became liable for the full costs. That is where we require flexibility, which is not necessarily limited to exceptional prescribing.

My Tübingen colleague, Professor Lippert, is sceptical of the treatments that rely on drugs alone and do not take an holistic view of the patient's past health and treatments, nutrition, nursing and other therapies. In general he—as I do—approves of a system of licensing and issuing of guidelines such as we have in Scotland through NICE, the SMC and NHS QIS. He is sceptical about the German experience and believes that of the roughly 1,000 well-marketed and often expensive cancer remedies on the market, only about 20 per cent benefit the patients. He believes that clinicians must concern themselves with factors such as nutrition, scanning and previous illnesses and treatments, and must work closely with pharmacologists, nursing experts and specialists, who have sometimes tended to remain marginal to the clinical process. He also insists that too much emphasis is placed on average rates of survival, rather than on concentrating on the particular situations of individual patients.

That approach—focusing on the individual patient in a more holistic view—is one aspect, but it must be viewed in the light of an Office of Fair Trading report that was published in February 2007, which accused the pharmaceutical industry of deriving £8 billion of excess profits from the national health service. I ask whether other medical approaches that do not involve expenditure on drugs, and other essential infrastructures, have advocates that are as persuasive and as well-heeled as the big pharmaceutical companies. As in so many other fields, equitability must lead to a stronger public presence.

16:16

Malcolm Chisholm (Edinburgh North and Leith) (Lab): I pay tribute to Michael Gray and Tina McGeever for the general contribution that they have made to Scottish life and for their particular contribution on this issue.

In considering the topic, we should set ourselves two complementary objectives. First, we need to maximise the number of effective cancer drugs for patients and secondly, we need to achieve that equitably throughout Scotland. The difficulty with co-payments is that they help the first objective but undermine the second, which is why we face a dilemma.

I will return to that point later, but I will start with the issue of getting effective cancer drugs. I will briefly put in a plug for the Beatson translational research centre, which will put Scotland at the forefront of translational research. A fundraising appeal for the centre has been launched, to which I hope the Government will be able to chip in.

With regard to improving the number of available effective cancer drugs, we need to take two actions in the immediate future. First, it is necessary, as members have said, to review the QALY process—people will know that, in this context, it means quality-adjusted life years—to reflect rising health costs. That would mean maintaining the cost-benefit approach, but allowing a higher cost for a given level of benefit.

Secondly, we need to examine the issue of risk sharing and value-based pricing agreements with pharmaceutical companies. That started in Scotland in relation to beta interferon and other drugs for multiple sclerosis in 2002, whereby if the drugs were not fully effective, the costs that the industry charged to the NHS would be reduced.

In relation to cancer, I have come across one specific example: a response rebate scheme for the drug Velcade, which is used to treat patients with multiple myeloma. Under that arrangement, patients who are making progress have the treatment fully funded by the NHS, but for patients who show no or minimal responses, the drug costs are refunded by the manufacturer. That model should be explored further as a way of getting better value for money.

Great strides have been made on equity in Scotland over the past 10 years, as Dr Andrew Walker acknowledged in his evidence to the Public Petitions Committee. I was pleased that Professor Johnson of Cancer Research UK praised the Scottish Medicines Consortium, saying that it

“is the envy of clinicians who work in England”

and that it is

“a model of good practice”.—[Official Report, Public Petitions Committee, 29 April 2008; c 709.]

When the SMC was set up, there was a debate about the relative balance between centralised and localised decision making. I am sure that we support local decision making in many other areas, but in relation to this matter there must be some central direction. That is why guidance was issued that stated that NHS boards should ensure that recommended medicines are

“available to meet clinical need.”

Improvements are needed in that area in relation to monitoring what boards are doing and intervening when necessary. That is highlighted in the committee’s report and in the submissions that were made to the inquiry.

There are also issues about exceptional prescribing procedure, to which we need to take a more standardised and transparent approach. Various members have talked about the need to improve data about hospital prescribing. Finally, we need to explain everything to patients, and I am glad that the Government has taken that on board in its response.

I have covered those points quickly, because the heart of the debate—the big controversy—concerns co-payment. I am glad that the committee has recommended a review and that the Government will go ahead with it. I listened carefully to what Nicola Sturgeon said about the issue on the radio this morning and in Parliament this afternoon and it seems clear to me that she accepts that there are serious clinical governance and risk issues with co-payment and that she will take those on board.

In the evidence, I was struck by a quote from Professor Alan Rodger, medical director of the Beatson oncology unit—to whom we should pay tribute as he is retiring soon. He talked about two clinicians treating a patient and said that there could be

“one in the private sector delivering one drug, the other in the NHS delivering three drugs. That is not good clinical care. It is a recipe for disaster.”—[*Official Report*, Public Petitions Committee, 29 April 2008; c 751-2.]

I am sure that those clinical governance issues will be considered, but the heart of the matter is the fundamental issue of principle and the risk of, threat of and concern about a two-tier health service developing on the back of co-payment.

We all have sympathy with patients who are in the situation that is highlighted in the petition, and members are aware of patients who come to the committee or to our surgeries who are in that position, but it is important that we exercise our imaginations today and look ahead to a situation in which the guidance is different. In that regard, I think Jackson Carlaw’s speech has been the most useful in the debate so far, because he described the future that will arise if we go down the route of

co-payment. Members should read his speech and reflect on the consequences of that approach. If we go down that route, another group of patients will come to us with their concerns. There will be a situation that does not exist now in which patients are side-by-side in beds in the NHS and one is getting one treatment while the other gets a different treatment because he or she can afford it. Not only poor people but many people on modest incomes will come to us and ask, “Why shouldn’t I get the treatment that’s available to someone else?” Members need to reflect on that.

We should also listen to the cancer charities, which have reflected seriously on the matter. I am sure that we have all read the briefing from Cancer Research UK, which says that co-payment

“has the potential to create more problems than it solves.”

We all received what is perhaps an even stronger submission against co-payments from Macmillan Cancer Support today. Yesterday I talked to a senior cancer clinician who gave the same objections. We must think long and hard about the issue. It will be interesting to hear what Mike Richards comes up with in his review in England, but we have to take a Scottish view. My current view is that we should be very wary of co-payment, but we should certainly take all the other necessary actions.

16:22

Ross Finnie: This has been an extraordinarily constructive debate. It has served to illustrate the fact that, as with all such matters, issues of due process arise in the complex area of approving drugs. We must get over those quickly so that we can concentrate on the outcomes that we all seek: better drugs and better availability of drugs.

Necessary though the process is, I am sure that the convener and members of the Public Petitions Committee would acknowledge that their understanding of it was greatly illuminated by having to consider the petition. I am sure that all members in the chamber this afternoon who have had to read the material, the report and the submissions would recognise that our knowledge has also been hugely improved. That is good for us, but it is the end users, our constituents—the patients—who ought to be able to understand the process. The process is, demonstrably, hugely complex, so there has to be a better way to conduct it. I hope that one of the outcomes from the report, following the further consideration that it will be given, is that we can help patients to understand the process to which they might find themselves being subjected.

Ian McKee explained—as usual, using his own background and experience—the obvious route down which one might go if the efficacy of a drug

has been determined. However, its efficacy is measured against a set criterion, so the process is not necessarily as simple as we might believe. That illustrates the difficulty of such a process in a demand-led service—any Government and any minister would face such constraints. Members made the point in their speeches, as did the SMC in the report to which I referred earlier, that in making such determinations, that the SMC gets poor advice from the pharmaceutical companies about the cost appraisals of drugs. That problem must be addressed as a matter of urgency.

I share Malcolm Chisholm's view that, in his excellent way, Jackson Carlaw illustrated the genuine problems going forward. Even if I am wrong and exceptional circumstances become the norm, some form of insurance payment—I am not trying to put words in Jackson Carlaw's mouth—would serve only to illustrate the difficulties, which must be addressed by a committee of the sort that the cabinet secretary spoke about.

I repeat that this has been a constructive debate. As I said in my opening speech, I hope that not only the excellent report produced by the committee but the valuable and constructive speeches made during the debate lead to a better outcome. I also hope that the cabinet secretary will give some thought to how that is to be achieved. We cannot rely simply on the *Official Report* as an entirely satisfactory way of addressing all the important issues that have been raised in the chamber this afternoon.

16:26

Mary Scanlon (Highlands and Islands) (Con):

I acknowledge Ross Finnie's point that many issues for wider debate have been raised today.

I thank the Public Petitions Committee for its excellent work on this complex issue, which was described by Professor Rodger of the Beatson Institute for Cancer Research as a

"moral, ethical and logistical nightmare and minefield."

I thank Michael Gray and Tina McGeever for raising the subject of our debate today, which I believe will lead to greater clarity, better understanding and, hopefully, as Nanette Milne said, cancer patients being given clearer options and better access to cancer drugs.

Cetuximab is widely available throughout the European Union, yet not in the UK. That raises questions about the appraisal processes of clinical cost effectiveness as well as the QALY process of NICE and the SMC.

It is worth putting on the record the fact that in Scotland we are world leaders in cancer research, yet we have the worst cancer outcomes in the whole of Europe. A study published in *The Lancet*

Oncology last year charted patients diagnosed in 21 countries who survived cancer for more than five years. With only 48 per cent of women surviving after five years, Scotland sits at the bottom of the league table despite having three times the health budget of countries such as Poland and the Czech Republic. Our 48 per cent survival rate compares with 53 per cent in England and 52 per cent in Ireland. Only 40 per cent of Scottish men live for more than five years after diagnosis, which puts us in the bottom four of the league table. Although we might equal EU health spending, we are far from equal in cancer outcomes.

I have discovered that there is a difference between co-payments and top-ups. I understand that a co-payment is a payment for the same episode of care and that a top-up payment is for a different episode of care. Unfortunately, no one seems able to define clearly an episode of care.

When we talk about a health service that is free at the point of delivery, as Duncan McNeil did, and which is based on clinical need, we are not being entirely truthful. We need to be clear that most people are not entitled to free podiatry treatment, that dentistry is certainly not free for many people and that many GPs do not even bother referring patients to physiotherapy because of the long waiting list—those patients are simply told to find a private practitioner.

Although many thousands of Scots access homoeopathy treatment—they would not have taken Ian McKee's advice—no one assumes that, having paid for such treatments, those patients are then excluded from NHS treatment. Neither has anyone been excluded from NHS follow-up treatments following surgery in other countries, which many people in Scotland access. Consultation on the issue has to be wide ranging and has to result in much greater transparency.

As I said to Ian McKee, it is worth pointing out that many hundreds of drugs that are prescribed day and daily throughout Scotland have never been evaluated. There is an assumption that we are in a perfect situation, but that is simply not the case, as he acknowledged. It is questionable whether all the drugs that are prescribed day and daily in Scotland would now pass the rigorous appraisals of NICE, the SMC, QIS, the area drug and therapeutics committees and a consultant's medical opinion.

I remember that when we arrived in the Parliament in 1999 Shona Robison joined the campaign for beta interferon to be given to multiple sclerosis sufferers. At one point, it was assumed that beta interferon would benefit all patients with MS; however, it benefited only 16 per cent of MS patients. I commend the Government for providing neurology assessments to ensure

that those who would benefit from that drug would get it. I make that point because the therapeutic value of a treatment can be different in different patients. Rather than having a blanket ban on, or a blanket acceptance of, a drug or therapy, we could do more to specify which patients would be most likely to benefit from particular treatments. More clinical trials might be the answer, but I would prefer a drug such as cetuximab to be made available to the patients who are most likely to benefit from it, rather than being refused to all patients.

Michael Gray was forced to pay for cetuximab, which was recommended by his oncologist. Only after it was proved to be effective did NHS Grampian agree to fund the treatment. Surely it is not for the patient to pay for the clinical trial and for the NHS board then to decide whether to agree to pay for the drug according to whether there is a health improvement. I hope that that important point is taken on board.

In the context of arguments for private provision and those for public provision, I hope that the cabinet secretary's consultation will look at the availability of orphan drugs, which are referred to in paragraph 106 of the committee's report. There is no doubt that state intervention is essential in such cases to ensure that pharmaceutical companies carry out research on rare conditions. Given the low numbers of patients involved, the costs of those drugs can be prohibitively high.

We welcome the Government's review of co-payment guidance and we trust that all the contributions to the debate will be taken into account.

The Conservative health team at Westminster has had a huge response to its consultation on this complex issue. I understand that the UK Department of Health is also consulting on the issue.

Although the SMC was set up to end postcode prescribing, that has not happened, given the role of the ADTCs. If no data are collected on the implementation of advice and guidance across NHS boards, a patient's chances of survival could vary significantly depending on where they live and what drugs are available locally.

If we are to respect clinical judgment, more credence has to be given to the patient's clinician. We want our NHS to provide optimum patient care and advice, not to have clinicians and patients fight their way through a mass of bureaucracy.

16:33

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I join the many members who have paid tribute to the petitioners. The petition is one of the

best illustrations of the petitions system working: a petitioner who had a personal problem and difficulty with the system generated a debate and pursued the issue vigorously for the greater good.

Ross Finnie said that the issue is not just about cancer. We should not lose sight of the fact that it is about many drugs other than cancer drugs. The report on cancer that is due to be published might help in relation to cancer drugs, but it will not solve the problem altogether.

A point that has not been made so far is that doctors are human beings and wish to do their best for their patients, irrespective of the realities of the evidence. They are taught to treat where possible. Sometimes treatment can be more harmful than beneficial to the patient, so the assessment of risks to and benefits for the individual patient has to be carried out in a partnership involving the doctor, the patient and, sometimes, another independent element.

Cathy Jamieson, Christopher Harvie and Jackson Carlaw referred to the fact that almost every one of us will be touched by cancer. The lifetime risk of developing cancer is one in three, and the risk applies especially to the over-65s. Annually, two in seven of all deaths in Scotland are cancer related. Many survival rates have improved, but cancer remains a massively important area of health. Cancer accounts for much palliative care and raises problems to do with extending life in a reasonable way.

No member has criticised the initial process of licensing a drug in Europe or in the UK. The question is whether that process is enough. In some countries, it is enough. Ian McKee suggested that if a drug is licensed—if it is effective and safe—it must be given if a clinician recommends it. However, we have chosen a different route, which involves another tier—the Scottish Medicines Consortium. We should take heart that many praise that system and that, in evidence, it was described as one of the best systems in Europe.

Ian McKee: Should the benefits of that extra layer of bureaucracy be extended to private patients who are receiving treatment?

Dr Simpson: I am not sure—I must think about that. The important point is that the Scottish Medicines Consortium draws together the evidence—such as it is, as Ross Finnie said. Some evidence about cost effectiveness from the pharmaceutical industry is still probably not as good as the industry would like and is certainly not as good as we would like. I will return to that.

Scotland has another tier. I understand that advice is not statutory, so the area drug and therapeutics committees decide when and at what speed drugs will be introduced in Scotland. I

gather that the cabinet secretary will examine that, which is fairly important.

We do not know exactly what happens. The new national medicines utilisation unit is giving us information, but we need better data collection to allow the Government to decide whether the system is working as well as we would like.

I have described the basic system, but we are concerned about what happens beyond that. If a drug is not yet approved by the SMC, is awaiting appeal after rejection or is finally rejected, that means that a licensed drug that appears to be effective in some circumstances is not recommended for use on the ground of cost effectiveness. Here enters SIGN, which does not have to take into account cost. SIGN makes recommendations only on the basis of effectiveness. That is a potential conflict that needs to be resolved.

That brings us to the exceptional needs situation, to which many members have referred. On 11 March, I wrote to ask every health board how it deals with exceptional needs. I was staggered by the variety of their replies, which ranged from a massive document from NHS Grampian—I recommend it to the cabinet secretary as a good starting point—to four lines. The criteria, the committees that ran the system and the appeals procedure were unclear. If that is just the general information that one can gather, how much harder is it for a patient and their clinician to wend their way through that complexity? One point from the committee's report on which we agree is that we need total clarity. We cannot continue to have the situation—to which Jackson Carlaw, among others, referred—in which Sutent, which is a kidney drug, is approved almost totally in some areas but rejected in others.

Co-payment is a fundamental and really difficult issue. Perhaps the original design of the NHS is no longer adequate. Duncan McNeil argued eloquently that whatever we do must be equality proofed. We must not introduce a new system that creates further inequalities or separates groups further. The two-tier issue will remain extremely difficult.

The Richards report might help us, but one possible solution is to have a new partnership with the industry, to which Malcolm Chisholm referred. In essence, under that partnership, the industry would pay for what does not work and we would pay for what works. That is a principle to which we could sign up to with the industry if it, too, was prepared to sign up to it. Such a partnership would remove the problem that some, but not others, are eligible on the ground of wealth. No member in the chamber, whatever their party, would accept a situation in which the ability to pay affects how someone copes.

Last year, the drug bill for Scotland passed the £1 billion mark. Back in 1999, that figure would have amounted to almost 30 per cent of our total budget; today, it is about 10 per cent. As a result of the Public Petitions Committee's excellent report, we need to review the interlocking structures in the NHS, QIS, the SMC and the cancer management networks, which I have not yet mentioned. Also needing review are the SIGN guidelines, the role of NICE in relation to the SMC, and governance issues between boards and the area drug and therapeutics committees.

We must ensure that there is data collection, to inform us and to be analysed. We must also ensure that the exceptional needs criteria are generally understood and readily available to the patient and that there is transparency in the system, including the appeals system. We need to avoid postcode discrepancies. We must achieve resolution and clarity in terms of co-payment. The basis on which drugs are issued should not be the ability to pay.

16:41

The Minister for Public Health (Shona Robison): First, I acknowledge the extent and quality of the debate. Members in all parts of the chamber have evidenced the fact that the issues are highly emotive, complex and often contentious. The accounts of individual experiences clearly demonstrate the very real impact of processes and decisions on patients and their families. I, too, pay tribute to the late Michael Gray and his wife Tina McGeever.

What has come to the fore today is a clear understanding of the numerous strengths of the Scottish system; in very many dimensions, it works, and works well. As Richard Simpson outlined, the Scottish Medicines Consortium makes decisions on every new medicine quickly. We can have confidence in that and that debate at the SMC is robust and that many perspectives are taken into account before a decision is reached. SMC decisions are authoritative and its recommendations are widely accepted. Cathy Jamieson was right to say that its guidance is not statutory, although it is important to make it clear that SMC guidance is not advisory either; health boards are expected to adhere to it.

The recent SMC evaluation work provides evidence of just how far Scotland has come. Indeed, some might argue how far ahead Scotland is in being able to undertake assessments of all new drugs at an early stage after they have received marketing authorisation.

We have evidence that area drug and therapeutics committees have robust arrangements to ensure that SMC

recommendations can be fully considered in the local context. In that context, it is important to mention the proactive role that regional cancer advisory groups take in supporting the introduction of new cancer drugs. Those who work in the system consider that the processes that have been put in place have congruence, are robust and reflect the key values of the NHS. However, as members have made clear this afternoon, and as others have set out in their oral evidence and submissions to the Public Petitions Committee in its inquiry, the public, patients and their families need to be given a much better appreciation of why arrangements are in place, how they work and how decisions will be made about patients' care. Those are, and will remain, difficult decisions.

After the evidence of benefit and disbenefit have been weighed up, decisions have to be taken in the cold light of day—on whether a new treatment will make a real difference to the quality of life and survival of a patient and whether a case can be made in the context of many competing demands. As Ross Finnie said, there will always be constraints in a health system.

In "Better Health, Better Care" we committed to providing high-quality evidence-based care. That is what we will strive to do, against a background of an NHS that faces increasing demands. Before I concentrate on co-payments, which have received considerable attention, I will take a few minutes to focus on the actions that will follow this important debate.

The forthcoming Scottish Government better cancer care plan, the e-health strategy and the outcome of the evaluation of the Scottish Medicines Consortium provide the basis for taking forward the recommendations in the Public Petitions Committee report. Further work is planned to deal with some of the more specific recommendations, but I underline that it is important that the recommendations are addressed as a whole and in a manner that demonstrates a coherent policy framework with a strategic plan for delivery. That will mean providing better information to the public, making better use of data, ensuring consistency of process based on a principled approach, undertaking further work to develop health economics methodology and continuing to engage in UK-level discussions on drug pricing. NHS boards will continue to be held to account through existing performance management arrangements, and the SMC and ADTCs will continue to develop and build on their success to date.

The fundamental point is that patients and their families will, in time, feel more supported and better informed about the decisions that are made on the care that is in their best interests.

Moreover, as we see the true benefits of mutuality within integrated organisational arrangements, patients and their families will feel more involved in such decisions when that involvement is appropriate for them, when they are able to be involved and, most important, when they want to be closely involved. All that is achievable, much of it through work that is already under way or planned, and through the enhancement of existing arrangements.

It is worth mentioning the work that the Association of the British Pharmaceutical Industry and the Scottish Medicines Consortium are doing together on market access schemes—something Richard Simpson and other members raised. That is important work that could lead to a new partnership.

Duncan McNeil made some wider points about health inequalities. I recognise that, as he said, for people who live in our most deprived communities, the issue is why they present later and die earlier. Those important matters are being tackled through "Equally Well: Report of the Ministerial Task Force on Health Inequalities"—we will have the implementation plan for that by the end of the year—and the keep well programme and its expansion. They are also being tackled through our continuing discussions about the development of the GP contract and our consideration of the minimum practice income guarantee—in which Duncan McNeil is well versed—and its relationship with the funding of practices in our more deprived communities.

It is important to recognise that some of the other work that is going on has a direct relationship to important issues that have been raised in the debate.

I will now address co-payments. Patients are entitled not only to receive free NHS care but to exercise choice about receiving some or all of their care privately. The NHS cannot charge patients unless legislation specifically allows for that to happen, but the fundamental and overriding principles must be patient safety, probity and clinical accountability, as a number of members said. In taking forward the work on co-payments, we will ensure that patients can continue to receive the free NHS care to which they are entitled, that the NHS's wider interests are protected and that patients who seek private treatment have a clear understanding of what the NHS will continue to provide. The policy position remains the same: we will not preside over a two-tier health system. That point was raised in the debate, and I hope that I can give reassurance on it. We recognise that the guidance must be clarified and updated—and it will be.

The measures that we have set out demonstrate a constructive and robust response to the

committee's recommendations. The focus will now be on implementation. We will be pleased to keep the Public Petitions Committee informed of progress.

I thank all members who have taken part in the debate and concur with many people that it shows the Parliament at its best. We can take the issue forward united across the chamber. The outcome will be all the better for that.

16:50

John Farquhar Munro (Ross, Skye and Inverness West) (LD): We have had an extensive debate. My convener said that it was a pleasure and a privilege to open this important debate on the Public Petitions Committee's report on its inquiry into the availability of cancer treatment drugs on the NHS. I echo those sentiments.

The inquiry identified where improvements are needed. As the convener said, the inquiry has been petitioner led. We have arrived at this point not because of something started by the Scottish Government, or indeed by the Public Petitions Committee, but because of what Tina McGeever and Michael Gray started all those months ago. We pay tribute to them both.

I thank fellow committee members. We worked well together as a team. I also thank those people who gave evidence to us. We took evidence from many groups and organisations, which contributed greatly to identifying what is working well and what is not working so well.

I will speak about defining roles and the guidance that is issued to NHS boards. I also wish to address some specific points that have been raised during the debate.

The committee was struck by the number of bodies that are involved in the drug appraisal and availability process. There was a lengthy debate about that. On the whole, the evidence suggests that the system works well and that the various roles and responsibilities are clearly defined. The overlap between bodies is minimal and the processes are easily understood. We were pleased about that. However, the committee asked the Scottish Government to consider the scope for monitoring the roles of the different bodies, the possibility of streamlining to produce efficiencies, how performance management arrangements would be put in place and the need to provide greater transparency in the roles of the bodies and to have more patient input into them.

The Scottish Government responded. It sought to ensure that the end-to-end process, from licensing through to exceptional prescribing panels, is explained in an understandable and accessible way. Its approach will be amplified in its forthcoming better cancer care plan.

I think that it was Ross Finnie who was anxious that the petition might not continue and that it might not receive the scrutiny it deserves. After the better cancer care plan comes to the committee, we will keep the petition alive and give it scrutiny until it is finally completed. I believe that Ross Finnie had some concerns about that very issue. *[Interruption.]*

The Presiding Officer (Alex Fergusson): Order. I ask members who are coming into the chamber to be quiet, please. We are in the closing stages of a debate.

John Farquhar Munro: The Scottish Government said that it will reflect on the outcome of the impact and effectiveness evaluation of the Scottish Medicines Consortium and on its continued work with the SMC, NHS boards and other bodies, to identify further improvements for cancer patients and their families who become involved in the process. The Government said that it seeks to build on examples of best practice locally and on requirements for patient and public involvement.

Many members described personal experiences, some of which had been traumatic and difficult. The committee was anxious to improve the situation and we cannot disagree with the Scottish Government's desire to improve patient involvement, decision making and the overall process—who could disagree with such a desire? We look forward to being given proper examples of how those improvements will be made and clear evidence that backs up the Government's response. We await those details with bated breath.

The committee considered the roles of everyone who is involved in preparing guidance and was interested in how guidance is issued and implemented across NHS boards. Are there regional variations? Is the guidance applied equitably? How does it filter down to clinicians—the people at the coalface? Is there clarity and understanding among clinicians? That is a matter for debate, but members suggested that the situation is not as we might have understood it to be. The committee concluded that there appear to be regional variations in how guidance is applied, but we cannot say what level of variation there is. We want to ensure that clinicians are not being put in a difficult position and that there are no adverse impacts on cancer patients—that is the last thing in the world that we would want.

Cancer Research UK said that it wants improved audit arrangements to record how NHS boards incorporate SMC advice into decision making, which is important. The Scottish Government said that it will keep NHS accountability and performance management arrangements under review, but we do not know how it will do that. We

will take advice on the matter. The Government said that in general the present arrangements for planning and provision of services work well and that the forthcoming better cancer care plan and response to the SMC evaluation will provide an opportunity to monitor and address variations.

We look forward to being given precise details of how the Scottish Government will action Cancer Research UK's suggestion that SMC advice be incorporated into local board decision-making processes. We also look forward to learning how the better cancer care plan will provide an opportunity to monitor and address regional variations in the application of SMC guidance.

I am squeezed for time. The committee will continue to investigate the issue that was raised in the petition, which is important. Questions are being asked not just in Scotland but elsewhere, for example about co-funding. We heard plenty about co-funding in the debate. Mary Scanlon asked whether people who pay for private treatment abroad are being deprived of NHS facilities on their return. That is an important issue. Questions are also being asked about exceptional prescribing processes and pharmaceutical price setting. There is much evidence on those important matters and in our report we refer to the debate that is going on in England.

We hope that the cabinet secretary and her officials will take away the many and varied points that were made in the debate and address them in the forthcoming better cancer care plan. As I said to my colleague Ross Finnie, the debate on the petition will continue in the weeks and months ahead. As the convener of the Public Petitions Committee said, we stand ready to work with the cabinet secretary as the matter is given further consideration.

Business Motion

17:00

The Presiding Officer (Alex Fergusson): The next item of business is consideration of business motion S3M-2626, in the name of Bruce Crawford, on behalf of the Parliamentary Bureau, setting out a business motion.

Motion moved,

That the Parliament agrees—

(a) the following programme of business—

Wednesday 8 October 2008

2.30 pm Time for Reflection

followed by Parliamentary Bureau Motions

followed by First Minister's Statement: Scottish Broadcasting Commission

followed by Scottish Government Debate: Scottish Broadcasting Commission

followed by Business Motion

followed by Parliamentary Bureau Motions

5.00 pm Decision Time

followed by Members' Business

Thursday 9 October 2008

9.15 am Parliamentary Bureau Motions

followed by Local Government and Communities Committee Debate: 8th Report 2008: Elections 2007

11.40 am General Question Time

12 noon First Minister's Question Time

2.15 pm Themed Question Time
Finance and Sustainable Growth

2.55 pm Ministerial Statement: Strengthening Scotland's Secure Accommodation

followed by Parliamentary Bureau Motions

followed by Stage 3 Proceedings: Scottish Register of Tartans Bill

followed by Parliamentary Bureau Motions

5.00 pm Decision Time

followed by Members' Business

Wednesday 29 October 2008

2.30 pm Time for Reflection

followed by Parliamentary Bureau Motions

followed by Scottish Government Business

followed by Business Motion

followed by Parliamentary Bureau Motions

5.00 pm Decision Time

followed by Members' Business

Thursday 30 October 2008

9.15 am Parliamentary Bureau Motions
followed by Scottish Government Business
 11.40 am General Question Time
 12 noon First Minister's Question Time
 2.15 pm Themed Question Time
 Europe, External Affairs and Culture;
 Education and Lifelong Learning
 2.55 pm Scottish Government Business
followed by Parliamentary Bureau Motions
 5.00 pm Decision Time
followed by Members' Business
 and (b) that the period for members to submit their names
 for selection for General and Themed Question Times on
 30 October 2008 should end at 12.00 noon on Wednesday
 8 October.—[*Bruce Crawford.*]

Motion agreed to.

Parliamentary Bureau Motions

17:00

The Presiding Officer (Alex Fergusson): The next item of business is consideration of two Parliamentary Bureau motions. I invite Bruce Crawford to move motions S3M-2627 and S3M-2628, on the approval of Scottish statutory instruments.

Motions moved,

That the Parliament agrees that the draft Public Appointments and Public Bodies etc. (Scotland) Act 2003 (Amendment of Specified Authorities) Order 2008 be approved.

That the Parliament agrees that the draft Housing Grants (Assessment of Contributions) (Scotland) Amendment Regulations 2008 be approved.—[*Bruce Crawford.*]

The Presiding Officer: The questions on the motions will be put at decision time, to which we now come.

Decision Time

17:01

The Presiding Officer (Alex Fergusson): There are three questions to be put as a result of today's business.

The first question is, that motion S3M-2598, in the name of Frank McAveety, on the Public Petitions Committee's report on the availability on the national health service of cancer treatment drugs, be agreed to.

Motion agreed to.

That the Parliament notes the conclusions contained in the Public Petitions Committee's 3rd Report, 2008 (Session 3): *Availability on the NHS of cancer treatment drugs* (SP Paper 133).

The Presiding Officer: The next question is, that motion S3M-2627, in the name of Bruce Crawford, on approval of a Scottish statutory instrument, be agreed to.

Motion agreed to.

That the Parliament agrees that the draft Public Appointments and Public Bodies etc. (Scotland) Act 2003 (Amendment of Specified Authorities) Order 2008 be approved.

The Presiding Officer: The next question is, that motion S3M-2628, in the name of Bruce Crawford, on approval of an SSI, be agreed to.

Motion agreed to.

That the Parliament agrees that the draft Housing Grants (Assessment of Contributions) (Scotland) Amendment Regulations 2008 be approved.

Action on Thrombosis

The Deputy Presiding Officer (Alasdair Morgan): The final item of business today is a members' business debate on motion S3M-2482, in the name of Trish Godman, on action on thrombosis. The debate will be concluded without any question being put.

Motion debated,

That the Parliament notes with concern that, according to provisional figures from the Scottish Government, the total number of deaths from thrombosis in 2007 was 12,275, which represents 21% of all deaths in Scotland; further notes that in 2006 thrombosis killed more than fifty times the number of people who died from MRSA and Clostridium difficile combined, and therefore considers that action should be taken to increase awareness of thrombosis among the public and health professionals and establish an effective prevention strategy for thrombosis in Scottish hospitals, such as some sort of screening regime, to help save valuable NHS resources from treating a disease that can often be prevented if a patient knows they are at risk in the first place and to help avoid tragedies like that of Katie McPherson from Langbank, who died as a result of deep vein thrombosis.

17:02

Trish Godman (West Renfrewshire) (Lab): Katie was 23 years old when she died of deep vein thrombosis. She had tried three times to get treatment, in two hospitals and from her general practitioner. She knew the symptoms. A friend of hers had written a thesis on DVT, which they had gone over line by line. Edinburgh royal infirmary carried out a venometer test, which showed a restriction in her left leg. A second test—a venogram—proved inconclusive. Katie was sent home. Why was no ultrasound or D-dimer blood test performed to be absolutely sure? Katie had tried to get help on 17 January. On 25 January, her father picked up a medical certificate that stated:

"Severe left calf pain—query DVT?"

Twenty-four hours later, Katie's self-diagnosis tragically proved to be correct. After Katie's death, the procurator fiscal concluded that Katie had been properly treated. Strangely enough, two months later, Edinburgh royal infirmary—the first hospital that she attended—changed its procedures for diagnosing DVT.

So what can we learn and what can we do? The key issue is to raise public awareness and to improve clinical practice. Both the public and the medical profession appear to underestimate the risk. Most people to whom I have spoken think that people get DVT if they have been on a long plane journey. That is wrong. Being a smoker, being over 40, being overweight, having an inherited blood-clotting disorder, having had major surgery

and—most certainly—having been inactive for some time are just some of the possible causes.

Hospital protocols differ, as we saw in Katie's case. Should they not be the same? Surely if there is any doubt, further tests should be automatic. After Katie's parents made representations to the Public Petitions Committee and the Scottish Public Services Ombudsman reported that several hospitals were failing to diagnose DVT, the Government funded Lifeblood: The Thrombosis Charity to produce an information leaflet. Every GP practice in Scotland received one. Unfortunately, we have evidence to suggest that some of them went straight into the bin. I know that MSPs have been asked to visit their GPs' surgeries. If they have already done so, I ask them to check whether the surgery has the leaflet and whether it is displayed prominently. If not, I can give members some copies. If members have not already visited their GP's surgery, I ask them to come and speak to me.

There is a need to consider local protocols, local access to educational material and local patient information that is easy to understand. There is also a need to be proactive and to research early screening and the causes, prevention and treatment of DVT. We need to get the information out there and to listen to patients.

Each mainland health board received £40,000 for the prevention and treatment of *Clostridium difficile*, which is quite right—no one is going to argue with that. Apart from the leaflet that Lifeblood produced, I can find no evidence of specific funding for the prevention and treatment of DVT. Why?

After almost six years, Katie's family is waiting to be offered screening for thrombophilia. We must seek an effective prevention strategy and eliminate the failure of hospitals to diagnose effectively those patients who have potentially fatal DVT. Katie's family deserves an apology for what has happened. Money should be made available for further research into screening, and the public should be made aware of the existence of screening. That must be our aim for Katie.

17:06

Ian McKee (Lothians) (SNP): I congratulate Trish Godman on initiating this important members' debate, and I join her in extending my condolences to Katie McPherson's family. We need to do our best to see what lessons can be learned from that tragedy.

The term "thrombosis" means a blood clot, and it covers a wide range of conditions. Cerebral thrombosis in the head leads to a stroke, and coronary thrombosis leads to a heart attack. However, it is obvious that we are talking about

deep venous thrombosis, or the blood clot that occurs in the deep veins of the leg. In itself, that does not kill, but when the clot moves on to the lungs, it causes a pulmonary embolism, blocks off the breathing and causes either severe illness or death.

I agree with the motion's call

"to increase awareness of thrombosis among the public and health professionals".

The National Institute for Health and Clinical Excellence already has guidelines for elective surgery, and the Scottish intercollegiate guidelines network has guidelines for thrombosis. I agree that there are times when either those guidelines are not followed or clinical staff are not alert to the possibility of DVT, so it is important that we take all opportunities to correct that situation.

I am not sure, however, that I go along with the idea that population screening is the answer. We know that approximately 2.5 per cent of the population has the factor V Leiden mutation that predisposes them to the development of thrombosis. However, there are strict criteria for population screening, the most important of which is that help is available for those who are found to be at risk. That is not currently the case with thrombosis. There is evidence that the long-term use of anticoagulants to thin the blood and make clots less likely to occur might do more harm than good because of the side effects. On the other hand, selective screening might have a place. For example, young women who have a family history of thrombosis and who want to take hormonal contraception could benefit from selective screening.

Trish Godman: I hear what the member is saying, but because there are so many questions about DVT—he is asking them himself—we need money so that we can research whether there should be screening and, if not, what else we can do. The situation is too vague at the moment. There are too many questions about DVT for us to say that screening is not right.

Ian McKee: I agree that research should be done, and that not enough has been done into the causes of DVT and its treatment. However, I still hold that it is wrong to embark on an expensive population screening programme until treatment is available that can be offered to the people whom the screening turns up. That is the general principle of screening. In the absence of the availability of such treatment, we will just frighten people without giving them any benefit.

As Trish Godman said, the general risk factors that predispose people to suffering from DVT are obesity, cigarette smoking and stasis or the slowing of circulation that can arise as a result of long aircraft flights or sitting in the chamber

listening to debates for three hours, for example. It is extremely important that we emphasise to the public that those are risk factors.

There are two other measures that we should take. Most cases of DVT are diagnosed in primary care. We should make it easy for people who work in primary care to refer patients to hospital—they should not have to encounter the battery of reasons that junior hospital doctors provide for not referring a patient. In many cases, especially among the elderly, DVT is a sign that cancer is present in the body, in which case it is no good just treating the DVT and not investigating whether there is a factor in the patient's background that could be causing the problem.

In general, I am extremely pleased that we are having a debate that will highlight an important problem. I can support most of the motion, except the part of it that calls for population screening.

17:11

Jackson Carlaw (West of Scotland) (Con): Once again, Trish Godman has brought to members' business an important and substantial issue. Seven months ago, the issue was the human rights of wheelchair users. I was delighted to participate in that debate, which left me committed to the issues that were raised in it. Today, on the back of a series of carefully worded parliamentary written questions that have teased out information that has illustrated the comparative enormity of the issue, Trish Godman has secured a debate on thrombosis. I congratulate her on that.

At the heart of the matter is the tragedy of one family in Trish Godman's constituency and the perseverance of Gordon McPherson, to whose efforts Annabel Goldie paid tribute when she raised the issue directly with the First Minister at First Minister's questions on 5 June.

As the terms of the motion illustrate, thrombosis is a huge reaper of lives. Because it is a sudden and silent killer, it is routinely identified as the cause of death after the event and, as a result, has not received the widespread public attention that it deserves. It is certainly true that for a time the media became excited about the possibility of fatal DVT developing on long-haul flights. As they competed to be more lurid, the news media gave the issue its 15 minutes of fame, but they have now moved on, even if sudden and unexplained deaths on flights might still make the news.

As the motion effectively illustrates, the issue has so far had none of the attendant public demand for action that issues that have taken fewer lives have attracted. That is not an argument against tackling MRSA and *Clostridium difficile*—far from it—nor is it an attempt to diminish in any way the lives that are lost through breast cancer,

from which my sister-in-law is suffering, or as a result of HIV/AIDS or land transport accidents, which as Trish Godman established in a parallel question in May, kill only a fraction of the number of people who are lost to thrombosis.

The figures confirm that, whether through well-organised support networks or sustained and prominent media attention, other conditions and potential killer situations receive much more prominence and attention than thrombosis does. That does not happen at the expense of thrombosis, but there is an obliviousness to the condition. In other debates, I have argued that men's health issues have similarly received less attention in the absence of the well-organised and proactive campaigns that have been conducted on behalf of women's health issues. I make no complaint against those who have done such progressive work on behalf of women; I merely observe that the absence of an overtly organised campaign seems to leave progress in the treatment of certain conditions out in the cold.

That situation needs to change, and I commend Trish Godman, Nanette Milne, Jackie Baillie and Annabel Goldie who, with well-chosen parliamentary questions, have in recent months all sought to prepare the ground for what I think we all recognise is needed—a structured national awareness campaign and a developing debate on the possibility of the provision of a screening programme and comprehensive treatment.

Ahead of this evening's debate, Trish Godman asked MSPs to revert to the GP's surgery that they might have visited during the summer recess, and she did so again tonight. She wanted us to find out whether the public information leaflet that was produced in memory of Katie McPherson was on display and whether we had noticed it on our visits. The response to the second part of that request is that the leaflet was not noticeable in my GP's surgery, if it was on view. I have not yet had a response about whether it was on view, so I might have to sneak back and look for myself.

The leaflet sets out the various at-risk categories. The list is not short—it includes far more people than just those who go on long-haul flights. It includes categories of people, such as those who are obese, who are at risk of a number of potentially fatal conditions and who are targeted by more than one information campaign. It is a good leaflet that sets out the facts and does not shy away from explaining complicated matters; it is certainly helpful and to be commended. Everyone who worked hard to produce it and have it displayed deserves our thanks. However, the leaflet in itself is probably not sufficient to sustain a national effort to improve awareness.

Those who are at risk can take certain sensible actions, some of which were mentioned by Ian

McKee: smoking cessation, cutting down on salt, having a balanced diet with less fat, eating more fruit, exercising and drinking less alcohol. We have heard them before and are familiar with the list. Around one in 20 people carries the thrombophilia gene and about 3,000 of those who die of thrombosis do so of DVT. That group's susceptibility could be established through a screening programme.

We have talked about screening programmes before, and I know that the response of all Governments will be that they act on advice. Screening has been rolled out before, but it will be subject to review again. From experience, I am certain that, in this campaign, public awareness and demand will play a part in bringing about screening. However, I suspect that it will not happen soon.

For the moment, despite our knowledge about the reach of thrombosis, we must contemplate having a long-term campaign with key milestone objectives. Screening for those with the thrombophilia gene will be a longer-term goal. However, building on the work of the McPherson family and ensuring that general practitioners give greater prominence to thrombosis to aid a general increase in public awareness should be an immediate priority. Resolving to ensure that those who need it receive good and detailed advice should also be a priority. When the minister sums up, we want to hear how the Government will act to make progress against those objectives.

Again, Trish Godman has us debating an issue of substance. I suspect that these are the early days of a long campaign, but I wish it well and assure it of my support.

17:16

Dr Richard Simpson (Mid Scotland and Fife (Lab)): I add my congratulations to those of other members on Trish Godman securing this debate and on the way in which she graphically illustrated the tragic early loss of life that can result from sustaining a DVT that moves to a pulmonary embolus.

The numbers involved, however, must not be confused with those for total thrombosis, where the number of deaths is substantial. Trish Godman's parliamentary questions elicited the response that about 172 deaths were recorded from that cause in 2003, which reduced to 130 in 2007. That indicates a measure of progress, although it is not enough. Almost every one of those deaths—not all, but almost all—would have been untimely. Tackling the problem is an increased priority, especially because it is, to an extent, preventable. It is important that measures are taken to identify risk, and that, if something

occurs, there is early diagnosis and rapid treatment.

What about screening, which is a core part of the motion? Dr McKee graphically illustrated the fact that there are rules surrounding mass screening. One of the fundamental tenets is that we must not create a situation in which we cannot ameliorate the condition that is being screened for. Frankly, it is not possible at present for us to do anything about the genetic condition of the so-called factor V Leiden gene. However, that does not mean that we should not have focused screening. It is certainly true that anyone who has a personal or family history of the condition needs to be much more aware of the potential risk and should be entitled to have screening if they so wish—that should be made available to them.

One of the best developments in surgical procedures in the past few years has been the pre-assessment of risk prior to the patient coming into hospital. That is undertaken by nurses, who are good at looking at lists of risk factors of the sort that NICE has produced, some of which were referred to by Jackson Carlaw and Ian McKee. However, as they said, the list is considerably longer and neither they nor I have time to address all of it in this debate.

I have particular concerns about two issues. One is the use of oral contraceptives, which is not generally recognised as a risk factor. The other is the use of hormone replacement therapy. Those two treatments have their consequences in increased risk, so tackling that in terms of stopping oral contraception before surgery can be important. For the pre-assessment of risk, it is important to look at the list and assess the likely risk for an individual.

The second part of the risk that needs to be assessed is whether the procedure, the likely stay in hospital and the degree of immobility are likely to contribute to increasing the risk. If they are, steps should be taken. At the most extreme, there should be prophylactic treatment in a preventive form, using either low molecular-weight heparin or aspirin. For very high-risk procedures, particularly orthopaedic ones, that may be an appropriate measure. For people at intermediate or slightly lower risk, the proper and effective use of compression stockings is believed to have considerable benefit.

During my professional life, we have moved a long way. In the past, for many surgical procedures one was required to stay immobile for long periods, and one was often kept in hospital for long periods. We have moved on—and I believe that we may at some point have a debate on day surgery. The amount of day surgery has increased enormously, and that reduces the risks of venous thrombosis. However, the great

disparity between health boards in the rates of day surgery is regrettable. We could contribute to the reduction of unnecessary deaths by making further movement in that direction. The use of regional anaesthetic rather than general aesthetic can also make an important contribution to reducing risk.

This matter is important. The deaths are preventable and we must address that. We must assess risk carefully, and we must provide prophylactic treatment when appropriate.

I close with an issue that I have not yet referred to, although Trish Godman referred to it in more detail. If any signs of problems are seen, there must be rapid and appropriate testing, diagnosis and monitoring. Sometimes the venogram can be equivocal, but simply to send somebody home is not good enough. People should be monitored in some way, so that risk can be assessed and treatment applied. In the cases that we have been discussing, treatment would prevent death. As I have said, such deaths are unnecessary and should be prevented.

17:21

Margaret Curran (Glasgow Baillieston) (Lab):

I, too, thank Trish Godman for securing tonight's debate. As others have acknowledged, she has made a significant contribution to raising awareness of thrombosis, and deep vein thrombosis in particular. I defer to the medical knowledge of my esteemed colleagues; I will not match their grasp of the subject, but please bear with me.

My awareness of this issue was increased by my responsibilities as shadow cabinet secretary for health. Sadly, I have since departed that role. However, during that period I met Gordon and Jane McPherson who, as Trish Godman said, have campaigned passionately for increased awareness of thrombosis since their daughter Katie died in 2003. It would seem that they were failed by the national health service, which did not diagnose Katie's condition despite her own knowledge of it.

Mr and Mrs McPherson are remarkable people who communicate their case clearly and effectively. Their impact on the political world and, I would say, the medical world has been significant. I expect that to continue. I am sure that the minister will become aware of it if she is not already.

One of my last responsibilities as shadow cabinet secretary for health was to chair an event in this Parliament on thrombosis, instigated by the work of the McPherson family. It was a telling experience. It brought together a formidable array of experts—and I urge members to look at the publication that will emerge from that extremely

informative event. It was also telling because of the striking facts that emerged. We should all know them.

On the same day, there had been a Labour debate in Parliament on *Clostridium difficile* at the Vale of Leven hospital. It was an issue of real public concern, and I think that many members who are present tonight were present at that debate too. It was a key health issue with immediate significance for the Scottish public, but I was to learn at the seminar in the afternoon that the death toll from thrombosis is five times greater than the combined death toll from MRSA and *Clostridium difficile*. As Jackson Carlaw suggests, that is not an argument for lessening our concern about other issues, but a clarion call for us to step up our work on thrombosis.

I was shocked, as we all should be, that so many people are dying when their deaths are clearly preventable. As Richard Simpson said, DVT has a mortality rate of 30 per cent when left untreated, but between 2 and 8 per cent when appropriate therapy is given. It is estimated that the total cost of managing DVT in the NHS would be around £640 million across the United Kingdom. That clearly gives us an imperative to try to manage the situation. The facts all insist that we should take action and give greater consideration to the work that is going on.

Trish Godman talked about the work at GP practices, which is an issue that I am sure we will all pursue. The McPherson family is deeply disappointed that their efforts have not been taken up more widely by GPs throughout Scotland.

We need to consider local protocols and changes in hospital practice, as Richard Simpson said, but we also need to raise awareness of the issues, which is something in which the Parliament has a particular role to play. NHS Quality Improvement Scotland has agreed to carry out a stocktake of health boards' DVT work and proposes to look into how hospitals are assessing patients and how they can intervene more effectively to minimise risk and encourage more effective treatment. I hope that the minister can report back to us on that.

I place on record my personal thanks for the information and support the McPherson family gave me when I was undertaking my work as health spokesperson. They have played a critical role in awareness raising and should continue to do so. There is a real place for debate on such issues, as Richard Simpson and Ian McKee have demonstrated often in the chamber. That is a debate that we should properly be having. As Trish Godman suggested, we must all step up our work on thrombosis because lives are at risk and we could take decisive and effective action. That

would be an appropriate tribute to Katie McPherson.

17:26

The Minister for Public Health (Shona Robison): I add my thanks to Trish Godman for securing a debate on this important but complex issue. Her motion mentions the death of Katie McPherson, and the first thing that I want to say is how much we sympathise with the McPherson family over their sad loss. We understand the family's wish to raise awareness of deep vein thrombosis to ensure that other families are spared the grief that they have been through.

The events surrounding Katie McPherson's death were investigated in detail by the Scottish Public Services Ombudsman. The Scottish Government and a range of agencies have been working on taking forward the key recommendations in the ombudsman's report. Before I describe that range of work, I will say something about the number of deaths in Scotland that are associated with thrombosis—a matter to which Margaret Curran and Trish Godman referred.

The vast majority of the deaths are due to a thrombosis, or clot, in the arteries. Arterial thrombosis causes heart attacks and certain types of stroke. Coronary heart disease and stroke continue to be clinical priorities for the NHS because of the degree to which premature deaths from those causes can be prevented. We are doing a great deal of work to tackle the underlying risk factors for CHD and stroke through encouraging people to stop smoking, to adopt a healthier diet and to take more exercise. We are also refreshing our national strategy on CHD and stroke. Our keep well programme is about identifying people in our most deprived communities who are potentially at risk, so that they can be offered a health check to assess their risk of cardiovascular disease. Those initiatives relate to far and away the majority of the deaths that are associated with thrombosis in Scotland. I make it very clear that there is no question of there being more than 12,000 deaths a year associated with DVT.

DVT can cause death when a blood clot that has formed in a deep vein, usually in the leg, breaks off and becomes lodged in the lung. That kind of clot is called a pulmonary embolism. According to figures from the General Register Office for Scotland, there were 257 deaths in Scotland related to pulmonary embolism in 2007. In the same year, there were also 112 deaths in which DVT was recorded as the underlying cause of death.

A number of risks are related to developing a DVT, but the only one that is related to lifestyle is obesity. It is therefore worth mentioning that we are pursuing several measures to promote healthy body weight, which are backed up with new resources of £56 million.

Ian McKee: Does the minister not agree that cigarette smoking is also a lifestyle choice that leads to an increased risk of DVT?

Shona Robison: Yes, of course. I will say a bit more about that.

The other risks for DVT include pregnancy, age, underlying cancer, being on the pill or hormone replacement therapy and immobility. However, in most people's minds, as Trish Godman said, DVT is associated with long-distance travel. Inherited abnormalities of blood clotting can also predispose people to DVT. I will return to that later.

One of the ombudsman's main recommendations was that we should develop a standard information leaflet about DVT. NHS Quality Improvement Scotland therefore identified what it considered to be the best existing leaflet. An adapted version of it was issued to all NHS boards in January by the chief medical officer and the chairman of NHS QIS. A letter was sent to the chief executives of the boards, asking them to provide information on how they intended to adopt the standard leaflet, because it was clear from the boards' returns that the matter was a work in progress. NHS QIS is carrying out a follow-up exercise in November, as Margaret Curran said, and it will then provide another report to the chief medical officer. I am happy to keep members informed of progress in that regard.

We also commissioned Lifeblood to develop an information leaflet on DVT, which was mentioned earlier. That has been distributed to every GP practice in Scotland and I am happy to follow up some of the concerns that have been raised about whether that leaflet is being used in all practices. One of the main messages in both leaflets is that there is no definitive test for DVT. If people are in doubt, they are advised to go back to their local DVT clinic or accident and emergency department.

All that work has been undertaken on an interim basis, until SIGN completes its revision of its guideline 62, on the prevention of venous thromboembolism, or VTE. That work is well under way, and I am pleased that SIGN has included Gordon McPherson as a member of the guideline development group.

The motion refers to the possibility of establishing a screening regime. The United Kingdom National Screening Committee advises all four United Kingdom health departments and has considered proposals for the introduction of a population screening programme for

thrombophilia. The discussion centres on a genetic abnormality called factor V Leiden, which has been shown to increase susceptibility to DVT and affects about 5 per cent of the population. However, it is important to realise that a positive test for that gene does not mean that a person will go on to develop VTE, and doctors would not offer any preventive treatment in those circumstances.

We have therefore accepted the national screening committee's advice that it would be inappropriate to introduce population screening for VTE. That has nothing to do with cost; it reflects a lack of evidence to justify introducing such a programme. Government action has to be evidence based.

Trish Godman: You are saying that screening would be done in some circumstances. It seems to me that Katie McPherson's family should have some support and screening, but that has not happened in six years.

Shona Robison: I am just about to deal with that issue. We agree that high-risk groups should be tested, and we are clear that the adult relatives of someone with factor V Leiden should be offered genetic testing and be given suitable advice in the light of the results. Testing would apply above all to people with the genetic abnormality who might be considering going on the combined oral contraceptive pill. The pill carries an increased risk of VTE for all women but, in women who carry the factor V Leiden gene, that risk is increased by a factor of three. Although that is a different process from population screening, it means that those who are most at risk should be picked up.

Attempts have been made to draw unfavourable comparisons between our attitude to thrombophilia screening and the programme that we introduced recently to assess the risk of sudden cardiac death in young athletes taking part in competitive sport. I emphasise that those are two very different issues. The cardiac assessment of young athletes is a pilot programme that is designed to contribute to the evidence base for another issue that the national screening committee has been looking at over a number of years, which is whether to recommend a population screening programme for a condition called hypertrophic cardiomyopathy. This is a good example of the way in which the committee keeps under active review the issues that it is asked to consider.

I hope that it will be clear from what I have said that we have taken the ombudsman's recommendation extremely seriously. We have also made sure that the McPherson family has been fully involved in all this work. Above all, we want to make sure that people who are at most risk of VTE are identified through genetic testing.

I am happy to keep Parliament informed of the developments as we proceed.

Meeting closed at 17:35.

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