Cynulliad Cenedlaethol Cymru
The National Assembly for Wales

Y Pwyllgor Iechyd a Gofal Cymdeithasol
The Health and Social Care Committee

Dydd Iau, 29 Tachwedd 2012
Thursday, 29 November 2012

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The proceedings are reported in the language in which they were spoken in the committee. In addition, a transcription of the simultaneous interpretation is included.
Aelodau’r pwyllgor yn bresennol
Committee members in attendance

Mick Antoniw Llafur
Labour
Mark Drakeford Llafur (Cadeirydd y Pwyllgor)
Labour (Committee Chair)
Rebecca Evans Llafur
Labour
Vaughan Gething Llafur
Labour
William Graham Ceidwadwyr Cymreig
Welsh Conservatives
Elin Jones Plaid Cymru
The Party of Wales
Darren Millar Ceidwadwyr Cymreig
Welsh Conservatives
Lynne Neagle Llafur
Labour
Lindsay Whittle Plaid Cymru
The Party of Wales
Kirsty Williams Democraitaidd Rhyddfrydol Cymru
Welsh Liberal Democrats

Eraill yn bresennol
Others in attendance

Nicola Davis-Job Cynghorydd Gofal Acifwt, Coleg Nyrsio Brenhinol Cymru
Acute Care Adviser, Royal College of Nursing Wales
Dr Phil Evans Cadeirydd, y Grwp Cynghori Arbenigol Cenedlaethol ar Ddiabetes ac Endocrinoleg
Chair, Diabetes and Endocrinology National Specialist Advisory Group
Dr Chris Jones Dirprwy Brif Swyddog Meddygol, Llywodraeth Cymru
Deputy Chief Medical Officer, Welsh Government
Julie Lewis Prif Nyrs Diabetes Arbenigol Cymru, y Grwp Cynghori Arbenigol Cenedlaethol ar Ddiabetes ac Endocrinoleg
Diabetes Specialist Nurse Lead for Wales, Diabetes and Endocrinology National Specialist Advisory Group
Dr David Millar-Jones Rhwydwaith Ymchwil Diabetes Cymru
Diabetes Research Network Wales
Dr Mike Page Cadeirydd, Cymdeithas Endocrinoleg a Diabetes Cymru
Chair, Welsh Endocrine and Diabetes Association
Richard Roberts Gwasanaeth Sgrinio ar gyfer Retinopathi Diabetig Cymru
Diabetic Retinopathy Screening Service for Wales
David Sissling Prif Weithredwr GIG Cymru a Chyfarwyddwr Cyffredinol, Iechyd, Gwasanaethau Cymdeithasol a Phlant, Llywodraeth Cymru
Chief Executive of NHS Wales and Director General, Health, Social Services and Children, Welsh Government
Lisa Turnbull Cynghorydd Polisi a Materion Cyhoeddus, Coleg Nyrsio Brenhinol Cymru
Policy and Public Affairs Adviser, Royal College of Nursing Wales
Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introductions, Apologies and Substitutions


[2] **Mark Drakeford**: Croesawaf y tystion cyntaf sydd gennym y bore yma, o'r grŵp cynghori arbenigol cenedlaethol ar diabetes ac endocrinolog. Croeso i Dr Phil Evans, cadeirydd y grŵp. Gyda ni hefyd y bore yma mae Dr Mike Page, cadeirydd Cymdeithas Endocrinolog a Diabetes Cymru, Julie Lewis, prif nyrs diabetes arbenigol Cymru a Dr David Millar-Jones, cadeirydd Cymdeithas Gofal Sylfaenol Diabetes, cymdeithas Brydeinig. Croeso i chi i gyd. Diolch i chi i gyd am ddod i’n helpu ni y bore yma.


[4] Dr Evans, I think that you will lead us off with a few introductory points, and then we will turn to Members, who I know will have questions.

[5] **Dr Evans**: Diolch am y gwahoddiad. **Dr Evans**: Thank you for the invitation.

[6] In terms of the diabetes national service framework, there has been some progress on...
delivery across Wales, and a prime example of that would be the diabetes retinal screening service for Wales, which was groundbreaking at the time it was developed, and it still continues to benefit many thousands of patients across Wales today. However, we do not believe that the national service framework will be delivered by 2013. The provision of structured diabetes education is a good example of that and is a testament to that point, with roughly 1.5% of type 2 diabetics and 2.5% of type 1 diabetics receiving structured education over the 12 months between 2010 and 2011.

The diabetes community also understands and supports the principle of setting the direction. Indeed, many, if not most, were already working towards these goals many years before the document was published in 2010. However, on its successful implementation, it needs careful service planning and resource if we are to develop the integrated services for diabetes that we all desire.

Finally, I would like to turn to the paper that we have submitted to you and the four points that we believe have led to a difficulty in implementing the NSF or could pose a problem going forward in implementing it. The first point is on an integrated diabetes patient management system, which is a key development in the development of diabetes services across Wales. As we have acknowledged on the final page of our paper, we are pleased that the Welsh Government has acknowledged that that needs to be developed and is supporting the delivery of this throughout the whole of Wales. It will need Welsh Government support to deliver this nationally.

The second point is on structured diabetes education. I have already alluded to the problems with this and it is pleasing to see in statements 34 and 35 from the Welsh Government that there is support and agreement that structured diabetes education should be available to all patients with diabetes throughout Wales. The challenge will be how that action and support can transmit into development and delivery on the ground within health boards. We will need central and local support for that delivery.

The third point that we have raised is the need for a central co-ordinator for diabetes services in Government to work with Government departments, with the diabetes planning and delivery groups and with the health boards across the service to enable the co-ordination and delivery of integrated services in Wales. That needs to be underpinned by a network of both administrative and research support for that person.

Finally, all of this needs to be done at a time when we have a constriction in resources and when diabetes prevalence is increasing. The dangers with this are that not only will we have difficulty in completing the implementation of the NSF, which has yet to be done, but that some of the work that has already taken place will be undone. One acute area where this is currently a problem is that of diabetes specialist nurses.

Mark Drakeford: Thank you very much for that and for the clarity of those four points in your paper. In this short inquiry, of which this morning is the final set of evidence sessions, we are interested in two things. We are interested in the lessons to be drawn from the 10 years or so of the NSF, but we are probably particularly interested in identifying those key priorities that we think the Welsh Government must see included in the document that it intends to consult on at the beginning of next year, for the period between now and 2016. Your points were very helpful to us in trying to ensure that we identify those issues correctly. So, I will now turn to William Graham for the first question.

William Graham: On care of patients in hospital, we have heard in evidence, and I will quote:

‘I agree with the point made that hospitals are a dangerous place for people with
diabetes.’

[15] We also heard that a number of patients with diabetes who come into hospital for elective surgery, for example, are not known to the hospital diabetes team, with dire consequences. What are your views on that and could you make any particular recommendations?

[16] Dr Page: Like a lot of comments, that is partially true. I watched some of the proceedings of a previous committee meeting and was struck by the evidence of one of the diabetic patients, who said, ‘You go into hospital and your insulin is taken away and people stop letting you manage your own condition’, and that is true. It is patchy; it is better than it was, but it is a long way from where it should be.

[17] One thing that Phil has not mentioned is the increasing concern among secondary care providers that the resource is being targeted more towards primary and community care, as part of setting the direction, at a time when we are more and more aware that we have an increasing hospital population of diabetic patients, all of whom are increasingly poorly, and at a time when we are pushed to try to move people through the system quickly. You can do that with hospital diabetes teams. However, those are the teams that have been most squeezed as a result of setting this direction and the drive to develop and improve community and primary care services. That is one problem.

[18] The second problem again relates back to the information technology problem. If you have 100 patients admitted to a hospital in one day, it takes a day or two to work out who is diabetic. If you had a team to go to see them, you could better use that first two or three days of admission targeting the patients who need to be seen by the diabetes team, rather than spending time working out who they are. The IT solution that is being proposed—which we are encouraged to believe might be introduced—will help that. There are two factors here: one is knowing who the patients are the minute they arrive, and the second is being able to target the limited resources to go to see them. I think that we can do it, but we are not doing it well at the moment.


[20] Kirsty Williams: Good morning, Dr Evans. In your presentation this morning, you talked about needing national and local support to drive improvement forward. One of the consistent themes that we have heard is that the failure to replace the lead in the centre—within the Welsh Government—has been one of the factors that has seen progress not go as far as everybody would have liked. Could you expand on why a national diabetes leadership role would be useful, and could you give an assessment of how diabetes planning and delivery groups have worked at a local level? Also, what should that local support look like if we are to drive improvement at LHB level?

[21] Dr Evans: We believe that diabetes services would benefit from having a central co-ordinator, because that person could be someone with a broad knowledge of diabetes, so they would have an understanding, first and foremost, about diabetes. They would have an overarching role, above various departments, working with and within Government departments and stretching out into the diabetes planning and delivery groups and the health boards. So, that person would have a national and local perspective, backed up by adequate information technology, which would allow them to have data on which to make decisions. They would need to have that support network underneath them, as we have already mentioned, to ensure that they have the information that is available. It is akin to what has been happening in Scotland. If you look, for instance, at the IT system that has been developed there over the last 10 years, it is fantastic. Not only is there information that can be drilled down by practice or locality, it can be done on a national basis as well. It is also
possible for patients to access their own data and contribute to it. So, things have moved on tremendously. Those involved have managed to co-ordinate things in such a way that they set up individual groups to look at different aspects of diabetes care, pulling experienced people in from across the localities nationally to give advice in those areas. That is the first thing.

[22] In terms of diabetes planning and delivery groups, it is key that they integrate well with their executive boards. A key development that needs to be ensured at a local level is that information passes to and from the executive boards. They also need feedback on best practice elsewhere, so that they can learn from other areas. That simply is not happening at the moment. Information technology deficiencies will, in part, lead to that.

[23] **Kirsty Williams:** How do we get that engagement between the executive boards and the groups? Executive boards have a million things to worry about, do they not? They have to get their budget sorted out by the end of the year, or thereabouts, and they have a variety of waiting-time targets and various things that they have to deliver on. Those are the things that the chief executive of the NHS is ringing them up about every week. What do we need to do to push the importance of diabetes up the list, so that they are concerned about whether diabetes services are hitting the mark?

9.30 a.m.

[24] **Dr Millar-Jones:** I would say that there are areas in Wales of extremely good practice, and those need to be advertised and shown to those areas where there is not such good practice. There are some areas of Wales where there is a fantastic service for looking after diabetic patients in nursing homes, and that needs to be advertised to the other DPDGs so that they can see those good ideas.

[25] It is quite sad in one respect that Diabetes UK, a charity, came up with the idea of getting all the DPDG leads together to exchange good practice. Surely a service such as that should be led by one co-ordinator, saying, ‘Come on, let’s get all you guys interested in diabetes around Wales to sit down and exchange good practice’. We need a pro-forma that they can give to their executive boards to show what is happening in north Wales, for example, and demonstrate that it is working, saving on costs and improving patient care. In that way, they can say, ‘Let’s introduce it because we have a plan’. However, unless each of the areas of good practice can talk, we will never get a good co-ordinated service. The big problem with diabetes across Wales is that provision is patchy. That is not just in Wales; it is the case in England and Scotland as well. However, as Phil said, having an IT system should help to improve things, and that is a big agenda. Having someone to take charge and co-ordinate the DPDGs to talk rather than having them fight their own battles with their executives is a very important issue as well.

[26] **Dr Page:** To add to that, you asked the question of how you can encourage health boards to give more weight to diabetes services and prioritise them. Well, you could prioritise them higher than you do. The success story over the past two years has been with stroke services. There have been big changes across Wales in stroke care, promoted by the Welsh Government and delivered by the Government and the health boards. It was led by someone.

[27] **Darren Millar:** My questions follow on from where Kirsty left off. We have heard about the issue of the lack of leadership from the Welsh Government. In fact, it is a recurring theme in many of the inquiries this committee undertakes that the national service frameworks just are not implemented, for whatever reason, whether that is finances, leadership—there are all sorts of reasons. We all know that, if the NSF were to be implemented, it would make a big difference on the ground. I have to say that it does not necessarily appear to come down to a lack of funds with regard to the implementation of many of the NSFs; it is just a matter of getting people to work smarter and more efficiently.
However, you have raised this issue of lacking an individual—a sort of diabetes tsar—at the centre ensuring that people are delivering on the ground. The funds were withdrawn in 2010. What representations did you make as a clinical forum, as an advisory group, to the Welsh Government regarding that post? Did you have any discussions with the Welsh Government at the time?

[28] **Dr Evans:** Before Mrs Husband left, we raised the importance of that role, and we have done so since.

[29] **Darren Millar:** What has the response of the Welsh Government been?

[30] **Dr Evans:** At that point, it was not its policy to have a replacement for Mrs Helen Husband.

[31] **Darren Millar:** So, it was purely a policy decision.

[32] **Dr Evans:** My understanding was that it was looking at taking diabetes services in a different direction. The idea was that the national specialist advisory group would work as an advisory body but, within Welsh Government, there was not going to be an individual to lead on diabetes.

[33] **Darren Millar:** So it was, effectively, trying to pass responsibility for implementation to you. Is that how you saw it?

[34] **Dr Evans:** I would not say that we were responsible for implementation, because we would clearly not be able to do that. We are a voluntary group providing our best advice. We operate in an advisory capacity to the Welsh Government.

[35] **Darren Millar:** However, when the Government does not take your advice, that must be a bit dispiriting.

[36] **Dr Page:** It happens all the time. [*Laughter.*] The clue is in the title: it is the national specialist advisory group. The membership is drawn from all diabetes clinicians who have an interest in the management of diabetes in many disciplines. Phil leads it and I represent the consultants on it. Phil has a full-time consultant job—many would say it was more than a full-time job. He does not have the time to go around Wales meeting with all the DPDGs and introducing all the good practice.

[37] **Darren Millar:** I want to try to understand why the Government made the decision not to continue this post.

[38] **Dr Page:** You would have to ask the people involved. We cannot answer that question.

[39] **Darren Millar:** I am simply asking what explanation it gave to you, as the advisory group, because it is important. The role of the Government is to lead, and if it produces a national service framework, it is its responsibility to ensure that it is implemented. Your group provides advice to the Government, but if it is not listening to your advice and withdrawing posts that you think are important in terms of the delivery of the NSF, and if we are finding that the NSF clearly has not been delivered, then we will want to make clear recommendations in that regard. Given the evidence that we have received so far, one of those is going to be about leadership. There is no point having a decent national service framework or any other working document unless it is going to be implemented on the ground. I hear what you say about your role and I am not trying to pin responsibility on you at all. I am simply asking, in the event that the Government does not take your advice, how else are you
able to function? There is not much point having you if the Government does not listen to you, is there? Does it listen? What advice has it taken on board?

[40] **Dr Page:** At the end of the day, I think that the integrated diabetes patient management system is an example of our advice having been heeded. I think that that is a key development, as we have already mentioned.

[41] **Darren Millar:** Do you have a list of recommendations that you have made to the Government and a list of those that have been accepted and rejected since the formation of the advisory group?

[42] **Dr Page:** No, I do not have a single list of those.

[43] **Darren Millar:** Okay. It would be interesting to see what advice was heeded and what was not.

[44] **Mark Drakeford:** Are your group’s papers public papers? Do people get to see the minutes of your meetings or your agendas?

[45] **Dr Evans:** The minutes are circulated among NSAG members, so they are available.

[46] **Mark Drakeford:** So, that sort of dialogue could be pursued by looking at those.

[47] **Dr Millar-Jones:** One problem with leadership—not just in Wales, but in England—is that diabetes has been put under the banner of cardiovascular disease. It is not being classed as a separate entity. You are speaking to a group of people here who live and breathe diabetes, so we are going to be very prejudiced, but it has been thought of as more of a cardiovascular entity. As regards the other comorbidities associated with diabetes, a recent publication by Duthrie stated that patients under 65 have three other comorbidities, and those over 65 have up to six and a half other comorbidities. So, there is a lot going on with diabetes. It is not just a cardiovascular problem. We think that it should be deemed as a disease entity by itself and have its own leadership over and above what has been proposed.

[48] **Dr Page:** I would like to make a quick comment back to you. You asked what advice we have given that has been successful. In the last four or five years, Phil and I and others have met with members of the Welsh Government and have fairly consistently talked about information technology. That is moving. We have consistently talked about moving the retinal screening service into public health for the benefit of Public Health Wales and Wales as a country, because the research possibilities are huge. That is moving, we understand. We have not made any progress on the lead or on the number of diabetes specialist nurses or on structured education. They are in our document.

[49] **Mark Drakeford:** Thank you. I will move on to Vaughan, then Lindsay and Rebecca, and we will go on from there.

[50] **Vaughan Gething:** I would like to ask one question about leadership and then move on to patient education. In the Welsh Government paper, which I understand you have had a chance to look at, paragraph 33 on the diabetes delivery plan talks about establishing a diabetes implementation group to provide strong and joined-up leadership. Have you had a conversation with the Welsh Government about that? If so, I would be interested in what the conversation has been like. It would help us when questioning the civil servants who are coming in later on.

[51] **Dr Evans:** The Welsh Government has asked us to develop a delivery plan and to submit our ideas on it. Part of that is the Wales diabetes implementation group, which is a
standard part of the delivery plans across Wales. We have briefly discussed it; we have not had long conversations about the content or who should be on that group, but it clearly needs a multidisciplinary advisory group and it needs to have strong leadership at its helm. Our perspective is that it would need to link in, or that a diabetes co-ordinator, or diabetes lead, should be a part of that group.

[52] Vaughan Gething: That is helpful; thank you. On patient education, I note what you state in your own paper. Other witnesses have also raised this as an issue. A previous witness talked about the fact that most of the current structure of patient education takes place in secondary care and referred to that as pretty much bolting the stable door after the horse has bolted. I am interested because, at present, it appears that there is relatively poor identification of diabetics in secondary care—and you talked about that earlier—but I am also interested to know where you see the greatest impact in terms of financial impact, and in terms of condition management between primary and secondary care. I do not want to put words in your mouth, but if you are going to tell us that it would be better to have greater focus in primary care, I am interested to know how you would see that happening between GP, pharmacy and other public health messages. Whenever I go to schools, you cannot miss healthy eating messages, and yet we are constantly told that we expect people’s physical health and their lifestyle choices to make things worse. So, I am interested to know how you perceive success in terms of general education, and then structured education for people who come to the health service, and how you would expect us to get there, because we obviously need to make some recommendations. I would be very interested to hear your views.

[53] Dr Millar-Jones: When we look at patients, there are two problems. One problem, as regards the NSF, is finding the diabetes, but then, once you find it, the problem is getting patients to be engaged with it. Looking at the NSF, we assume that the patient who comes into the process of diabetes wants to take control, and we have to just give them the control. However, they have to recognise the need to have empowerment. So, the difficulty is in trying to get them engaged and to recognise this. Unfortunately, to a certain extent, we are doomed to failure. I can use smoking as a classic example. Twenty-five per cent of the population in my locality still smoke, but they can have prescriptions to help them stop smoking. They have had all of the education—we have given as much as we possibly can about that—and it is now anti-social to smoke in certain areas, but they are still smokers. There is a large group of patients that we are going to see and with whom it is very difficult to engage and say, ‘This is something that will happen to you in the future’.

[54] It is important to get the education in very early once they recognise it. We have several programmes available, but they are very limited and, as you have already said, many of them are secondary care programmes. Even in primary care, the programmes that give the most good are those that take several days. It is time out of a patient’s working life. So, it is a very difficult one to get around. We need a programme where we can start the patient off easily in their diabetic history, and then have structured education that we can easily refer to and be easily available to patients, both because GPs can refer them to it and it is suitable time-wise. Unfortunately—and Julie has been doing quite a lot of work with this—it is a difficult one to get our head around.

[55] Ms Lewis: The majority of education for people with diabetes does not take place in secondary care; it takes place in the community and in primary care. I am referring to the type 2 structured education programmes that are delivered largely across Wales but at a very low rate of delivery. In secondary care, you are looking at more of the specialist service, such as the type 1 structured diabetes education, because they are relying on diabetes specialist nurses and diabetes specialist dieticians to deliver that. They are largely based within the secondary care environment at the moment. However, as David said, we have been looking at getting some sort of access for people, particularly those with type 2 diabetes who are newly diagnosed, so that we can use consistent evidence-based messages right from the outset.
One of those examples is the Deeside locality model, and, as a national specialist advisory group, we have a task and finish group to look at implementing these consistent evidence-based messages at diagnosis for people with type 2 diabetes. It is that model, and the way that it has been implemented, that has been key to the success in the Deeside locality. So, a person will come to see their practice nurse or their GP to be informed that they have been diagnosed with type 2 diabetes, but the next appointment for that person will be a group education session—a two and a half hour education session about diet and lifestyle and to introduce to them the concept of carbohydrates and glucose control. It is set at a basic level—we are assuming that nobody knows anything about diabetes—and it is about giving people the confidence to determine some lifestyle choices that can help them to manage their diabetes. It is done in a group format, thereby releasing one-to-one dietetic time, as people would traditionally have been referred to a dietician, and that releases the dietician to do other things. So, the GP and primary care are engaged with referring the patient to the group model, and there is a commitment from the patient, who signs a statement saying, ‘I can attend this group on this day’. The statement is faxed over to the dietician service and the patient attends the group session. That is the second appointment.

So, it is about trying to change the philosophy around what a diabetes education programme should be, so that it becomes an expected part of somebody’s care to go to a group session, where possible. There will then be an expectation, six months down the line, that the person with type 2 diabetes accesses an expert, six-week programme, for two and a half hours a week. So, it is about changing expectations, and until that change is firmly embedded in primary care, it will not realise the success that it could. I am talking about success in terms of having more confidence to manage diabetes and improved biomedical outcomes, over and above what a first prescription for a drug might do; outcomes that are sustained for the long-term. You have a much more scholarly dialogue with a person with diabetes once they have undertaken this programme.

Vaughan Gething: I understand what you are saying about getting people to engage, and I do not underestimate the scale of that challenge, but are you trying to say, ‘Trying to make it easier is difficult, and we do not know how to do it’, or are you saying, ‘Trying to make it easier is difficult, but the best example we have at the moment is the Deeside project’?

Ms Lewis: That is one element; it is a stepping stone. The randomised controlled evidence around structured education is there and it is robust. There are outcomes not just for the patient or for the biomedical side of things, but in relation to cost savings to the NHS in the long run. So, this is an expectation of how a diabetes care programme should be managed, in terms of developing a person with diabetes to become particularly well informed so that he or she can self-care for the long-term; it is not a short-term fix.

Darren Millar: Given that the take-up of the structured education is so low at the moment, is there sufficient capacity within the system to allow everybody who needs it to access it? So, if more effort was made, would those people who refuse to participate do so? Is there sufficient capacity? It seems to me that it would be pretty tricky to get everybody included.

Ms Lewis: It depends on how we look at capacity. I have just completed a piece of work to illustrate a cost-saving model. We require the investment in the first instance, particularly for type 2 education, because we are talking about a huge number of individuals who would need to participate in that. However, if it is understood from a health perspective and a patient perspective that this model is an expected component of care—and I understand
that that might take some time to become embedded—then I believe that the majority of people, if it was something that they were expected to do, would be quite happy to learn more about their condition. Certainly, it has been a huge benefit to every participant—every graduate of structured education—in terms of confidence, improving their biomedical outcomes and managing their diabetes to best effect.

[62] We have calculated that, for north Wales for example, we would need just two band 6 educators to deliver expert education to 7% of the type 2 population annually. That is not a huge level of investment, but its cost-saving potential is in excess of £100,000 a year, by reducing complications and the need for that person to have more one-to-one consultations with a health professional. There is a potential to reduce medication as well, because they are able to make some lifestyle changes, to set those goals for themselves and then to realise an improvement. So, sometimes, the drugs can be reduced.

[63] Mark Drakeford: I have one final question on this, because it is an area that we will want to say something about in our report, but I am not absolutely sure in my own mind yet what the key thing for us to say should be, because we have heard things that are not contradictory, but do not always exactly match one another. Some witnesses have said to us, ‘Isn’t it shocking that structured education is available only to this tiny fraction of the people whom it should be available to?’, and others have said that it is not the right question to be asking, and, rather, it is not that it is available only to this tiny fraction, but that only a tiny fraction takes up the offer of education that is there, and what we should be looking at is the number of people who have been offered education, not the number of people who are taking it up. I am sure that it is not an either/or, but where do you think the emphasis ought to be, going forward? Is it making more education generally available or is it, if I understood what you said, Julie, more that we need a bit of a culture change? So, we do not simply offer education to people and say, ‘Here’s a group that you can go to, if you like’, but that it becomes an expectation, and we say, ‘This is what you’re now expected to do if you are to manage your condition effectively’. It is not just an offer, but something that the system is more than encouraging, and is expecting people to get involved with.

[64] Ms Lewis: When a person is newly diagnosed with diabetes, you have a window of opportunity in which they are quite motivated to make some changes, because it is a disastrous diagnosis. So, if that person then has to wait a long period of time until there is some intervention, six months may have gone by and they do not feel any different, but the damage has been done. We know that the longer we can help somebody to maintain good diabetes control, the better, and initial good control will have a long-term, positive legacy effect. From a personal perspective, it is about changing the culture of expectation, not just of the person with diabetes but of the health service’s engagement with that.

[65] Dr Millar-Jones: Maybe some of the confusion has been because two types of structured education are on offer. There is the expert structured education that Julie has been talking about, which is open to newly and already-diagnosed diabetics, and there is DESMOND—diabetes education and self-management for ongoing and newly diagnosed—which is available only to new diabetics. So, that might be where it seems to be limited to only certain groups.

[66] Mark Drakeford: Okay, and there is a difference between type 1 and type 2 in that, is there not, so it is not necessarily as simple as it looks on the surface?

[67] Dr Millar-Jones: There is indeed.

[68] Lindsay Whittle: Good morning, ladies and gentlemen. In case you are feeling too disillusioned, I welcome your advice and guidance today, although you should not get too excited, because I am not a member of the Government, of course. When I was first elected to
the National Assembly, one of the first events that I attended was a diabetes awareness-raising event, where I was very taken by the insulin pump therapy that I was shown. I know that we do not meet the National Institute for Health and Clinical Excellence’s guidelines on that particular treatment in Wales, and I have heard from witnesses that it does not suit every person who suffers from diabetes. Apart from not being suitable for everyone, some patients do not want it either, and I fully respect that. I know that, in Northern Ireland and Scotland, there is some ring-fencing for that treatment, but none in Wales. I would be extremely interested in your opinions, please, on whether funding should be ring-fenced for that particular treatment.

[69] **Dr Evans:** We are seeing an increase in insulin pump usage throughout Wales. You are quite right that it has to be used on the appropriate patient at the appropriate time and, generally, apart from when these pumps have to be started acutely, as in pregnancy, individuals will have received structured type 1 education beforehand, because that is a key component to this whole process. First, they will have structured diabetes education and, ultimately, that enables them and empowers them to be able to handle the pump, if that is the suitable modality of treatment for them. So, we have a hurdle to clear before we get to the pump-therapy action.

[70] On pump therapy, there has been an increase in the number of pumps throughout Wales. It is not at the point where NICE would say we should be at present, and there is variability throughout Wales in the number of pumps currently being delivered, but we are seeing an increase in pump therapy being delivered throughout Wales.

[71] **Dr Page:** It is not just about giving a patient a pump. They have to be supported and they have to be taught how to use it. They need to understand insulin dynamics, the effect of food, exercise and illness before they even get hold of a pump. They have to commit to using the pump and use it properly; otherwise, it is dangerous. In order to support someone on to a pump, you need an educational team within the institution that is prescribing it that is itself trained and experienced in the use of pumps. These teams have a capacity. That capacity can be reached and, at that point, you cannot start anyone else on a pump.

[72] **Lindsay Whittle:** I would just like to follow that up, Chair. Clearly, I do not want to encourage anything that is even more dangerous than diabetes, but, from what I saw, the young man who had the insulin pump therapy, who was only 14 years of age, was getting on with his life. We have heard from some witnesses who are in favour of it or are against it. Are you in favour of this and a real advocate for its use?

[73] **Dr Page:** Insulin pump treatment, in the right patient with the right support, can be life changing.

[74] **Lindsay Whittle:** I hate to bring up the finance, but sometimes, the powers that be like the financial issues. Would there be long-term savings, perhaps?

[75] **Dr Evans:** It is being considered by NICE. It is a NICE technology appraisal, so it has looked at the cost-effectiveness in the right and appropriate patient. The key thing is that you select the appropriate person who would suit that therapy and ensure that they are an empowered, educated patient who understands the concepts of diabetes and the pump therapy and then takes it forward. In that patient, that would be an excellent therapy and it should be available to them.

[76] **Kirsty Williams:** So, just to be clear, it is not the cost of the pump but the system that the patient has to go through and the time that it takes to educate them with the right team of people. That is the barrier.
Dr Page: We have never been prevented from prescribing a pump to any of our patients in Cwm Taf. I cannot say that across Wales, but we have never been told ‘no’. Our capacity issue is the number that we now have on pumps. We are stuck.

Kirsty Williams: So, it is the team of people that we need to concentrate on, rather than the supply of the pumps.

Dr Evans: Yes, and structured education, because, ultimately, that is the key to being able to take that forward. A number of areas do not have type 1 structured diabetes education in place.

Dr Page: This is type 1 structured education.

Dr Evans: Yes, type 1, as opposed to type 2.

Kirsty Williams: So, how many areas would not have that?

Dr Evans: A document was drawn up two years ago—a structured diabetes education review for the whole of Wales—and information will be available on that. I cannot specifically tell you every area in Wales that does or does not have it or the capacity within each area. However, a document was sent to the Welsh Government two years ago on that very issue.

Mark Drakeford: I might ask Philippa to have a look at it for us.

Dr Millar-Jones: That leads on to another point about the availability and frequency of visits to diabetes specialist nurses. The numbers have reduced because the prevalence has increased. The concern is that diabetes specialist nurses are being seconded elsewhere out of the diabetes specialty and are not being replaced. It is the DSN’s role to give the patient support, to maintain them on the pumps. I know that my learned colleagues sitting beside me will turn around and say that they could not put patients on pumps without qualified DSNs to offer the support and the counselling that the patients need.

Dr Page: We reached a high-water mark for DSNs in Wales about three or four years ago. Since then, the numbers have dropped.

Ms Lewis: To clarify the point about the diabetes specialist nurses, in preparation for this meeting, I liaised with my diabetes lead colleagues across Wales about some of the points that they felt I should try my best to get across during this meeting. Certainly, on increasing prevalence, the number of diabetes specialist nurses has reduced in Wales. We have posts that have been frozen and maternity leave that is not covered. When you have a very small team of specialists, that has a huge impact on your ability to maintain a service.

10.00 a.m.

Largely, we understand and completely agree with the direction being set for diabetes services, and many areas are trying to work collaboratively with their primary care and community care colleagues. However, with an increasing in-patient demand, with in-patients having a diabetes rate of about 20%, we are fighting against a tide of in-patient diabetes problems while trying to meet the strategic agenda of getting out to primary care and community care services.

Moreover, there is evidence from across Wales that diabetes specialist nurses are being required to spend up to 10% of their time working as general nurses on the ward, because our management structures are finding it very difficult to plug that gap. While
diabetes nurses have shown a real preparedness to assist in acute critical situations to maintain safe patient care, they are becoming overwhelmed by requests to fill those gaps in the service. As a specialist service, we are very clear about what we are there to do, and we devolve other non-specialist services as much as we possibly can back to primary care: to our practice nurse colleagues, GP nurse colleagues and to general nurses and long-term condition co-ordinators out in the community. We have a specialist role, but we also have a health professional education role, and we are just too overwhelmed as a specialist service to be able to provide that, even to a basic standard. We are just fighting against the tide, really.

[90] Mark Drakeford: Thank you for putting that on the record for us. I am glad that you had the chance to reflect the views that you have collected. I am keen to ensure that members of the committee who have not yet had a chance to ask a question get their chance, too, so I go to Rebecca next, and then Elin and Mick.

[91] Rebecca Evans: I was going to raise diabetes specialist nurses with you, but you have answered a lot of my questions. What you said certainly gels with what we have heard from the Royal College of Nursing, which has expressed concern that nurses are increasingly being asked to cover on general hospital wards. What is the most useful recommendation that this committee could make regarding diabetes specialist nurses?

[92] Ms Lewis: Speaking from a personal perspective, we do not have a recognised number of diabetes nurses per prevalence or per population, and there are models out there. So, there is huge variability across Wales. That has probably been brought about by the fact that, as health boards have been reconfigured, we have seen quite a lot of investment in diabetes services, and ultimately in diabetes specialist nurses, in some places and, in others, there has been none. That applies to diabetes nursing and structured education. So, if there were a recommended number of diabetes specialist nurses per population—and dieticians, as well, I have to say—health boards would at least have some idea of a baseline against which to measure their diabetes nursing service.

[93] Rebecca Evans: Do you have a number in mind as to what that ratio would be?

[94] Ms Lewis: There is one contained in a 2010 document on adult diabetes specialist services, which has been endorsed by Diabetes UK, the Primary Care Diabetes Society, etcetera, and that is one in-patient diabetes specialist nurse per 300 beds, and one DSN per 50,000 population. We are not really meeting that agenda across Wales, largely.

[95] Moreover, rather than saying that we need a whole load more diabetes nurses, dieticians, or whoever, to support this diabetes service, we need to have targeted interventions so that we can measure the benefit of that investment, rather than continuing to do more of the same.

[96] Dr Evans: I do think that there needs to be a twin-track approach between primary care and secondary care in the community. You cannot just take from one and place in the other or you will denude the services that you are providing in one area that are already struggling. As Mike has already mentioned, they are struggling with in-patient numbers, the structured education, the pump services and the antenatal adolescent care. They are trying to provide all that with reducing numbers, so it is not just an issue of moving one to another. You need to have a twin-track approach to develop those specialist nursing services in both the community and in-patient care.

[97] Elin Jones: I want to ask again about in-patient care. You mentioned the role of diabetes specialist teams in hospitals in your earlier answers. We have had evidence from the Association of British Clinical Diabetologists and it said that one of its top three priorities would be a formalised, consultant-led diabetes in-patient team in all acute hospitals in Wales.
In your view, how far away are we from having that kind of network in all acute hospitals in Wales, and if at the moment we are quite far away—bearing in mind what has already been said about frozen posts in diabetic nursing—how realistic would it be for us as a committee to include that as a priority recommendation in the financial scenarios over the next five years? To go one step further, as part of the response to the ombudsman’s report on in-patient care, we have also heard about the ThinkGlucose work in Cwm Taf primarily, and in some other health boards. Is that one model of developing further and ensuring that there is, at least, a minimum level of in-patient services throughout Wales?

Dr Page: There are lots of questions there. On the point about establishing an in-patient consultant-led diabetes team, I think you would find, if you went looking, that all health boards and hospitals have that to a greater or lesser extent. The problem that they have is that they have been reactive teams rather than proactive teams, so they wait to be told where the diabetics are and then they go to see them. The benefit of being proactive, as we demonstrated in Cwm Taf three or four years ago—Phil will tell you more about that—is that when we committed dedicated diabetes nursing time to that team to go out to the wards daily, looking for the diabetics and the problems, we reduced length of stay by three days for the diabetic patients. That is 20% of the hospital population. It is a lot. I will tell you that one of the nurses who left the organisation for her own reasons was not replaced. That team then ceased to be proactive and became reactive again because we were not allowed to replace the nurse. The consultant staff are there ready, willing and able to lead those teams. The diabetes specialist nurses are able to do it, but they are pulled in many directions, as Julie has told you.

The ThinkGlucose campaign is merely an educational campaign. It is another facet of diabetes education, this time delivered to healthcare professionals by specialist nurses or educators. What this committee could do would be to rule that that sort of in-hospital campaign and system for highlighting diabetes, and the problems associated with diabetes and the benefits of being proactive about dealing with those problems, would make a difference across Wales.

Dr Evans: The national diabetes audit has become a tier 1 audit this year in Wales; that is, it is a must-do audit. It is dependent on obtaining information via information technology because it is such a huge audit. If you think about it, there are 160,000 patients with diabetes in Wales and, to pull all that information together, it has to be done via information technology. Up until this year, it has utilised a system called Audit+ in Wales, and that required primary care to allow Audit+ to pull that information from their systems. Last year, the uptake was just under 50% in Wales in terms of participation in the national diabetes audit. With regard to the developments that we have already talked about today, specifically on information technology, in Scotland they would be able to do that via their
system, which is exactly the point that we have been trying to make, that we would be able to have those data at the touch of a button, if we had that information technology. The importance of the audit is that it demonstrates processes of care, things that are measured and what is being achieved for people with diabetes. So, it looks at the processes and the values of what is being achieved.

[108] **Mick Antoniw**: I can understand its importance in terms of the imminent development of the IT, but it has been operational since 2007. What has happened between 2007 and last year? You talk quite positively about the recent year. What has been the status of it?

[109] **Dr Evans**: My understanding of how the national diabetes audit has been run in Wales is that Audit+ has been the tool that they have utilised to try to achieve that. This year, the uptake of that has improved. I do not know the figures for that, but last year it was less than 50% and this year it has improved significantly. However, I would not know more than that.

[110] **Mark Drakeford**: On information collection, we have heard evidence from the beginning of this inquiry about concerns that LHBs have been required to collect information and to submit it to the Welsh Government, but that, in recent times at least, the information has sat there inertly without any concerted effort to analyse it, to find the messages that are there to be found, and to relay those back to the LHBs in order to ensure that there is some sort of loop for improving services. So, there are a couple of questions for you there. In your experience, is the sort of information that is required to be collected by LHBs the right sort of information? Are people just filling in forms for no real purpose, or is it all good stuff that ought to be collected? Is it your impression that, having made the effort to collect it, not enough is done with that information to draw out of it the lessons that are there to be learnt?

[111] **Dr Evans**: There was certainly frustration that they were asking the health boards to provide information quarterly, but that things were not changing sufficiently quickly. We were filling in these forms quarterly, but not getting feedback on the information that was then passed on. That was very frustrating.

[112] The NSAG developed a self-assessment tool some years ago that was felt to better reflect on ascertaining processes in relation to the diabetes national service framework, and there was then an agreement with the health boards, the NSAG and the Welsh Government to do that. Those assessments were sent in, but, again, they have not been collated and no information has been fed back.

[113] That was based on a system of self-assessment from England, from Innove, which is a separate company to the NHS. It allowed us to develop this and explore that opportunity in Wales. We looked at those forms. In England, all of this is done electronically via local services and is combined with data from the national diabetes audit and the QOF data, which means that you then get a national and local picture on diabetes services. That is the sort of position that we wanted to find ourselves in, given that we did not have this overarching information technology to draw upon.

[114] **Mark Drakeford**: Just to ensure that I have understood the developing picture: we have moved now to a position where the quarterly returns are no longer happening, but we have a self-assessment tool that you were helpful in developing. Did I then understand you to say that the self-assessment tool results get fed into the Welsh Government, but that, again, there is no loop through which you then hear back what is happening across Wales, for example, where there are good things happening and where there are gaps that need to be filled and so on?
Dr Evans: The self-assessment tool superseded the quarterly reports.

Mark Drakeford: Okay; that is good to know.

Dr Evans: The last time we had a collation of the national picture of the national service framework was when Mrs Helen Husband was a co-ordinator for diabetes in 2009. Ultimately, since then, we have had the self-assessment tool results, which have been going in.

Mark Drakeford: So, these two things come together: we started by talking about the need for a national lead and the capacity to use the information that comes in through the self-assessment tool and to feed it back into the service. Those two things go together, in your mind.

10.15 a.m.

Dr Evans: That person needs the research network and the administrative support underneath them to be able to pull out information from the variety of departments that deal with diabetes. It is not just about health; it is about education, transport, planning, the health boards and the diabetes planning and delivery groups. The person needs to collate all that information, which needs to be passed along freely. Everything related to diabetes should be funnelled up through that central diabetes person.

Mick Antoniw: Since 2009, do we know whether anything specific has happened with the information that is being fed through? Has there been any product or benefit at the end of that process?

Dr Evans: I am not aware of any feedback to the health boards on the national service framework based on those reports. I am aware that Diabetes UK pulled together some data and discussed those with the diabetes planning and delivery groups.

Mark Drakeford: Thank you all very much indeed. The hour has passed very quickly while we have been exploring these important points with you. Based on your paper and what we have heard this morning, I think that we know which key priorities you believe we should be focusing on in our report for the future. However, I will make the same offer to you as I make to all of our witnesses: if, after the meeting, you feel that there are further points that it is really important for us to capture in our report, we would be very grateful if you could write to us about them, if you have a chance. A number of witnesses that we have seen, maybe at the point where the emerging picture was not as clear as it has become since, have done so. They have written to us, and it has been helpful.

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I would now like to wish Professor Richard Roberts a good morning, and thank him for coming here to help us with our work on diabetes. For the next half hour, we turn to the diabetic retinopathy screening service for
With us to discuss this subject is Professor Richard Roberts, who has been a part of this service since the outset.

Thank you very much indeed, Professor Roberts, for coming to help us with our inquiry. If you have any opening remarks that you would like to offer, we will hear them first. I know that there will then be many questions that people will want to ask you in the next half hour.

Mr Roberts: Thank you, Chair. First, I would like to take the title off my name; I am not a professor. I am many other things, and people call me many other things. I am an optometrist and I have, up until the end of this month, been the chief optometric adviser to the Welsh Government. As Kirsty will know from the all-party group, I was responsible—for setting up the Welsh eye care initiative, out of which came the diabetic retinopathy screening service, of which I think we can all be justly proud. That is all I need to say as an opening statement.

Mark Drakeford: Thank you. We will therefore go straight into questions.

Darren Millar: Thank you for your paper. It seems to me that the retinopathy screening programme is one of the big success stories in the whole picture of diabetes service provision across Wales. Are there specific targets for the proportion of patients who are accessing screening appointments? I assume that, in an ideal world, everyone would be accessing screening on a regular basis, but that tends not to be the case. What proportion of patients is screened, and what are your targets?

Mr Roberts: You heard from contributors earlier—I was watching you in the other room—that we have 165,000 patients in Wales who are diabetic. The target is that of all of those who are diagnosed as being diabetic are referred to a screening programme, to see whether there is any evidence of diabetic retinopathy.

In terms of what DRSSW has done, perhaps you can all take succour from the fact that it is a success story, in the sense that it is all-Wales and community based. Patients do not travel long distances for the screening service, because it is delivered in locations within hospitals, GP practices and health centres, together with a van-based service that can pull up in any location. The original access to screening target involved making sure that no patient, if possible, travelled more than 5 miles, no matter where they were located in Wales; that is what is delivered.

The target is to get all 165,000 diabetic patients in Wales in for screening. There are many methodologies that the DRSSW has tried. I am not here as a spokesman for DRSSW, because I do not work for it, but I was on the project board that set it up. The data that we have currently are that, of those patients invited for screening, 84% are targeted and turn up. Of those, we get feedback of roughly 82% uptake. So, we get did-not-attends, varying by region, of between 16% and 20%. The purpose is to target those who do not turn up. There are mechanisms in place: the fail-safe device would be referral back from their GP. They are picked up in primary care by optometrists and, if they have not been for screening, they are referred. We are also in the process of doing two things, one of which is an ongoing review of the service itself, which is managed by a service level agreement, currently held by Cardiff and Vale University Local Health Board. Within that process we are looking at different ways of working and different ways of using different technology. I have been around Welsh Government long enough to know about a 12-month plan for IT in Wales, but I do not think that I will live long enough to see it being delivered. However, I think that we need focused IT systems that link in by central portals, so that we can target various areas very quickly.
Currently, the response would be communication by letter, because we have to recognise that a lot of these patients are elderly and do not use modern methods of communication. Texts and e-mails are not, first and foremost, our means of communication, but we need to investigate that, to try to get these numbers up.

Darren Millar: In terms of tightening that net, it sounds as though you are doing pretty much everything that you can to capture as many people as possible. You mentioned primary care optometrists; would that be for a certain proportion of people who have eye tests on a regular basis?

Mr Roberts: Yes. Normally, patients would come in over the age of 60, under current Government legislation, UK-wide, on general ophthalmic service, which gives them free entitlement to an eye examination. In Wales, we are taking that several steps further by putting in a specialist investigative examination, as part of the eye care initiative in the Wales eye care service, that includes dilation, looking at fundoscopy and at evidence of diabetic retinopathy, grading it accordingly, and then referring it to the service. Part of the link that I have been working on is making that connection with DRSSW. That is currently going forward in a Wales eye care plan.

Darren Millar: That is super. You feel that the really important thing that we need here is more sophisticated data capture within an IT system, to capture as many people as possible in the retinopathy programme—is that right?

Mr Roberts: I think that we need to be savvy in terms of our use of IT—it is not my bête noir, by any means, but we are looking at easy means of communication. We have a problem, perhaps, in IT in looking at things across the board and being over-prescriptive in how we communicate. There is a good example: in ophthamology, one of the other things that we are looking to focus on is pathways in various aspects—diabetes being the next one in line for which to produce pathways. It is about how you communicate that. We need to have communication from primary care into secondary care quite easily. You can put in very sophisticated IT systems—they have done that in Scotland with the Scottish eye care system. However, that means an investment of £50,000 per optometric practice. That is a nonsensical use of public money. We should be using OpenEyes over an http connection with a secure portal so that they can get this done very cheaply via the internet. It is secure; it does work; it is currently being trialled in Moorfields. That is how you can really beef up the system of referring back.

Kirsty Williams: I think that Wales can be justly proud of what we did with the Wales eye care initiative. It was world-leading at the time and there were exciting developments. You mentioned an ongoing review of the service. A review provides opportunities to improve things, but there are also potential threats when a review of the service is undertaken. What do you think the review gives us the opportunity to do to improve things? Do you have any concerns about where the service may go in future?

Mr Roberts: That point is well made, Kirsty. Looking at the service itself, and to refer to what was said by my diabetologist colleagues who were in earlier, my point of view is that there is a disconnect between the phenomenal data we now have in DRSSW and what that could be used for in terms of research for diabetes in general. With regard to what I have been trying to do, I have met Phil Evans and others to bring forward discussions on where we take DRSSW. Does it remain as an SLA with Cardiff and Vale health board? Should it be linked to Public Health Wales? I certainly think that there needs to be a connection with Public Health Wales, because it is out on a limb at the moment.

If Public Health Wales does what it says on the tin—I have misgivings about whether
it is achieving that at the moment, but I hope that it does—you use the best data that we have, because the good news for politicians in the Welsh Government is that diabetic retinopathy screening in Wales is way ahead of anywhere else in the UK. The nearest is Scotland. In a very small area, it is doing slightly better than us in terms of the feedback of data, but it is restricted to just a few Scottish health boards—it is not, by any means, being done across the whole country. In Wales, we are doing much better. England is in a state of disarray from primary care trust to primary care trust. Northern Ireland is looking at our model and having a discussion about how it can improve matters.

[140] To come back to your original question, the risks are that you can take any review of the service and say that you can dismantle something because it is expensive. I know what is said in the wider community; people get the wrong end of stories and the implications are that the whispers start and people begin to wonder what is happening. I can give the committee an assurance that no decisions have been made. We are looking at the economic use of a van-based service and at whether that can be streamlined. We are looking to achieve better use of the service by bringing patients in in a variety of ways. At the moment, we have a one-size-fits-all approach, which is not what should happen, speaking as a clinician at the front end of this. We have a 12-month recall on diabetic retinopathy screening. If patients are early preproliferative diabetics, they could be safely rescreened every two years. Patients who are almost on the borderline of producing either microaneurysms or haemorrhages in the eye should certainly be screened every 12 months. Patients whose condition is more advanced should perhaps be screened every six months, but the chances are that, by that stage, they will already be in secondary care.

[141] I have been pushing for this in the four-nations diabetic group—England, Scotland, Wales and Northern Ireland—and, at the last meeting a year ago, I got some movement on getting them to agree to carry out research looking at the methodology of screening. We have got so far with the national screening committee but when Muir Gray was leading it he was adamant that it had to be 12 months and nothing else, and I think that we need to move on from that. If we can get some flexibility on screening, it would take some of the pressures out of the system. What is coming back to beat the deliverers of the service and cause concern for patients is the fact that people think, ‘I was due to be screened at 12 months; it’s now 15 months and I’m getting terribly anxious’ when, really, they do not need to be. There is an unnecessary anxiety creeping into the system, so that needs to be looked at.

[142] Mark Drakeford: I will come to Rebecca next, Mr Roberts, but I have one question first. Earlier, you said to us that key to the success of the service is the way in which more specialist forms of treatment have been moved into the primary care setting. We have heard this morning, and previously, about the difficulty that exists in trying to bring about that shift within the Welsh NHS. Are there more general lessons that can be drawn for diabetes services and even beyond that, perhaps, from the way in which that shift has been brought about in diabetic retinopathy?

10.30 a.m.

[143] Mr Roberts: Perhaps I could broaden it slightly in talking about eye care services in general. One of the success stories I have worked with in the role—my role as chief optometric adviser was for just one day a week; I worked more than that, but that is what I was paid for—was in trying to look at issues that we felt that we could improve upon. Kirsty has made reference to the all-party group that was set up on the Wales eye care initiative; that has been phenomenal, because it has engaged with all partners. It has been a case of primary care, secondary care, the third sector and everyone else getting together, breaking down barriers. The biggest barrier we had to break down was in the voluntary organisations that, at one stage, were not even communicating with each other. That is a great credit to the people involved. We have now moved on significantly.
Going back to when Jane Hutt was Minister for health, the thrust at that stage was that this had to be a primary-care-focused, bottom-up service. I fundamentally believe that that is absolutely right. As a patient, I get concerned if I go to my GP practice and—with no disrespect to GPs—they no longer actually look at their patients and at how well they are. They sit behind a computer, inputting data, because they are at risk from the whole issue of legal services—there are compensation lawyers hovering outside GP practices.

I will give you an example. In the old days, if someone over a certain age went along with abdominal pain, they would be examined by their GP, who would say, ‘Get up on my couch. I will palpate your abdomen. I will prescribe this for two weeks. If it does not clear up, we will investigate further.’ I can guarantee that no GP today would say anything to that patient other than, ‘We will refer you for further investigation; off you go for your endoscopy’. What is the result? Of the endoscopies taking place in secondary care in the health service, 73% produce a negative result. To me, that is a dramatic waste of resource. That is nothing to do with eye care, but if you look at what we are trying to do with eye care, and what we are trying to do with optometric manpower, you will see that there are people with skill levels—we have taken them from degree level and above—who are quite capable of making accurate diagnoses. I ask ophthalmology colleagues of mine, ‘What is it that you want, when a referral comes in to you, that will enable you to undertake the tasks and the work that you want to do efficiently?’ They want visual fields to have been done, the slit lamp biomicroscopy to have been done, disc analysis done, entropic pressures measured et cetera. So, when those referrals come in they should go straight in to a consultant for a decision to be made on treatment.

I spent 12 years working at the University Hospital of Wales in secondary care running two specialist clinics. I was appalled by the number of outpatient appointments made. If you had patients going in, for example, with glaucoma, they would bounce around the system three or four times before they saw a consultant for a diagnosis to be made. That is nonsense. We should strip away outpatient appointments other than on a first occasion. What we need to do in Wales is get diagnostic centres where the treatment follows the patient pathway on one occasion. If you are travelling across Wales on a 30 to 40-mile journey to get to secondary care, the last thing you need, coming away, is to be told, ‘Yes; we need further investigation. We will make an appointment for you, which will be six months down the line and the chances are that it will probably get cancelled’. To me, that is nothing more than methodology, making things work and process. It is not to do with investment.

Mark Drakeford: Finally, is it your view that the evidence from what has been achieved in the retinopathy service bears out the sort of diagnosis that you have just described?

Mr Roberts: It is a very good example of it, but it needs to go further and it needs to be sharpened up. We need—and we will deliver—focus on the pathway from the DSU, which is based in Bridgend, as you know. It will go out into the community and look at the pathways for the diabetic retinopathy service from the point at which they are screened in, to being seen and to being delivered. The good thing is that, within the budget of DRSSW, there is an amount ring-fenced for treatment so that patients who are seen should have appropriate laser treatment early on. That will prevent any secondary complications. I muse and smile quietly about NICE being about to make an announcement on diabetic macular oedema and the use of Lucentis, which we use for wet maculopathy, as you know, because other drugs are being
used at the moment, but this is deemed to be better. If you are treating and managing patients with diabetes appropriately, the number of patients who end up with oedema will be very small indeed. If that is the case, I am very happy to say that I will accept the drug company’s proposed reduction of 40% in the drug cost if NICE gives it permission to do this because that will be a 40% saving on what we are spending on wet AMD in Wales, and that would produce a saving of about £4.8 million.

[150] Mark Drakeford: Thank you. I am sorry to have rather dominated the questions for a few minutes, but it is now Rebecca’s turn.

[151] Rebecca Evans: You have talked about the excellent uptake of screening. What can we do to engage that last 10% or 15% of people? Are there characteristics that link the people in that group? Do they share the fact that they are younger people or older people? Are they from particular communities?

[152] Mr Roberts: That is a very good question because it highlights what the issues are. There is the issue of mentoring patients, particularly elderly patients, who can be forgetful. It is about how you follow things up when that appointment does not take place. What is the next part of the process? At the moment, the service is fighting very hard to deliver what they need. It is a very lean organisation; there is not a lot of flesh within DRSSW, I can assure you. I would like to see better communication if a patient does not turn up for an appointment. Notification should be sent to their primary care optometrist, who can then contact the patient, bring them back in and re-refer them. They have that opportunity. The good thing about a screening process of this kind is that, if the patient does not turn up but is regularly being referred and examined by their optometrist every 12 months, that is a safety net. If anything is happening in the pathology within the eye, they will be referred back straight away. That is your catch-all system. It is a very cost-effective service because if it comes in on a general ophthalmic services basis the money used is not part of the Welsh Government’s budget. That is at least encouraging.

[153] Mark Drakeford: Do they share common characteristics, those who do not turn up?

[154] Mr Roberts: I do not think that anyone has looked into it. I think the review will highlight this. You obviously have the problem of appreciation of the issue within various socioeconomic groups, which is sometimes a difficult problem to crack. Strangely, younger patients in those groups seem to be very good at attending for treatment. However, elderly people living on their own, perhaps with very little family support, represent the biggest risk; that is what I see in other aspects of my practice.

[155] Darren Millar: With regard to the outcomes, because that is what is critical at the end of the day, I assume that, as a result of the screening programme, we are able to demonstrate that we have lower rates of diabetic blindness or eye problems. What are the percentages compared with elsewhere in the UK?

[156] Mr Roberts: We are probably about 18% better off than anywhere else in the UK.


[158] Mr Roberts: Let me take you back: when I first started practising, if I saw a diabetic patient, their prognosis would be that, within 25 years, they would be severely sight-impaired. Now, when I see a diabetic patient, I would expect them to live all of their normal lifespan retaining normal vision. That is the turnaround you can achieve by doing this. Why is this happening? It is due to better drugs to control the diabetic problem. These are changing all the time and there are two new drugs due on the market in the early to middle part of next year. It is also due to management of different types of insulin and the point at which that is done.
People with type 1 diabetes do extremely well with diabetinopathy because they are injecting as a normal way of life; they are very good compliers with the service. The big issue with any medication, as is the case with eye drops for glaucoma, is compliance. It comes down to how you ensure that patients are taking the tablets or putting their eye drops in. To be fair to general practitioners, they try to follow up these issues. Every time I give a lecture, the thing I talk about is how you counsel patients not just in looking at their eyes in an eye examination, but so that you know exactly what is happening in terms of what medication has been prescribed; their wellbeing is vital. If that does not happen, then the risk is greater. If it does happen, then compliance is good, and we have a success story in Wales in terms of outcomes from screening. The English figure, in terms of the proportion of patients who received key processes for diabetic care in 2009-10, was 76.86%; the figure in Wales was 84.02%. Our figures have increased since then and are getting close to 90% currently. So, that is where we are.

[159] We have looked at the service in terms of cost; the initial cost was £4.4 million, and we are now up to roughly £6.2 million. There has been a lot of reorganisation, and credit must be given to the service director and to the clinical lead, who have looked carefully at costs in an attempt to control them. The review needs to be mindful of what has been achieved to make sure that certain savings are made. At one point, the mantra coming out of the Welsh Government was ‘invest to save’. I fully appreciate that that was in difficult financial times, but if we look at this in the slightly longer term, even in the current climate, we need to make sure that you do not underfund the critical services right at the interface of first access to care.

[160] Mark Drakeford: I have one more question to follow up on Darren’s point. We have heard evidence throughout this inquiry about the need for structured patient education and the challenge of persuading people to commit themselves to that education. In terms of the points that you were making about persuading people to comply with regimes, are there lessons from this whole experience about how we engage patients better in their management of conditions of this sort?

[161] Mr Roberts: I think there are lessons. In eye care and eye health as a whole, and in health in general, it has always concerned me how patients who desperately need to be targeted are targeted. When I first started my professional career, I worked in the Rhondda valleys. I was there for three years, and when I first came to Cardiff I thought that I had lost the plot because I was not diagnosing conditions that I was diagnosing in the Rhondda valleys; the extent of the pathology was that much less because people were better informed. So, you need to have initiatives to engage with people. If you are putting notices up in a GP surgery, it is too late; engagement should happen much earlier on in the process. So, engagement should happen in schools, because children are very good at educating their parents, and there is a need to engage with groups, such as black and minority ethnic groups. If you have various ethnic minorities you have a higher incidence of diabetes—so, you do not engage these people to come to live and integrate in our country without realising what the cost is and how you can support that with the information that you have given.

[162] Every healthcare professional working in the field has a role to play in terms of counselling. I say that to my colleagues, and I would say the same to dental surgeons; that is a role not just for GPs. The biggest and the best communication links I have ever encountered are with nurses and nurse practitioners, who do a fantastic job in monitoring patients, particularly in GP clinics. A diabetic-led service within primary care in GP clinics is probably the best thing that has happened, because GPs are totally dedicated, very knowledgeable and give time to their patients. So, that has been one of the successes.

[163] Going right back to the beginning, in terms of communicating, Public Health Wales has a big job to do, and it needs to be strategic in what it is doing. To take this one stage further, if you can put notices on cigarette packets stating that smoking kills, then you can put
notices on certain foodstuffs to say that the same outcome is possible if you eat enough of them. So, you need to be mindful of how this is done. It is important that every key healthcare worker within the whole system, in primary and secondary care, takes every opportunity, if they see it, to make that communication.

[164] **Mark Drakeford:** Thank you very much indeed. Diolch yn fawr iawn i chi.

[165] A oes unrhyw gwestiynau eraill? Are there any other questions? I see that there are none.

[166] Thank you very much indeed. This session has been helpful to us in thinking things through. We will now adjourn for 10 minutes and resume at 10.55 a.m.

**Gohiriwyd y cyfarfod rhwng 10.44 a.m. a 10.59 a.m.**

The meeting adjourned between 10.44 a.m. and 10.59 a.m.

[167] **Mark Drakeford:** Croeso yn ôl, a chroeso i Lisa Turnbull, cynghorydd polisi a materion cyhoeddus Coleg Nyrsio Brenhinol Cymru, a Nicola Davis-Job, cynghorydd gofal aciwt yn y coleg. Rydym yn siarad y bore yma am ein hynychwiliad i’r gwaith o weithredu’r fframwaith gwasanaeth cenedlaethol ar gyfer diabetes a’i datblygiad yn y dyfodol. Diolch yn fawr am ddod i’n helpu ac am y papur rydym wedi ei dderbyn yn barod. Fel arfer—rydych wedi bod yma o’r blaen, wrth gwrs—a oes gennych chi unrhyw ddatganiad agoriadol byr? Ar ôl hynny, bydd cwestiynau gan aelodau’r pwyllgor.

11.00 a.m.

[168] Lisa, are you going to lead off with any comments?

[169] **Ms Turnbull:** There are three essential points that we want to make, which are around education for patients, education for healthcare professionals, and the concern we have about the risk to specialist nursing posts in this field. I am happy to elaborate on those in response to any questions.

[170] **Mark Drakeford:** As I have said to everybody, this is a short inquiry in which we are focused on two key things: we are looking back over the nearly 10 years since the NSF was introduced to see what has been achieved and where the gaps remain, and we will undoubtedly want to make some recommendations to the Welsh Government about future planning for diabetes in response to its intention to go out to consultation on some of this early next year. We are looking forward as well as back, and we will be interested to hear what you have to say about those issues too. I will go to Elin and then to Darren.

[171] **Elin Jones:** Morning. We had evidence in the previous session on diabetic special nurses and reference to frozen posts and reallocation of diabetic special nurses in the hospital setting to more general ward responsibilities. Do you have any evidence of the extent of any reduction in numbers of diabetic special nurses in Wales, or the watering down of those responsibilities in various contexts?
Ms Turnbull: Yes, this is a real concern for us. What we are seeing is posts not being filled if individuals move on. We are also seeing reviews with a view to perhaps downbanding or downgrading some of the nursing posts. We are also seeing people being asked to return to general duties—that could be for 20% of their time, which is obviously significant, because then they will not be able to do the role they are actually employed to do, the specialist nursing role—clinics and so forth, and the support work there. That is an area of quite serious concern for us.

We also believe there needs to be better gathering of national information on this in terms of numbers and levels. It is very difficult at the moment to gain an accurate picture. It really takes a lot of time and a lot of enquiries—not at health board level, but with individual hospitals and departments—to try to track down exactly what is happening. It seems to us that it would be more sensible to have a national picture so that people can understand how many specialist nurses are available in a particular local health board region, for example.

Elin Jones: So, if we look at the other side of the equation in terms of the supply of diabetic specialist nurses, there is no shortage of supply. It is just that health boards are possibly looking to their finances to reallocate moneys in a different way within their hospital settings. It is not an issue of recruitment or supply.

Ms Turnbull: It is not, and that is an important point, because issues around medical recruitment in Wales are extremely different from nursing recruitment. That is an important point to draw out in that the situation in nursing generally, and with diabetes here, is not that there is a shortage of people willing to work or to be in education to a certain level, wanting the career pathway. We are fortunate in that we have a lot of those people in Wales. Exactly as you just described, the difficulty is the short-term financial approach of saying that we do not want to employ somebody on that salary, we want to downgrade those posts and make a short-term financial saving. What the health boards are missing there is the long-term financial gain that they get from employing these specialist nursing roles. You have already heard evidence this morning about how these posts can really pay for themselves and more in terms of the money they release.

Elin Jones: We heard a suggestion earlier that one way of addressing this lack of information and this patchy scene across Wales with regard to where diabetic specialist nurses were working in hospitals or communities was to almost set targets for health boards on the minimum number of diabetic specialist nurses that should be working in various communities. Would that be a useful way of progressing our work and our recommendations—to set a minimum, or for the Welsh Government to consider setting a minimum?

Ms Turnbull: We have never been happy with the word ‘minimum’. The expression that we tend to use is ‘appropriate’. The Royal College of Nursing has always taken the approach that it is very useful to have guidance on the appropriate levels relating to the population, as health boards would then be in a position to explain any deviation. There may be very sensible reasons for that, but the question cannot be asked and answered unless you have the guidance and the information. So, we would certainly be very supportive of moves in that direction because, at the moment, as I said, it is quite ridiculous in any sense that we have national policy that should be implemented when it is difficult to understand how it is progressing and what the barriers to progress are because you do not have basic information about the capacity of the service to deliver. We need that information at a national level on the workforce. Indeed, there is established guidance from professional bodies, including our own, on what those kinds of numbers should be.

Lindsay Whittle: Is there any evidence of spend-to-save schemes being used for diabetes nurses? I do not know why I am even asking this, because I do not approve of the
agency nurses, I am afraid. Nonetheless, is there any evidence that agency nurses are being used for diabetic treatments?

[179] **Ms Turnbull:** We are not aware of any of that. We came across some very innovative schemes whereby pharmaceutical companies were investing in specialist nursing posts. That is perhaps one example of an innovative type of scheme.

[180] **Ms Davis-Job:** Agency nursing may be too short term for what you would need a specialist nurse to do. Going back to the number of nurses, I think that it would be better to look at a per-population figure than a per-bed figure, because the brilliant thing about specialist nurses is that they can span primary and secondary care and fit where the patient’s need is best met.

[181] **Darren Millar:** My questions follow on from that. First of all, however, I congratulate the RCN on the excellent awards evening last night. I was pleased to be able to attend that; I was very impressed. I hope that it will become an annual event.

[182] I want to ask about the balance of specialist nurses between primary and secondary care. We have heard from a previous witness that there should perhaps be a greater focus in the community rather than through secondary care. What is access to a specialist nurse like for a diabetic patient in the community? Is that an easy thing? Are there parts of Wales where there is particularly good coverage and other parts where there is poor coverage? Perhaps you could just tell us a little bit about that.

[183] **Ms Davis-Job:** It is a bit hit-and-miss across Wales. Some areas have really excellent support, but other areas are not so well supported.

[184] **Darren Millar:** Where would you point to as a good example of good access for patients to specialist diabetic nurses? Is it better in the north, the west or in mid Wales, for example?

[185] **Ms Davis-Job:** It is difficult really to name names. However, if you look at the ThinkGlucose campaign, north Wales and Cwm Taf have really embraced that service. They have put extra specialist nurses in there as educators, to educate professional staff, not patients. The benefits of that are massive.

[186] **Darren Millar:** In terms of the ratios, you have suggested that it ought to be on a population basis. What sort of ratios are we looking at in terms of the RCN’s recommendation for the number of specialist nursing posts in Wales?

[187] **Ms Davis-Job:** We think that one nurse per 50,000 of population is probably a good recommendation.

[188] **Darren Millar:** What do we have at the moment?

[189] **Ms Turnbull:** To be honest, we are not in a position to give you a national figure, and I think that that speaks of the lack of data. In preparing for this committee meeting, we spoke to a number of organisations. We spoke to each of the LHBs, and we spoke to members working in the field from different LHBs. So, we spoke to a wide variety of people to gather the evidence, but it was very difficult to come up with a national figure. I suspect that Assembly Members have had the same experience in that, if you ask a question about the numbers of specialist nurses in any field, you will invariably get the reply that these data are not held centrally. That is obviously a problem for us as the Royal College of Nursing, as much as it is for you. Unless you have the time and the capacity to do an extremely detailed freedom of information request, it is very hard to get these numbers. To return to my earlier
point, I do not see any benefit in hiding these numbers and I see a great deal of benefit in making the position clearer. We can then see where there are areas of good practice and where there are gaps in the service. So, I regret that we are unable to give you a definitive answer on that.

[190] **Ms Davis-Job:** I would like to add one point. Although we cannot give specific numbers, we know that the numbers have gone down, in general, but the number of patients with diabetes has risen.

[191] **Ms Turnbull:** We often become aware of a situation where, perhaps not necessarily a member but a well-known nurse in the field—a specialist nurse or a consultant nurse—has left or moved to another post and not been replaced. That is how we become aware that there has been a fall in numbers.

[192] **Mark Drakeford:** Rebecca and Kirsty both have points on this particular issue.

[193] **Rebecca Evans:** Do you think that the figure of one DSN to 50,000 people might be a bit too crude in the sense that certain communities have a higher prevalence of diabetes than others and it could mean that some areas are under-resourced and others might have too much capacity? Is that potentially a problem?

[194] **Ms Turnbull:** I agree with that. It is an important point. What we were talking about is guidance on numbers and supplying information about what people have so that you can then ask those questions. There may very well be extremely good reasons for any kind of deviation and discrepancy. It may be that a slightly different service is needed to respond to local need. So, variation in itself is not necessarily a bad thing, but having some kind of picture enables you to understand why there is variance and whether there is a good reason for it.

[195] **Rebecca Evans:** So, it is more about guidance rather than being very prescriptive.

[196] **Ms Turnbull:** Yes, exactly.

[197] **Kirsty Williams:** I would like to go back to the point you made regarding the fact that the number of posts has been dropping. In the evidence we heard from previous witnesses this morning, they identified the same phenomenon and said that those posts started dropping away about four years ago. Does that chime with your experience? Given the difficulty of trying to find figures, do you have any idea about what the numbers looked like four years ago? Do you have an idea of how many posts have been lost?

[198] **Ms Turnbull:** I would not like to give a figure. I am happy to go away and perhaps try to make some more enquiries on this, but I think it would be very difficult to come up with a definitive figure. However, I agree with you about the timescale. As I said, we have seen this happen not just in the field of diabetes; it is, unfortunately, a general trend with specialist high-level nurses. For all such posts, over the past two or three years, we have been contacted much more regularly by people who have serious concerns about this.

[199] **Kirsty Williams:** If we are talking about this beginning to happen four years ago, which is what the last witnesses said, that was before we saw some really acute issues in terms of public expenditure. So, is this purely down to money or is there a political decision to move away from the concept of specialist nurses? If it is not just happening in relation to diabetes but with other specialist nursing posts, is it solely about the cost or is it because a political decision has been made somewhere that that is not the way we want nursing to go and that we want to move back to more generic posts?
Ms Turnbull: I would not necessarily say ‘political’, but we have always, at the Royal College of Nursing, had some concerns that Wales in general needs to embrace specialist nurses and nurse-consultant posts more forcefully. We have had that concern for quite a number of years. Even longer ago than four years ago—around 10 years ago—we felt that we were not as advanced as England in grasping the opportunities that developing these career pathways and these advanced posts could bring. So, I would agree that there is, perhaps, an issue in terms of the NHS in Wales and that it does not, perhaps, really understand the benefits and is not committed to them.

11.15 a.m.

Of course, when we talk about nurses, we are not talking about the same level of remuneration as medical colleagues have, but there is a tendency to look at band 7 or band 6 as being a potential short-term financial saving by getting rid of those and having a band 5 nurse or whatever. That is a dangerous path to go down because it is those higher level nurses in any field—in diabetes, it is very important—who provide the education for other colleagues, for professionals who will champion an issue in the hospital environment or community environment, or provide patient education. Those posts are fundamental.

Kirsty Williams: So, perhaps what we are looking at is the fact that there was a reluctance to embrace the concept early on, so we were starting at a lower base. When the financial pressures become more acute, it is like a perfect storm—we had less in the first place, the financial pressures kick in and we see these big drops.

Ms Turnbull: Yes.

Mick Antoniw: What is your understanding of the role played by specialist nurses in the LHB diabetes planning and delivery groups? What is happening at that level?

Ms Turnbull: I am happy to go back and ask that specific question.

Mark Drakeford: Would you expect them normally to be members of those groups?

Ms Davis-Job: Yes, I think that they are, but if their time is stretched, they are taken away from their clinical case loads and their clinics to attend those groups. I am also not sure whether they would be in a powerful position to make changes at a very senior level if they were the specialist nurse.

Mick Antoniw: Are you aware of any specific change in the role of specialist nurses at that level since 2009 or since the loss of the clinical lead?

Ms Turnbull: We can go away and have a look at that. We have colleagues who would be in a position to answer that question.

Mick Antoniw: Has the quality of training for specialist nurses and non-specialist nurses changed at all because it is an increasingly important part of core knowledge? Has there been much development or change in the quality of that training over the past few years?

Ms Turnbull: We can certainly measure that there has been a drop in the quantity of continuous professional development training provided to generalist nurses. We know from quite extensive surveys that it is at much lower levels—it has always been at lower levels—than that afforded to nurses in the NHS in England, so we started from a lower base, and that has declined. Part of the issue is around the financial pressure, not due to the cost of the training, but if you put nurses on a course, even for an hour, you obviously need to back-fill
their posts, especially in the hospital environment. We know that there is a problem in general with access for nurses to continuous professional development.

[212] Mick Antoniw: Do you have a specific view on training for the diabetes strategic framework and future strategies?

[213] Ms Turnbull: We would recommend that education for healthcare professionals, including nurses specifically, should be a goal or a target—whatever language you want to use; it should be something that is done. It is important in order to recognise nurses explicitly, because nurses, unlike colleagues, have no guarantee of continuous professional development within their contract, so they are often unable to access that. They are also within different environments too. Another example would be to look at what access to education and new resources practice nurses and healthcare support workers in primary care have. The LHB should be able to answer that question and say, ‘We are aware that this is our population of practice nurses and healthcare support workers; we are aware that these people are specialists and have been educated to a certain level’. They should be able to answer that question and also say what they are doing, because we are concerned that that population of nurses and nursing staff is not gaining access to that kind of education.

[214] Mick Antoniw: Do you have a specific concern about the quality or content of the diabetes training that currently exists, or do you have a particular recommendation about that specifically?

[215] Ms Davis-Job: It is patchy across Wales, and if you look at the two health boards in particular that have embraced the ThinkGlucose campaign, it would be excellent if the 1000 Lives Plus people were to embrace that and we could have general nurses using that campaign in the same way that they have used the hand washing or the sepsis campaigns, which have gone really well. Within ThinkGlucose, they have a box, so if your patient has low blood sugar you know where to get that box to rectify the problem in a similar way that you would know for a cardiac arrest—you would know where to get the cardiac arrest box. Visual things like that really make a difference to patient care.

[216] Mark Drakeford: We have heard a lot of evidence during this short inquiry about structured patient education. We have heard a couple of times this morning from earlier witnesses some very positive things about the part that nurses have to play in making patient education effective. Thinking ahead, if we were to make any recommendations with regard to the patient education field, where do you think we ought to concentrate our recommendations and what part do you think nurses in particular might be able to play in making patient education more generally available and more likely to be taken up by patients in future?

[217] Ms Turnbull: One issue specifically around nursing is capacity. If you do not have the right numbers of nurses at that level, then you do not have the capacity to deliver patient education, so it relates to that and that is one area that should not be neglected. When we looked into patient education, we were very much of the opinion that it should be offered to everybody and we are concerned that it is not. When we looked into this, we were trying to investigate what the barriers were and we had some opinions that the cost of the programme was discouraging LHBs from taking it up. We had some comments that they did not have the capacity to deliver and, therefore, they did not want to take up the programme. It was interesting; there seemed to be different perspectives from the people we spoke to about what the barriers actually were that were preventing the LHBs from taking up either a specific programme or an alternative that would have to be validated to the same level of quality.

[218] We have said in this paper that we would urge the committee to ask more specific questions of the LHBs and understand from them why they feel they are not delivering this programme. We are not clear what the barriers are, but we would certainly be looking to say
that all newly diagnosed patients should certainly, as a matter of course, be given support and access. We are quite concerned, going back to my point about primary care, that the experience of patients varies quite dramatically between surgeries as to what they are offered or not offered.

[219] Mark Drakeford: We have also heard evidence that even when programmes are available, and are offered at primary care level, the take-up of them by patients is also very variable. Do you have any thoughts, from a nursing perspective, as to how that offer might be made in the future in a way that is more likely to get people to respond?

[220] Ms Turnbull: You raised an interesting point earlier about the expectation and how it is offered. Patients need to understand that it is almost a prescription—just as a particular drug might be beneficial to them, this programme will be beneficial to them—rather than just being told, ‘Oh yes, and you could also do this’. The way in which the offer is made makes a difference. That also relates to the education of the person who is making the offer: if they know the course and understand the benefits and the education, they will obviously be more positive about it in the way in which they discuss it. The nurse is key to this, because it is the nurse, or sometimes the healthcare support worker, who has that face-to-face contact with the patient. If they do not know anything more than the fact that it is available, then, with the best will in the world, they will perhaps not be as able to convey the benefits of that programme to the person to whom they speak. Those are two relevant points that would impact on uptake.

[221] Ms Davis-Job: Also, it needs to be tailored to the needs of the patient because families with children with diabetes may need a different structured education approach from someone who has discovered they have diabetes because they are pregnant or elderly people who might have other comorbidities such as difficulties with hearing and vision. It all impacts on the delivery of structured education.

[222] Mark Drakeford: That is very useful; thank you for those points. Does anyone have any further questions? I see that you do not.

[223] Lisa, I think that there were a couple of points as we went along when you said that if you were able to find any further information, you would send it to us. It may not be available, but if it were to be and you could, that would be helpful.

[224] Ms Turnbull: I will let you know. May I make a quick point on the earlier discussion on the review of the retinopathy service? We have concerns that the review might pose a risk to the capacity of the service to deliver and we wanted to put on record that we do have concerns about that and would welcome the committee’s continued involvement in looking at that review.

[225] Mark Drakeford: Thank you for that. As I say to all other witnesses, after the session is over, if you have any further thoughts on the key recommendations that we should make for the next period of diabetes services, we would be keen to hear those. They may already be represented in your evidence and as we have progressed with our inquiry, we have probably become clearer about what those are likely to be, but if any supplementary points occurred to you, we would be grateful to receive those. Thank you for your evidence.

[226] As we wait for our next witnesses, I was reminded of an issue that I would like to share with Members because the RCN contacted me about this in the first place. It is concerned about some changes that are proposed by the Welsh Government to how some health statistics are to be published in the future. There is a consultation going on at the moment about moving some data that are currently published under the umbrella of the statistics service to be published under ‘management information’. There may be good reasons for that and it may not mean any diminution in the level of publicly available
information, but I felt that on behalf of the committee, I should write to the Government, stating that we would be concerned if the change meant that the information that is currently available as a right to the public will, in future, became available on a discretionary ‘if-we-choose-to-let-you-know-it’ basis. So, I will circulate a letter for you to see and if you are happy with it, we will send that off.

We will press on with our final session in our inquiry into the implementation of the national service framework for diabetes and also into future developments. I thank the current witnesses. We are all familiar with them, but I would like to welcome David Sissling, Director General of Health, Social Services and Children for the Welsh Government, and Dr Chris Jones, Medical Director of NHS Wales and Deputy Chief Medical Officer for the Welsh Government. Thanks to both of you for attending this morning. Who wants to start off?

If you would like to make any brief introductory remarks, that would be fine. We will then go into questions. We have already received your written paper.

Mr Sissling: I have a few brief comments to make. First, thank you for the opportunity to offer evidence and respond to your inquiry on the prevention and treatment of diabetes. I am sure that the committee is aware of the scale of the issue—160,000 people are living with diabetes and that number is increasing by 7,000 each year. We think that there is a significant number—60,000 plus—of undiagnosed diabetes cases across Wales. So, it is a very significant issue, and the Minister has positioned it as a clear priority for the Welsh Government and the NHS.

11.30 a.m.

One of the immediate consequences of that is the development of a diabetes delivery plan, which will be out for consultation in the next month, with much stronger national implementation arrangements that connect to local implementation systems, building on achievements—of which there are examples—while acknowledging some gaps in the services that are currently in place. However, we think that there are achievements that it is important to acknowledge and build upon. Using 2003, when the NSF was published, as a reference point, we have seen some important developments. The standards have clearly been established and many of the NICE guidelines have been implemented in full. Also, there have been some very significant and impressive developments in our participation in audit, with some good results. I will briefly mention some of those. All LHBs now have diabetes planning and delivery groups, clinical leadership and local diabetes delivery plans, and all LHBs are reporting progress. For example, all have structured education programmes for type 1 and type 2 diabetes. There are care models in place, with people who have diabetes offered an annual review based on the nine key processes specified for the national diabetes audit. There is implementation of NICE-compliant assessment of care pathways for the newly diagnosed, and implementation of NICE guidelines for diabetes treatment and management of risk factors and complications. NICE compliant guidelines for in-patient care have been implemented and there is patient education in place for those with foot problems.

Looking at the audit data, because those are important, we are trying to focus increasingly on outcomes. Our research shows that, in terms of the national diabetes audit on
care processes and treatment targets, for example, 60% of patients received all nine key care processes. That is not where we would want it to be, but it is 11% better than the same outcome position for England, where the audit covered some 2 million patients. So, it is 60% for Wales—11% better than England—but 60% is a figure that we would want to improve. A big area of focus for the future is prevention, because we know the risk factors. An enormous amount of attention is given, and will increasingly be given, to healthy lifestyle, diet, drink and smoking. The public health endeavour is really gearing itself up; today, we have seen the publication of the Green Paper on public health, with its opportunity for public health legislation.

Finally, in terms of in-hospital management and the whole-system management of diabetes, there is evidence of significant improvement in our integrated system. Last year, there was a fall of 15% in emergency admissions for patients with diabetes. That is tremendous. The length of stay was reduced by 16%. There was a 30% fall in emergency re-admissions. It appears that we are getting the integrated system working well for this particular condition. Lots of things have been achieved, but we are not complacent. We know that there is more to do, and we know that we need to strengthen, particularly, the implementation arrangements. We know that we can describe good, we are not short of standards, and our emphasis now is to make sure, locally, that there is clear ownership and that, nationally, there is a clear framework that enables swift delivery of all relevant areas to improve care over the next year and beyond.

Mark Drakeford: We will turn to Members for questions. All those that we have heard from are able to point to some places where things have improved. We recognise that completely, but I would not be surprised if, in the questions, we wanted to probe those places where there are still things to be achieved.

Mick Antoniw: I have a couple of questions. We have had a lot of evidence on the issue of ownership and leadership. Where does the ownership of the strategic framework actually lie, and who, effectively, is in charge of ensuring the leadership and co-ordination of that framework and its delivery?

Mr Sissling: I will kick off on that, and it may be that, at various points, Chris Jones will support me. Ownership of delivery of high standards of diabetes care sits with the health boards—they are responsible for the planning and delivery of care. However, we, as the Welsh Government have a very important role in ensuring that the standards, at all points, are monitored and improved, that delivery is monitored and that we provide support and, where appropriate, intervention to allow them to pursue good paths of improvement. We have a self-assessment arrangement that is consistently applied across Wales, whereby they can hold a mirror up to themselves and ensure that they are aware of their own performance levels. We have audit information that provides authoritative information with national rigorous standards that allow us to say how well we are doing compared with those standards and other health systems and, within Wales, against each other. Now, we recognise that we need to strengthen some of the national approaches, which is why, in the context of the new delivery plan, we are setting up an implementation group with national leadership, chief executive leadership and all clinical leads, which will report to me to ensure that this priority area is accorded the priority that it merits. Chris, do you want to add anything to that?

Dr Jones: Perhaps I can describe the leadership arrangements for diabetes throughout the NHS in Wales. After seven years of monitoring the NSF, the chief executive of the NHS at the time wrote to health boards requiring them to put in place a diabetes planning and delivery group. Each health board has such a group and, generally, they are clinically led, so there are clinical champions for the very large LHB populations throughout Wales. Those are significant leadership roles that should not be underestimated. At a national level, as is the case with all other specialties, we look to the chair of the NSAG as a national lead figure; of
course, he attended the committee in that capacity this morning.

[237] From a Welsh Government perspective, the policy focus for diabetes is held within the chief medical officer’s directorate. I oversee it as a practising clinician, and I am supported in that work by Dr Heather Payne, a senior medical officer for paediatrics and maternity services, and Dr Karen Gully, a senior medical officer covering general practice. So we have quite significant clinical leadership around the issue of diabetes within the Welsh Government and, I believe, a distributed model of leadership through the NHS. Nevertheless, we are seeking to strengthen national-level leadership through the delivery plan, laying out the Welsh Government’s expectations of the NHS. As David mentioned, that plan will put into place a group that I believe will oversee the self-assessments that are routinely being reported to the boards as well as other areas that we know require improvement.

[238] **Mick Antoniw:** During the course of the evidence that we have been receiving, a contrary position has been presented, and there has been quite a high degree of criticism of what has been described by a variety of witnesses as a lack of leadership and co-ordination. Among some of the first evidence that we received was from Diabetes UK. I am sure that you are aware of the nature of the evidence. I will read out some of what was said:

[239] ‘When I read the NSF, I thought that it was a great document and that it was really working. So, where was the problem? The problem came when I tried to work out who was responsible for overseeing the NSF. In England, there was a diabetes lead. In Scotland, there was a diabetes lead. In Wales, there was nobody.’

[240] I will not take you through all of the evidence, but the witness went on to say:

[241] ‘The health boards have been feeding information back to the Welsh Government for some time. It is quite detailed information about their progress in individual health boards and processes et cetera, but they have received little or no feedback since 2009 from the Assembly.’

[242] It seems very clear from the evidence that many of those who are involved in the local delivery boards feel that there has been an absence of leadership since 2009 and that that has had an impact on the quality and consistency of the implementation of the framework. How does that fit in with your analysis?

[243] **Dr Jones:** As David said, the responsibility for the implementation of the NSF and NICE guidance is with the health boards, and the health boards have clinical leads for diabetes. It is true that, in England, there is a national clinical director for diabetes, who works three days a week for the whole of England. However, of course, England does not have professional advisory structures. We have a Welsh medical committee, as we have other professional committees, and the national specialist advisory group is part of that system, so we should appropriately draw on that. I accept that it works better in some specialty areas than in others, but I think that our colleagues in the diabetes NSAG have been genuine partners and will be genuine partners to us moving forwards. I do not feel that we need to replicate the English leadership model, although I think that the NSAGs, their positioning and effectiveness, and the question of national clinical leadership are generally under review. I know that Dr Ruth Hussey has concerns, as well as the responsibility to promote national clinical leadership. We will be discussing that further. However, I think that we do have leadership in the system; it just needs to be strengthened.

[244] **Mr Sissling:** I will add a couple of comments to what is a really important point. Obviously, we look forward to seeing the position of the committee in terms of the advice that it would offer us. We are genuinely interested to hear that. We are not saying that everything has been fine. From 2003 to 2011, it does not appear that we had an arrangement in place that
was working as well as we might have hoped. Our focus now is to put in place arrangements that do work. We are very keen to emphasise health board accountability for the delivery of good-quality care, locally. That seems to be a really important characteristic of a good delivery system.

[245] When I first came to Wales, as chief executive of one of the health boards, it was not awfully clear. There seemed to be an awful lot of traffic on things like this, with multiple-page documents to fill in. We filled them in assiduously, and they were sent back to us, asking us to do it again, but there was not a sense of being held to account— I have to say—to the extent that I would want with health board chief executives and others. We need to make sure that we are looking to patients and outcomes rather than to a bureaucratic process that does not necessarily achieve the outcomes that we would all want. That is why I want it to be much crisper and clearer, so that we position responsibility and standards with health boards, and that we have a very clear arrangement, nationally, with the right people around the table to monitor progress and to connect with accountability arrangements that ensure that we are driving up standards at all points.

[246] Mick Antoniw: So, in terms of all the data that have been fed in since 2009, what has been done with them, and what has been achieved from the use of that information?

[247] Mr Sissling: I am sure that Chris will want to add to this, but we saw the results of the health board self-assessment, which described progress in many areas. If there were areas where there was a lack of progress, or where there were shortcomings, they would become a matter for discussion with the health boards concerned. In terms of audit, we are sending out messages about particular issues to which we need to pay more attention. There is a sense of continuous interaction with the system in terms of the issues that come through from this analysis.

[248] Mick Antoniw: This is my final point. The feedback that we have had from those giving evidence in respect of the local delivery boards is that there has been no feedback since 2009. It is almost a stark absence of any feedback. It caused concern, and we have been given evidence that that, to some extent, has demotivated the boards, because they felt that they were doing a lot of work but that nothing was happening.

[249] Dr Jones: I think that it is true to say that the model of leadership from Welsh Government is evolving with time, and I think that it is right that it does so. The NSF was published in 2003. Clearly, the clinical evidence has changed significantly since then. If we simply monitor the NSF, I think that you would think that a very poor way of developing diabetes care. NICE has published over 100 technology appraisals in the area of diabetes, most of which have been published since the publication of the NSF. We last undertook a formal review of the NSF in 2010. In 2011, we worked with our clinical colleagues to produce the self-assessment, which covers not only the NSF, but also the key measures relating to the NICE guidance that has emerged subsequently. That is a very extensive and comprehensive piece of work, which was given to the health boards last year as a tool for them to facilitate board reporting. There are 230 or so measures, some of which have subdivided measures. That is a level of detail that is clearly more appropriate for a board to monitor than for the Welsh Government to monitor.

[250] Last year, we asked health boards to produce delivery plans for diabetes. We received those and we fed back to health boards what we thought of those delivery plans so that they could refine them. So, there has been ongoing interaction. The model of leadership has changed appropriately as the evidence and the clinical guidance has changed. It will now change again as we put in place the delivery group.

[251] Mark Drakeford: Kirsty is next, Vaughan has a point on the stuff that we have been
talking about already, and then I will move on to Darren.

11.45 a.m.

[252] **Kirsty Williams**: The current Minister for Health and Social Services and the Welsh Government have consistently said, since coming into office, that the NSF would be fully implemented by 2013. In paragraph 29 of your paper, you restate that that is the Government’s aim. We are almost at 2013 and every single witness who has come to this committee, whether representing patient groups, nurses or clinicians, has said that that will not be implemented by 2013. Could you restate whether you believe that it will happen and, if not, what the new targets for implementation will be?

[253] In answer to a written question in October 2010, the Minister said that the new medical director, Dr Chris Jones, has the lead responsibility for ensuring the delivery of effective diabetes services by local health boards. Dr Jones, could you explain what you have been doing in the two years since that statement was made by the Minister for health to fulfil that lead responsibility?

[254] You paid a great deal of attention just now to the NSAG and its role. The NSAG said this morning that when the previous diabetes lead left post back in 2009, it made recommendations to the Welsh Government, and has continued to make recommendations, on the importance of replacing that post. It was unable to give a reason today why the Welsh Government had decided not to do that and suggested that we ask you that question. So, could you explain to us why the advice from the NSAG, which you have just said had the lead for taking things forward, was ignored at the time and has continued not to be taken up?

[255] **Dr Jones**: The NSF has been monitored significantly since it was published and, as David said, there has been a great deal of improvement in all aspects of diabetes services. So, although I accept entirely that there are still some areas that have not been fully implemented, there has been an enormous improvement across public health, primary care and lots of elements of hospital-based services as well. It is true that there are still some areas that are marked red on the scorecard. Some of those are matters of process, which I presume the health boards have not thought to be all that important. Some, however, relate to a central question around information. I think that the NSAG will have told you about the Scottish patient management information system, which will facilitate a number of the areas where, currently, we are scoring red. At the moment, there are red scores against questions such as whether health boards are comparing rates of complications, amputations and those kinds of things. An information system would facilitate turning those areas green. I have instructed NWIS, the informatics service, to implement such a system in Wales. That work is ongoing and I think that it has reported that work to you.

[256] In relation to my role, I think that I have described, to some extent, the work that the Welsh Government has been doing. We have moved from a system of perhaps passive monitoring to a more active system whereby we provide health boards with tools. We have been working to ensure that there is a clinical information system in place and we are also now working to produce a delivery plan, which will strengthen the national leadership arrangements moving forwards.

[257] I cannot remember your last point.

[258] **Kirsty Williams**: In 2009, when the previous diabetic lead left, NSAG advised the Government that there should be a replacement, and it has subsequently gone on to repeat that advice. One of its challenges and recommendations for us is the need for a diabetic lead. Given that NSAG is there to advise the Welsh Government, could you explain why that advice to replace the clinical lead was not followed in 2009 and why, subsequently, when
your own advisory group keeps saying that that is what it needs—and, after all, its members all have day jobs and are all trying to deliver a service to their patients—the Government feels that it is not appropriate to listen to that advice and fill that post?

[259] **Dr Jones:** We certainly do listen to its advice. As I understand it, the role that it feels should be replaced was a two-year secondment—so just two years of the nine years have passed since the NSF. You can judge as a committee what the success of that role has been. I indicated that the positioning of diabetes within the Welsh Government, policy wise, has changed. It is now under significant clinical leadership. I am a practising clinician, and I am a cardiologist by background who is used to talking about blood pressure, cholesterol, type 2 diabetes and these issues. The chief medical officer is also a relevant clinician, and I have mentioned other professional leads who are working in the area also. I do not necessarily recognise the position that it describes within the Welsh Government. It seems to be a different position from that advocated by Diabetes UK, which wants the NHS in Wales to appoint a lead clinician. I think that not sufficient regard is paid to the clinical champion roles in the health boards, because they are significant leadership roles.

[260] **Kirsty Williams:** Could I also just get a simple answer to my first question? The Government says that the NSF will be fully implemented by 2013. Will that happen? A ‘yes’ or a ‘no’ will suffice.

[261] **Mr Sissling:** We are still seeking to do that, yes. On the comments, statements and commitments made in the evidence paper, it would be entirely wrong, at this point, to indicate that we were going to slip that.

[262] **Vaughan Gething:** I want to pick up briefly on this continuing question of leadership, because, in your introduction, you spoke about wanting to ensure that there was greater LHB accountability and you also said that, from your experience, while you provided data and information, you did not feel that you were held to account. You also talked about appropriate intervention from the centre, where that was not happening. The evidence that we have had is that leadership has been dissipated, and the experience that you say you have within Government is not what witnesses are telling us is the reality, from their perspective. Given the uneven delivery by local health boards to date, what do you expect appropriate intervention to look like and why has it not happened up to now? We are nine years into the NSF, and one would have thought that appropriate intervention from the centre would already have happened. I would like to understand why it has not happened, and whether it is down to the nature of the post, but I also want to understand how that will happen in the future, because the danger is that, even if there is an implementation group to provide that strong leadership, unless there is clear role and there are examples of that intervention taking place, we will come back again in two years’ time and say, ‘There’s a group, we don’t know what it has done and everyone keeps on telling us the same message about a lack of effective leadership and intervention’.

[263] **Mr Sissling:** That is a really fair set of points. The implementation group, to an extent, marks a break from the past and, given some of your observations, I suspect that you want to hear that. We will need to put in place more rigorous arrangements, so that it is an implementation group that is firmly positioned on the map of accountability, that reports directly to me in the context of our Minister saying that diabetes is now one of her key priorities, with leadership at chief executive level, and with all clinical leads represented on it, with access to real-time data and the ability to feed through to me—although it cannot intervene itself, as that would be entirely inappropriate—to determine what kind of support, interaction or intervention is needed. It would be wrong and difficult to prescribe exactly what that would be, because it may be to do with the degree of organisational focus and grip on an issue, or more to do with clinical aspects and concerns. So, the extent, the degree and the nature of the intervention would depend on the circumstances that arose, but this would need
to be a fairly swift, smart process to allow that to happen, and to enable us to deploy any support that we would need to offer to individual health boards.

[264] **Vaughan Gething:** So, what has happened up to now? These are not new problems. They have been happening over time, and you are getting all these data coming back telling you what each local health board is doing, so I am interested in why there has not been effective intervention up to now, as well as in how you expect to solve that problem. If you say that you will get it right in future, that is great, but where was the challenge that has not been met in the past? There is already patchy output and delivery by health boards. Some are in far better positions than others, so how do you envisage ensuring that there is a more even upward curve in delivery? Why has that not happened in the past, from your point of view?

[265] **Mr Sissling:** Since the period of 2003 to—

[266] **Vaughan Gething:** Up to now.

[267] **Mr Sissling:** To an extent, some of the earlier responses indicated that it would, first, be right to position 2003 to 2009-10 in the context of the organisational environment, which was clearly a more complex and, at times, changing environment, with commissioners and providers of services. Having, in preparation for this, looked back at some of the data, I know that it was a different kind of interaction. There was interaction with providers and interaction with commissioners, and I think that some of those caused some difficulty, just in identifying where the centre of gravity would be in driving things forward. So, to an extent, that was one of the reasons why there may have been less consistent progress than we want for the future.

[268] The other thing is that, at times, we need to make sure that we have clarity on outcomes, and we are looking at outcomes rather than at processes of collecting information, data and reports. At times, the balance there was wrong. Part of the answer to your question is that, in the current environment that we work in, the organisational environment, there can be absolute clarity about accountabilities and who is responsible. Health boards are responsible for all aspects of planning and delivery, so there is no ambiguity about that, and there is no ambiguity about the standards that we require them to deliver, from the NSF audit requirements and other good practice recommended by NICE. There is a growing understanding in Wales, not just in relation to diabetes, but all areas, of how we can deploy accountability arrangements and how we can make continuous improvement happen through how we collectively hold ourselves and each other to account for the delivery of care.

[269] In summary, for organisational reasons, I do not think that the system was set up to clarify and reinforce accountability sufficiently, and that is what we are doing now. We need to get the balance right. There is a sense at times that the answer is to load the national, the centre, and that the answer is to have a stronger, more muscular centre. There may be some elements of that, but we need to make sure in doing so that we do not in any way displace responsibility from the health boards that are set up to deliver care. It is not, in a sense, the traffic—the number of forms that are filled in, and the degree to which we can perpetually see the gradings for how well they are doing—but more that they own the issue, and are therefore in a position to take this forward. That has been the conversation that I have been having with chief executives, and that our Minister has been having with chairs: to make sure that there is this sense of local ownership and responsibility. They should be monitoring themselves. They should be self-disciplined, self-governing organisations, and our role should be to ensure that that is done to a reasonable extent and that they can persuade, convince and reassure us that they are on good paths to improvement.

[270] **Dr Jones:** I feel that, in your question, you have framed this as if it is a problematic area. I have seen some of the evidence that you have received from different groups, and they seem to have emphasised areas of problem without necessarily balancing that against areas of
performance. Allow me to draw your attention again to the national diabetes audit that was recently published. This is the world’s largest clinical audit, and it has encompassed 85,000 patients with diabetes in Wales and over 2 million in England. Wales is performing significantly better than England. Now, 60% receiving all nine essential care processes is perhaps not good enough, and I would accept that, but this is highly evidence based, based on NICE clinical guidance, and we are doing significantly better than England.

The same, to a lesser extent, was seen in the paediatric diabetes audit, as well, where there was again a slightly lower rate of uncontrolled diabetes in Wales than in England, and consequently a slightly lower rate of hospital admissions with diabetic ketoacidosis. So, although there are problems and it is not perfect, this is not necessarily an area where you would trigger intervention first off, because there is actually evidence of significantly good performance in Wales.

Mark Drakeford: I will go to Darren and Elin next, but first I want to ask you one specific question. In relation to the work that is going into developing and preparing the new delivery plan, and in the new implementation group, is the pharmacy profession involved and represented?

Dr Jones: Yes.

Darren Millar: I have to say that I am quite surprised by the constant references to, ‘We are better than England’. We are obviously here to look at the system in Wales today. There is no doubt that there have been improvements, and I think that everybody accepts that, but we are a long way off where we need to be, certainly when it comes to achieving what we want to achieve in diabetes care.

12.00 p.m.

May I turn our attention to public health? I know that, today, the Minister has issued a consultation document to see whether there is a need for a public health Bill, and one of the issues that has been drawn to the committee’s attention is this issue of the need to prevent diabetes complications, which can of course be very expensive to the NHS to resolve. If there is more investment upfront, prevention is obviously better than cure.

You have listed in your paper quite a number of actions on public health that the Welsh Government has been undertaking: the all-Wales obesity pathway, the Change4Life campaign, et cetera. Can you tell us how you measure the impact of those actions at an all-Wales level?

Dr Jones: The reason I mentioned England is simply that national clinical audit provides an opportunity to benchmark against large numbers of outcomes, so that you have a very reliable comparative—that is what clinical audit is about. The national clinical audit for diabetes is an England-and-Wales audit, and it is presented as English data and Welsh data, and it is presented in the way I described it to you. It is not that I have a thing about England; it is just that that is the benchmarking environment in which we work, I am sorry.

Darren Millar: It is just that it is obviously important to benchmark local health board areas against each other, and we have heard that there is a dearth of data on that in Wales, or that they are not necessarily easily available for people to access.

Dr Jones: Before returning to your central question, the national diabetes audit does show variation in data by health board in Wales.

Darren Millar: So, those data are easily available and easily accessible, and people
know where they can pull their socks up et cetera.

[281] **Dr Jones:** Yes, I can give you individual health board data, and there is variation.

[282] **Darren Millar:** Okay. The other frustrating thing has been this constant batting things back to health boards all the time, saying that they have to be accountable—and they certainly have—when, ultimately, the responsibility lies with you two gentlemen at the end of the table and the Minister for the implementation of these things.

[283] Getting back to public health, where are we with that and how do you measure the outcomes? Do you see diabetes as being a feature of any new public health Bill that might be on the table?

[284] **Dr Jones:** Yes. Clearly, the public health agenda in relation to diabetes is absolutely crucial. Type 2 diabetes, as you know, accounts for 90% of all patients with diabetes; it is caused by obesity and is an avoidable condition. We have seen some progress in Wales, in the sense that the rate of increase in obesity has slowed, but that is not good enough; we still have a relatively overweight and obese population, but one understands that. There are a number of different programmes in place to attempt to address that, starting at school age and working through communities, and they are all evaluated for the way they work for the people who attend and for some of the uptake of information. In the end, the outcome is the rate of obesity and the rate of diabetes.

[285] As you know, we are refreshing our thinking around the whole public health agenda at present. Dr Ruth Hussey is our very senior lead for public health, and she thinks that it is very important to address the issue of obesity, looking very much at the causes of the lifestyle behaviours that contribute to it. There may be a role for legislation in this, and that is also the essence of the White Paper that is about to be released for consultation on whether there should be legislation in this area.

[286] This morning, the Minister met colleagues from the Welsh medical committee who have also been talking very much about the need to do more about the issue of obesity. The Minister has written to the UK Government to express her support for controls of some sort around different foodstuffs. Again, we really need to work at the societal drivers to change some of the lifestyle behaviours that we know are so damaging.

[287] **Darren Millar:** With regard to the evaluation of some of the schemes that have already been undertaken, I appreciate that there have been a number of schemes, some of which, anecdotally, appear to have been successful. What hard evaluation tools do you use to determine whether something has been successful or not as successful as might have been hoped for?

[288] **Mr Sissling:** For any programme or intervention that is set up, part of the design has to be a means of evaluating its impact and effectiveness. In some areas—as you know, we were discussing another setting earlier this week—the impact might be over a number of years as regards preventative aspects, so we have to look at proxy measures for process issues or input issues with regard to, say, the take-up of particular areas. There are also the issues of difficulty in attribution of input to output over a number of times. So, the key is to make sure that, at any point, we are guided by evidence, because many of these have been tested in other settings, and we make sure that we apply interventions and programmes that have some track record of success so that we have some degree of assurance. We measure them in terms of the best available measures in the short term, but, clearly, the real measure over a number of months or years is, for example, the impact on weight, obesity, or diet and how that feeds straight back into issues such as the level of diabetes across Wales. However, it is quite a complex area. It would be lovely to say, ‘Here is input A, and we are monitoring graph B
from day one’, but it is more complicated than that.

[289] Darren Millar: I appreciate that. It is obviously very difficult to embark upon a programme that will take 10 or 20 years to pay dividends and to bear fruit. To what extent will public health feature within the delivery plan that is being developed? Are you hoping to introduce new programmes, for example?

[290] Dr Jones: The delivery plan, in fact, delivery plans in general, represent something of a shift of approach at Government level away from micromanaging 230 process-related measures of clinical services, where health boards should be doing that, to a much more population-outcome-based approach. In the end, we know that we can implement service standards and not necessarily get out the best patient experience or the best patient or population outcome. We know that we need to start with the outcomes that we need as a Government. So, the delivery plan is based around, first, identifying the very high level population outcome and then how you might measure that through outcome indicators and then consider what contribution certain services can make to that population outcome. We know, particularly in the case of diabetes, that preventing diabetes is absolutely crucial—possibly more important than anything else. So, that will figure very strongly in the delivery plan, as it would appropriately do based on this population approach.

[291] Darren Millar: Obviously, early diagnosis is an important part of prevention in terms of problems as well. To what extent will that be featuring in the delivery plan? I assume that there will be quite an emphasis on it.

[292] Dr Jones: Yes. All of the delivery plans recognise the need for prompt diagnosis. We know that, in the case of type 2 diabetes in particular, there are probably tens of thousands of people in Wales with type 2 diabetes who do not currently know they have it, and so they are not getting the best secondary prevention to avoid complications. So, that will feature in the delivery plan, as it does in other delivery plans.

[293] Darren Millar: There will be an opportunity, I suspect, in the over-50s annual health checks to screen in some way for diabetes or to determine some indicators of diabetes. Is that something that you are planning to feature within the over-50s health checks?

[294] Dr Jones: Yes. I do not lead on that area of work, but I know that diabetes and obesity are very important. There may well be some kind of mechanism to identify somebody who has an annual review who is obese and clearly at an increased risk of diabetes and ensure that they then get the blood test.

[295] Elin Jones: I want to ask you two questions. The first is on the Public Services Ombudsman for Wales’s report on the complaint against Hywel Dda Local Health Board. The Minister said in, I think, June that her expectation was that the health boards would fully implement the recommendations of that report and that officials would be monitoring this very closely. Six months have passed since then. Can you give us any confidence that all health boards are now implementing the recommendations of the ombudsman’s report?

[296] Secondly, on the audit and the figure that you have shared with us this morning of 60% of people having their nine checks, we have heard excellent evidence this morning and we have all been very impressed with the retinopathy screening, which is showing a figure of 85% plus. Other areas are not doing as well as that. Are there any particular areas in relation to those nine checks that cause you concern and that do not allow us to get 85% for everybody? In my experience in Ceredigion, the podiatry service within the NHS is particularly concerning to some constituents. So, I want you to tell us how you will shift from the 60% to the 85%, at least, that retinopathy is reaching.
[297] Dr Jones: The ombudsman’s report made for terrible reading; we all felt very upset that that process had happened for that patient. I know that David wrote to all the health boards to draw their attention to the recommendations from the ombudsman. We know from the work that we have done over the years that each health board has guidelines in place for the in-patient care of people with diabetes.

[298] We also know about the ThinkGlucose initiative from the NHS Institute for Innovation and Improvement in England, which has been rolled out in Cwm Taf health board area with the same types of benefits seen in many NHS trusts in England. It is a matter for health boards as to whether they implement that initiative, but we would be very strongly supportive of their decision to do so; I do not think that we should tell them to do so, but I think that it makes obvious sense. So, we are clearly concerned that standards of in-patient care for all patients are at the highest level.

[299] With regard to the nine care processes, the national diabetes audit indicates that some of the measures are more consistently applied than others. Basically, five of the measures relate to risk factors—I am taking a risk by trying to mention them, but I think that they are obesity, blood pressure, cholesterol, glucose and urinary microalbuminuria, or very small protein molecules in the urine. There are four measures relating to early detection of complications, namely eye photography, foot pulse checking, a urinary test of protein size and leakage through kidneys and a blood test of kidney function. The areas where there is greatest variability are generally in those latter four—particularly eye photographs and foot pulse checking, as you have indicated. The conclusions of the national diabetes audit are that if we were more consistent in those areas, we would make a step-change improvement from 60% upwards.

[300] Mr Sissling: In response to the ombudsman’s report, it is a good example of how we will make sure that standards are driven up when we know that there is a departure from or variation against good practice. The specific area where the case occurred was Hywel Dda Local Health Board area, so it has been subject to appropriate intervention and support. In terms of an action plan, Health Inspectorate Wales has been deployed to monitor progress and to provide a very clear, impartial and authoritative point of perspective on whether things are going right and whether the health board is on track to improve those areas that were seen to have shortcomings. On a system level, we could, for example, make sure that we have the right arrangements to enable progress. Our inspectorate comes onto the field of play when we know that there is a problem. It is also developing arrangements to monitor all LHBs, because we felt that this was so significant that we needed to make sure that there was a rigour of approach across the board.

[301] To go back to questions about how we will make sure that there is accountable delivery of improved services, it is these kinds of things that we will do. That is quite sharp and quite specific. It is a different approach to the one we previously took. It is saying, ‘Here is an issue, let’s make sure we get this right and let’s not try to address 300 different indicators; we’re looking at very specific areas, let’s make sure they’re right and let’s use our inspector to shine a light on them and make sure that there is sufficient progress on a timely basis’.

[302] Elin Jones: Thank you for your response. I was pleased that you mentioned the ThinkGlucose campaign. We had evidence from the diabetes clinical lead of Aneurin Bevan Local Health Board that he would want to see the ThinkGlucose campaign being rolled out throughout the Aneurin Bevan LHB area but that financial constraints led to that not being possible at present. You said in your response that you did not think that it was the role of national leadership to tell local health boards that they should be implementing the ThinkGlucose programme. I am not sure whether I agree with you on that, but it would be for national leadership to ask local health boards ‘Why not?’.
Mr Sissling: I completely concur with that. What goes with local ownership is an ability to describe decisions in a very clear way. If there are decisions at any point to depart from what might be seen as the optimal path forward—there is a difference between the optimum and just the bottom line of acceptable, which is a slightly different issue—then there needs to be a clear explanation as to why those decisions have been taken. That seems to be entirely reasonable, so I would completely concur with the thrust of the question.

12.15 p.m.

Elin Jones: So, you would do that.

Mr Sissling: Yes.

Mark Drakeford: To return to the point that Elin raised, we have heard very strong evidence on diabetic retinopathy. Concerns have also been raised with us about podiatry and whether podiatry services are sufficiently strong to be able to deal with the very serious issues that that gives rise to in relation to diabetes. Are we right to be concerned?

Dr Jones: I do not profess to great expertise on podiatry services across Wales. I do know that management of the feet is very important in diabetes. A foot pulse check, as in this audit, is required on an annual basis for everybody in the community with diabetes. I also know that that is a requirement within 24 hours of going into hospital if you have diabetes, and that that does not always happen. I am not sure that always needs to be done by a podiatrist. Clearly however, once foot problems, complications and infections arise, then podiatrists, I am sure, offer expertise that others cannot. In some health boards, I understand that questions are being raised about podiatry, because it is distributed on many sites and perhaps, therefore, not working with the critical mass that it otherwise might, but I am afraid that I do not know about levels of podiatry care in all the health boards.

Mark Drakeford: Maybe it would be helpful from the committee’s point of view if, after today, you are able to reflect on that for us. We have seen evidence that the services are not there in the place and at the time that they are needed in order to prevent further complications that then become much more expensive for the health service and much worse for the individual. It would be interesting to know what the Welsh Government’s view of that would be.

Darren Millar: I just want to draw attention to the statistic in the national diabetes in-patient audit, which suggested that only 13.3% of patients included in the audit documented a foot examination at any time during their hospital stay, let alone within the first 24 hours. It would be interesting to see whether there is significant variation between health boards on that. I am sure the information is available somewhere, but it would be interesting to see it.

Dr Jones: That is the type of issue that I would expect the clinical champion—the chair of the delivery group for each health board—to be addressing with urgency.

Darren Millar: With you in the leadership role, it would be important for you to stress that. Have you stressed that to them?

Dr Jones: Whenever any national clinical audit is published, we look very carefully to see what the lessons are for Wales and we write to health boards, the medical directors and chief executives to point out areas where they need to pay attention. We do that and we will have done that after the in-patient audit. Professor Jean White, as the nurse director, and I do that jointly.
Darren Millar: I see. Thank you.

Lynne Neagle: Just to go back to ThinkGlucose, which is a bit of a bugbear, I think, if we know that it works, and if in other areas we are monitoring the implementation of the ombudsman’s report, because the lessons were so very serious, why is it not right for Welsh Government to tell the health boards, ‘We think it would be a good idea if you did this’?

Dr Jones: I think that the Welsh Government expects the highest standard of inpatient care and it is up to the health boards to consider how they deliver that. There is an educational component to ThinkGlucose that they may feel they can deliver locally through their own mechanisms. There is a tool that facilitates the regular monitoring of blood glucose and, if they feel they can make sure that blood glucose is monitored as it should be by a different means, that is their business. ThinkGlucose is a supportive and supported tool that other organisations have found helpful, but they may feel that they can manage this without it. However, we expect them to provide the highest standards of care.

Darren Millar: The key feature of the ThinkGlucose campaign appears to be the availability on each ward of the kit in order to be able to use it if someone has a hypoglycaemic episode. Is not even a simple recommendation or piece of guidance about that something which you may consider issuing an instruction on?

Mr Sissling: That is a good point and I can understand the thrust of the question. There is an outcome and it relates to how that is delivered. It is entirely reasonable that we should be unambiguous in saying that there should be adequate arrangements on wards and in appropriate settings to monitor blood glucose. That is important. How that is done is, to an extent, a local decision. If it is not done, we then have to be searching and hold to account, but if there are standards that are established, we need to ensure that the health boards are clear about the minimum requirements. How they do it and the means to that end would be for them to decide, although, quite often, it makes sense for them to do it collectively in a consistent way rather than have six or seven variant approaches to it. So, it is important to say that we will focus on outcomes and things such as that. The issue that you raised is an important area and we need to ensure that we are clear about our expectations to health boards in terms of how they manage this particular area of care.

Lynne Neagle: In relation to the health boards that are not implementing this, are you confident that they are undertaking the monitoring of blood sugar levels, which you just described, and are treating it appropriately in all of those areas where there is not the ThinkGlucose campaign? Are you absolutely confident that that is happening?

Dr Jones: That is their responsibility. If they are failing to do that and harm is occurring, we will know about it and we will hold them to account on that basis. That is their responsibility and we expect them to deliver excellent care.

Kirsty Williams: May I just go back one question? It occurred to me, while we were talking about the ThinkGlucose campaign, that there seems to be a massive disconnect between what we have heard from the local health board clinicians about a lack of feedback from Welsh Government, and the fact that Dr Jones and Mr Sissling seem to spend a lot of their time writing to these health boards about what they are supposed to be doing as a result of ombudsman’s reports or of audits. Is it possible to see the letters that you wrote to the health boards as a result of the audit, because I would be interested to see what you said to them? They keep telling us that, ‘We send all this stuff, but we never hear from them. How are we supposed to know what we are to do?’ However, you are obviously spending a huge amount of your time writing to these people. I would be specifically interested in seeing the letters that followed the audit and what you said to individual health boards about where they
needed to improve. Is it possible to have those?

[321] **Dr Jones:** Yes. It is fair to say that we do not write to health boards all the time, but we have written to them on diabetes. That is an area where we have, on occasion, had reason to write to them as described. We can certainly share the letters in relation to those audits.

[322] **Kirsty Williams:** That would help me to try to get my head around this lack of feedback that we have been told about.

[323] **Mark Drakeford:** I have one last question. We fully accept that there have been some significant improvements and we have heard that from all of the witnesses. However, one area where I do not think that anyone has suggested that there has been anything other than quite a significant gap is structured patient education. The paper that we have from the Welsh Government today says that, in future, structured patient education should be made available to all people with diabetes at the time of the initial diagnosis and then as required on an ongoing basis based on formal, regular assessment of need. What confidence can we have that the new delivery plan and its new implementation group will move that on from being an aspiration, which everyone whom we have seen shares, to improved services on the ground?

[324] **Dr Jones:** This clearly has been a disappointing area so many years after the publication of the NSF and of the reaffirmed NICE guidance in 2006. When we were monitoring the NSF, we were told that it was in place for type 1 and type 2 diabetes. Once we introduced the self-assessment, which was more quantitative, we learned that the organisations were reporting very low rates in some cases. There is clearly huge variation. For example, Abertawe Bro Morgannwg University Local Health Board reports that 50% to 75% of patients with diabetes get structured education; others report less than 5%. So, this area concerns us, because it is subject to a NICE technology appraisal. The NHS is supposed to take on board the recommendations from technology appraisals. They are highly evidence-based and will save money in the long term. That is one reason why the delivery group will have, as one of its outputs, the responsibility to ensure that that is now implemented properly. Having said that, it is one of 112 technology appraisals in relation to diabetes, and the vast majority of the others are fully implemented in NHS Wales.

[325] **Mark Drakeford:** Diolch yn fawr am y dystiolaeth y bo re yma a diolch am ein helpu yn ein hymchwiliad. Rydym wedi dod i ben y sesiwn.

12.25 p.m.

**Cyngwysedd:**

Cynig o dan Reol Sefydlog Rhif 17.17 i Sefydlu Is-bwyllgor i Gymryd Tystiolaeth ar y Rheoliadau Mangreoddd etc. Di-fwg (Cymru) (Diwygio) 2012

Motion under Standing Order No. 17.17 to Establish a Sub-committee to Take Evidence on the Smoke-free Premises etc. (Wales) (Amendment) Regulations 2012

[326] **Mark Drakeford:** Mae gennym un neu ddau beth i’w wneud yn gyflym cyn diwedd y cyfarfod.

[327] **Mark Drakeford:** We have a couple of things to go through before the end of this meeting.

I move that y pwyllgor yn penderfynu, o dan Reol Sefydlog Rhif 17.17, sefydlu is-bwyllgor i the committee resolves, under Standing Order No. 17.17 to establish a sub-
gymryd tystiolaeth ar Reoliadau Mangreoedd etc. Di-fwg (Cymru) (Diwygio) 2012;

mai cyllch gwaith yr is-bwyllgor hwnnw yw
 Gymryd tystiolaeth, ar yr un pryd â’r is-
 bwyllgor a sefydlwyd gan y Pwyllgor Menter a
 Busnes ar Reoliadau Mangreoedd etc. Di-
 fwg (Cymru) (Diwygio) 2012. Bydd yr is-
 bwyllgor yn ceisio cytuno ar gynnwys
 adroddiad a lunnir ar y cyd â’r is-bwyllgor a
 sefydlwyd gan y Pwyllgor Menter a Busnes er
 mwyn llywio trafodaethau’r Cynulliad ar y
 rheoliadau. Bydd yr is-bwyllgor yn cael ei
 ddiddymu unwaith y bydd y Cynulliad wedi
 trafod y rheoliadau yn y Cyfarfod Llawn; a

that the remit of the sub-committee is to hear
 evidence, concurrently with the sub-
 committee established by the Enterprise and
 Business Committee on The Smoke-
 free Premises etc. (Wales) (Amendment)
 Regulations 2012. The sub-committee will
 seek to agree on the content of a joint report
 with the sub-committee established by the
 Enterprise and Business Committee to inform
 the Assembly’s consideration of the
 regulations. The sub-committee will cease to
 exist when the regulations have been
 considered by the Assembly in plenary; and

bod aelodaeth yr is-bwyllgor yn cynnwys
 Mark Drakeford AC, Vaughan Gething AC,
 Elin Jones AC, Darren Millar AC a Lynne
 Neagle AC, gyda Mark Drakeford AC wedi’i
 ethol yn Gadeirydd.

that the membership of the sub-committee
 comprises Mark Drakeford AM, Vaughan
 Gething AM, Elin Jones AM, Darren Millar
 AM, and Lynne Neagle AM, with Mark
 Drakeford AM elected as a Chair.

[328] A yw holl aelodau’r pwyllgor yn
 fodlon ar hynny? Gwelaf eich bod.

Are all committee members content with
 that? I see that you are.

Derbynwyd y cynnig.
Motion agreed.

[329] Y wobr i bob un sydd wedi cael ei
 ethol yw cael gwybod y bydd cyfarfod cyntaf
 yr is-bwyllgor am 8.45 a.m. fore dydd
 Mercher nesaf.

The prize for everybody who has been
 elected is to learn that the first meeting of the
 sub-committee will be at 8.45 a.m. next
 Wednesday morning.

12.27 p.m.

Papurau i’w Nodi
Papers to Note

[330] Mark Drakeford: Y papurau i’w
 nodi yw cofnodion ein cyfarfodydd yn mis
 Tachwedd. A yw pawb yn hapus gyda’r

Mark Drakeford: The papers to note are the
 minutes of the meetings held in November. Is
 everyone happy with the minutes? I see that
 you are. Thank you very much.

Daeth y cyfarfod i ben am 12.27 p.m.
The meeting ended at 12.27 p.m.