HOUSE OF COMMONS

Welsh Affairs Committee

Oral evidence: Cross-border health arrangements between England and Wales, HC 404

Tuesday 16 December 2014

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Written evidence from witnesses:

- Royal College of Physicians
- British Medical Association
- Genetic Alliance UK
- Rarer Cancers Foundation
- Department of Health (supplementary evidence)

Watch the meeting

Members present: David T.C. Davies (Chair); Geraint Davies, Glyn Davies, Jonathan Edwards; Nia Griffith; Simon Hart; Jessica Morden; Mr Mark Williams

Questions 149-296

Witnesses: **Dr Alan Rees RCP**, Vice President for Wales, Royal College of Physicians, **Dr Frank Joseph RCP**, Acute Care Fellow, Royal College of Physicians, **Dr Stephen Kelly**, Welsh Consultants Committee, British Medical Association Wales, and **Dr Peter Horvarth-Howard**, General Practitioners Committee, British Medical Association Wales, gave evidence.

Q149 Chair: Could I first thank Drs Joseph, Rees, Kelly and Horvarth-Howard for coming along to give evidence here this morning? There are four people on the panel and it may well be they have similar things to say. I do not want them to feel that everyone has to contribute to every question if essentially all are saying the same thing; otherwise, we could be here for quite a long time. Could I start off by asking anyone on the panel about funding? We know that approximately 20,000 English residents are registered with Welsh or Welsh-registered GPs. I believe that the other way round it is about 15,000, which suggests there is a net loss to Wales of about 5,000 patients who are being cared for by Welsh GPs but are not being funded. Is that having an impact on the resources of GP surgeries on the border? Do you feel funding arrangements should be changed so that GPs on either side of the border receive funding appropriate to the number of patients they are looking after?

Dr Horvarth-Howard: I am a Welsh borders GP and am working in Hay-on-Wye. From the point of view of general practice, there is no loss of funding to us because we are funded within our global sum for the patients we look after, whether or not they live across the border. At service level, there is not an issue; there is a good, healthy relationship between Welsh border GPs and patients living in England.

Q150 Glyn Davies: To come in straight away on that point, the Welsh NHS gave evidence to us. Undoubtedly, the impression given to us was that the difference in numbers, which can vary all the time—it is 20,000 one way and 15,000 the other—did have a financial impact. The impression I took from the meeting was that that had a financial impact on the finances of the Welsh NHS.

Dr Horvarth-Howard: On the finances of the Welsh NHS, possibly. I do not understand how the national deficit, one way or the other, is balanced up. At my level of the service, my understanding is that that is looked at once a year or so and balanced up. At service level there is not an issue. There are other issues, which will come up later on, but that is not an issue at service level, as a borders GP.

Q151 Chair: So, if there is a problem, it is probably higher up at the Welsh Government level rather than for you as a GP.

Dr Horvarth-Howard: It is.

Q152 Geraint Davies: So we are clear on this, we have already been told that 20,000 people in England opt to have a Welsh GP and with that the funding streams for treatment that follow for the Welsh NHS, and 15,000 people in Wales opt for an English GP. There is a differential of 5,000, so the Welsh Government are losing out. You have said it does not affect you on the front line, but do you feel that the funding should be provided by England to Wales if there is that difference?

Dr Horvarth-Howard: From the clinical perspective, it will depend on the quid pro quo with other services as well, because you cannot really take primary care on its own. We do not operate in a silo like that. It is the whole service: secondary care, district nursing and the rest of primary care.

Q153 Geraint Davies: Putting it another way, do you feel that, if someone living in England jumps over the border to have free prescriptions and all the other benefits of the Welsh system, that payment should be borne by the Welsh grant or Welsh services, or do you think we should have a free-for-all with English people coming over and taking our Welsh services?

Dr Horvarth-Howard: That was not how it evolved. When I first came into border practice 25 years ago, those differences did not exist. Most of those patients and their families were already registered with Welsh GPs, because that was the way the geographical biscuit crumbled.

Q154 Geraint Davies: I understand that.

Dr Horvarth-Howard: Then things changed politically with free prescriptions, and parking in England, and differentials came across. It is not so much a matter of people registering to get certain benefit; things have changed around them.

Q155 Jonathan Edwards: You talk about the historic relationship with GPs across the border. There has always been that deficiency in terms of more English patients registering with Welsh GPs than the other way round. Have the policy decisions taken by the Welsh Government—for instance, free prescriptions and other measures—led to a greater number of people switching across the border?

Dr Horvarth-Howard: Not in my experience.

Q156 Geraint Davies: I have been told that performers' lists in England and Wales have had a detrimental impact on recruitment to GP practices in Wales. Can you explain that? Maybe Dr Kelly of the BMA could respond

Dr Horvarth-Howard: It is definitely an issue for recruitment for general practice. There is a potential UK-wide issue about recruitment to general practice, and we are feeling that particularly in rural areas of Wales. We would want that flexibility for people to be able to work across the border both ways without having separate performers' list, so from a BMA perspective we would like to see one UK performers' list.

Q157 Geraint Davies: There is a different list, and you cannot go across the border. Can you explain why there is a difference in performers' lists in England and Wales?

Dr Horvarth-Howard: My understanding is that Wales decided it wanted its own performers' list, for whatever reasons. The BMA perspective is that in the current climate of recruitment and retention we probably cannot afford to do that, and we need to facilitate easy work force movement both ways across the border and have one performers' list.

Q158 Geraint Davies: Have one national health service.

Dr Horvarth-Howard: UK-wide, yes.

Q159 Glyn Davies: Can I explore this a little further? I went to a rural GPs' conference in Cregennen. One of the biggest issues it had in Wales was this one. Listening to this, it seems bizarre that you can be fully trained up as a GP in England and you cannot work in Wales without going through a new expensive process to become registered. Does it work the other way as well? If you are registered as a GP in Wales, do you have to go through a separate performance to practise as a GP in England? How much of a problem is it? At the conference I attended, it was a pretty serious problem. I was asked to follow it up, which is why I am asking this question with some vigour now. We need to understand just how big an issue this is, because there is a huge shortage of GPs in rural practices, certainly in my constituency and most of rural Wales.

Dr Horvarth-Howard: We would totally agree with you. When it gets down to a level of micro-management where you have to reregister from health board to health board to get on different health board lists, we totally agree with you.

Q160 Glyn Davies: Does it happen the other way in England?

Dr Horvarth-Howard: I am not entirely sure whether a Welsh GP has to do that.

Q161 Glyn Davies: I do not think they do. It's a Welsh thing.

Dr Horvarth-Howard: I would not say it with a lot of confidence, but certainly this way it does and it is a problem.

Q162 Glyn Davies: It is mad, is it not?

Dr Horvarth-Howard: I would agree.

Q163 Chair: Similarly, you talked about the way training rotas operated. You suggested they should operate across the England-Wales border. Could somebody clarify what that problem is?

Dr Kelly: That does cause problems. I am a respiratory doctor. We have a rotation which goes north to south. A decade ago, I applied all across England for registrar jobs, but I avoided Wales literally because of, "Where are you going to live over your five-year training period?" and the difference between north and south makes it difficult. There is no easy solution, but exploring

whether some rotations in the north might link in with Liverpool or Manchester training schemes may be of benefit in terms of recruitment.

At the moment, we have gaps in registrar grades and Wales is less popular than other areas, so it is an issue for us. The north-south geography is difficult. There is no simple solution, but I know of some rotations that do link in with the north-west, and there may be advantages in exploring that further. That has its own disadvantages, because they have to agree and we may then become the outlier for them. I do not know whether the royal college has any thoughts on that.

Dr Rees: The Royal College of Physicians acknowledges that this is an issue. We have had discussions with the Minister, Mark Drakeford, and the deanery. They acknowledge this is perceived to be a problem and they are very supportive in looking for a north Wales-north-west rotation. This historic problem has now been addressed.

Chair: That is good.

Q164 Nia Griffith: We have talked about the position with GPs but, when we get to the next stage where people are being referred on, how straightforward is the process? We know that historically there were a lot of cross-border links. If a patient on the Welsh side needs to go for treatment in England and so forth, how is that working out at the moment?

Dr Horvarth-Howard: There is still a very full and active clinical relationship. For instance, in the area of Powys where I work, with Hereford and further north to Shrewsbury, the answer to your question is that it still works well in most cases. There are some issues, which we will come to later, in terms of IT springing up, but there are still a lot of good, healthy clinical pathways that are well trodden both ways.

Q165 Nia Griffith: You are saying that for people registered in your practice the process is quite straightforward for you to refer them for treatment, whether it is in Wales or England, at secondary level.

Dr Horvarth-Howard: Most of the time, yes.

Dr Joseph: I work at the Countess of Chester, which is a north-west English hospital, and 20% of the patients we look after are from the Flintshire corridor in north Wales. While the referral process is quite straightforward and patients are able to access English services, at the choice of Welsh GPs in that region and also through patient choice, certain administrative processes have made that care slightly more fragmented. I can give you an example. I look after patients with diabetes. When patients are referred to me I see them. We try to do a shared care management strategy. I see them maybe every six months or a year, and in the interim the GP would look after them for intermediate visits, but all of the blood samples taken at the Welsh practice are sent to the Wrexham Maelor. Therefore, when a patient comes to me at the Countess for review I am at a loss because I am unable to access those results. It is imperative for the patient to get to the doctor at the surgery before the appointment to see me to get a piece of paper or fax that then has to come to me. If I am unable to get those results, I have an incomplete consultation. I can either stay on the phone for 15 minutes to the Wrexham laboratory and say, "Please can you send me these results," or say, "I'll get the results and write back to you," which is unsatisfactory for the patient, so there are issues there.

Q166 Nia Griffith: How could that be put right? What is the simple way to make sure that you get those results very quickly, without having to waste time?

Dr Joseph: The answer lies in the IT solution that was referred to and having integrated records that allow us to deal with it across borders. That is not a cross-border issue; it is an issue within the

NHS in England itself as well at the moment. We are trying very hard to overcome the barriers so that information sharing can be open, transparent and easily accessible.

There are local pockets of good practice where people are trying to put together integrated records, but, as a physician, my personal opinion is that the barriers in terms of confidentiality and what can and cannot go on to these records is stifling good patient care. That is something we have to work on, and that does not just transcend the border issues; it is right across.

Dr Kelly: Speaking from the other side of the border, if I have a patient who is admitted to the Countess, it is a black hole, and I rely on information from a discharge letter which gives some but not all the details. We do not have access to the blood results. As a chest physician, we have urgent suspected cancer referrals. We used to have a problem related to IT. For example, patients on the coast, say Dolgellau, would have their x-rays in the Bangor x-ray system. We used to have to phone up and ask for a CD to be posted to us. Even though, sitting in a small hospital in Dolgellau, you could look at both systems, we were not able to do it in the Maelor. That has now been rectified. If I have a referral from there, I can look at the x-ray and decide whether to see them. It might come on a Tuesday. We will see them next morning. If we cannot see the x-ray, we do not know whether it is suitable for a scan. If they have their x-rays or CT scans in Gobowen or the Countess, there is a delay in getting the images to us and prioritising when we see them. That might add a delay for a small number of patients of a week or so when we could otherwise see them quicker, so there could be better IT solutions and access to IT in Chester and Gobowen.

Q167 Nia Griffith: You are saying that has been resolved.

Dr Kelly: It has not been resolved. It has been resolved within Wales.

Q168 Nia Griffith: It has been resolved within Wales in terms of Bangor to Wrexham, but it has not been resolved cross-border in terms of getting all the details of cancer patients. It is obviously a huge area that needs to be put right, because it is quite simple to do it.

Dr Kelly: You would think it should be relatively straightforward to be able to access the pathology and x-ray systems at the Countess and for its clinicians to be able to access the North Wales system. That would be a simple solution, but it does not seem to happen.

Q169 Nia Griffith: We have talked about secondary care. What about tertiary care? Is it relatively easy for Welsh patients to access that if it happens to be across the border?

Dr Kelly: Speaking of my specialty, there are a small number of tertiary services that we would routinely refer to, because those are things we do not have in-house. It is very straightforward to refer to those pathways, if they are established. If something new cropped up, we might have to explain why, but once the explanation is provided, there has not been a significant block. On occasions, things have been questioned, but once we explain why we are referring outside our local hospital, it does not seem to be a major problem. If the pathway is set up, it is very straightforward, so it does not really affect us.

Q170 Nia Griffith: You as clinical experts have the last say as to where that takes place.

Dr Kelly: That seems to be the way. I do not think that is a major issue.

Q171 Nia Griffith: There has been talk of the repatriation of some services, more at secondary than tertiary level, in the sense of having them in-house in Wales. Have you been affected in any way by any plans or the implementation of directives to follow that particular path?

Dr Kelly: My experience is slightly separate. In my own specialty, I can quote the example of endobronchial ultrasound, which we started doing locally as a sub-specialised service for some of

our cancer patients. We discovered, probably by chance, that a lot of that was happening in Liverpool, but we did not know about it. From the Welsh NHS side, the impression I get is that we are not as financially driven, or as involved in finances, as perhaps our colleagues in England are. I was not aware of the number of procedures happening across the border. Once I found out, more by chance than planning, we were able to repatriate those services, mainly because we could do it quicker and more locally, so it is better for the patients. We could do it at lesser cost, but that was driven by me as a clinician, not by an imposed structure. Some of the repatriation makes sense because there are things we can do, that are perhaps going across the border unnecessarily. You are probably asking about a higher level.

Q172 Nia Griffith: You were able to get access to equipment, and that meant patients in the local area did not have to travel so far and were able perhaps to have those services in the same hospital where they were seeing you.

Dr Kelly: There were still some things that needed to be done across the border. There are one or two more specialised things than we would do, but probably 80% of that could be repatriated. The reason it had not happened before was that we did not know it was happening. I spoke to my colleague and said, "I didn't know you were referring to X," and the reply was, "Oh, yes. We can do that for you," or, "We can do it quicker." Some of the repatriation can happen because you can do it better, more locally and probably cheaper and quicker. I think you are asking what things are imposed on us. I have not seen so much of that.

Nia Griffith: No. I am asking you what the situation is and you are telling us as you find it. It is very helpful.

Q173 Chair: Let's go back to Dr Joseph.

Dr Joseph: That is a very good example of how things can work in repatriation, but there are impacts of repatriation on services that have previously existed. For example, a few years ago, we were able to share our cardiac angiography suites: the area where tests are done to look for blockages in circulation to people's hearts. The Welsh cardiologist from Wrexham used to come over to the Countess and there was an economy of scale. You were able to run a bigger unit with multiple users, and therefore it was economical to do that.

A couple of years ago, the angiography service was repatriated to Wales and that impacted on the English service because we had to reduce the number of staff. That had an impact on how that unit could be staffed for a much lower volume. At this point, we are now in a position where demands are increasing with the demographic and the number of people we are looking after who need these services. We are in a position where we are unable to escalate that volume. Therefore, the impact of two years ago is now not allowing us to meet the demands required of us now. Therefore, there are impacts for English patients.

In terms of Welsh patients, another area where we have had some issues is gastrointestinal endoscopy. There are patients who now have longer and longer waiting times. We have been approached by some of the north Wales hospitals to assist them with the long waiters to do some of the endoscopy tests for gastrointestinal patients.

Q174 Nia Griffith: You are being paid by the Welsh Government to carry that out.

Dr Joseph: Yes. If we had been able to plan this earlier, without having had that repatriation, and had worked together on the volume, we might have been better able to deliver a service, whereas our hand has been forced because the volume has reached a point where we are now struggling with recruitment.

Q175 Geraint Davies: Dr Kelly gave an example where repatriation ended up with a better, more localised and cheaper service for Welsh patients. Presumably, in terms of the trade of health, for want of a better expression, there will be examples of the opposite, will there not, and in both ways? Dr Joseph gave an example of economies of scale. How do you see the future emerging in such a way that we could encourage things to be done in Wales or in England, wherever it is done better, and clustered where it is appropriate? Or are there all sorts of barriers to that? In terms of the movement of data, whether about blood, bones or whatever, am I right to say that in terms of x-rays and the like there are problems not just in moving data across the border but within Wales and within England, or am I wrong? Where are these problems? Are they general or specific problems?

Dr Kelly: They are general problems. Moving data is becoming easier. Instead of posting CDs, we now send things electronically, so it is getting better, but the fact is that everybody has a slightly different system. Those blocks are not just cross-border. When you have two hospitals like the Countess and Wrexham, which are very close, where patients go between the two, it is a particular problem. You can have two systems, but the clinicians really need access to both. That would work. You could not have access to multiple systems all through the UK. With the rare exception of a patient from down south where you want an x-ray sent up, you accept that, but when it is your daily bread and butter, better access is needed.

Q176 Geraint Davies: In terms of trade and clustering, are these things getting better or worse?

Dr Kelly: Slowly better, but it remains a big problem.

Q177 Glyn Davies: The waiting list in Powys is the biggest issue that affects people by a long way. I think it is currently about 28 weeks. It was 36 weeks, 12 months ago, and it is coming down. I think the aim is 26 weeks by the end of the year. It is about 28 at the moment. In Shropshire, over the border, it is 18 weeks. For orthopaedics, it is over 40 weeks at the Robert Jones and Agnes Hunt. There are two things I want to ask about. The first is to reflect on the impact on patients. I know from people who have written to me or contacted me, that this is the biggest issue. It makes the people of Powys in particular feel that in health terms they are very much second-class citizens. I know of one person who gave up his job and moved to England because his child needed treatment, simply because he was going to have to wait too long. How common is this? How do you reflect on what seems to my constituents to be a completely unacceptable position?

Dr Horvarth-Howard: It is a big problem, not just from the patient's perspective but from a GP work load perspective.

Q178 Glyn Davies: That was the second part I wanted to come to.

Dr Horvarth-Howard: We are having to see those patients more regularly; we are writing expedite letters on a daily basis, which takes up GP and secretarial time. From time to time, patients ask, "Were I an English resident registered with an English GP, would the wait be different?" I have not been aware of any large-scale movements in my patch of Powys for that reason. Last year, Hereford CCG wrote to all patients, including those registered with us, to point out that they had the option of moving to an English GP, but it is probably important to point out that since that time the neighbouring English practice has had to shut two branch surgeries due to recruitment issues, which are affecting all of us. In a way, patients are between a rock and a hard place. I have not seen a lot of people moving to get operations more quickly, but it is a discussion that does come up. Waiting is bad for all of us.

Q179 Glyn Davies: The other aspect is the impact on clinicians, which you have touched on, and on hospitals. I remember walking into the orthopaedic hospital in Shropshire, as I do on a regular basis, just to see how the situation is. There was a letter on the desk saying, "Do not treat anybody until 36 weeks. If you do treat them earlier, you won't be paid." That was a huge issue for the hospital to have

to cope with suddenly. Clinicians have to tell patients, "I'm sorry. You're from Wales, so we can't treat you until later." Some clinicians find it very difficult to explain to their patients that just because they are on the other side of the border they cannot treat them. It is a big issue for the morale of people working in the NHS. It is a big issue for me, because everybody in Powys and Montgomeryshire goes over the border; it is not as if some do for tertiary treatment; it is everybody as far as secondary care is concerned.

Nia Griffith: Could you clarify where the letter had come from?

Glyn Davies: From Powys local health board.

Q180 Chair: Do you have any comments on that, gentlemen?

Dr Joseph: It is a difficult conversation for clinicians. It is difficult because most clinicians are just trying to do the best they can for the patient sitting in front of them. There are times when I will see a brittle young type 1 diabetic and say, "I'd like to give you this new insulin which might help get rid of your low blood sugar levels that are happening so often. I can do that if you are registered with an English GP, but I cannot do that if you are registered with a Welsh GP, because there are different drug formularies, depending on which area you are from, and the processes are slightly different in terms of approvals." That is a difficult conversation.

You then have the opportunity to do individual funding requests. They are laborious and are an administrative waste of time. From my point of view, you can get the outcome you need but it is with a lot of pushing, depending on where you are. There are situations where you may deem someone fit for weight loss surgery in England and you can refer them on and say, "You'll be discussed by a team and we'll make a decision based on that," whereas I am unable to make similar decisions on someone from the Welsh side of the border because that decision is made by a team in Cardiff. The goal posts are slightly different. There are issues around that to some extent.

Q181 Chair: Dr Joseph, as a specialist in diabetes, have you noticed a difference in service in terms of access to pumps for diabetics in England and Wales, because that has been raised as an issue with me?

Dr Joseph: We have an understanding with north Wales where we can start north Wales patients on pumps, if we see patients who come to us. The numbers we are allocated are smaller than the numbers allocated from our CCG in western Cheshire. While we can, we work on the basis of an annual number that we are able to utilise. They are slightly different. We have been able to have those conversations over the years. It is possible and doable, but it is slightly more difficult because the restraint on numbers is slightly different.

Q182 Simon Hart: I have a specific question for Dr Joseph on individual funding requests. I am aware of at least two constituents of mine who require gastrointestinal surgery. Technically, it is routine and is available in Wales, but the constituents' consultant cannot fit them, or give them a date at all, let alone one, two or three years hence, on the basis of pressure of more urgent surgery. By the way, this operation can be done in six weeks in England. One person in particular, who has been off work for 12 months, could have the operation in six weeks in England and cannot get the individual funding. Technically, it is available in Wales, though practically it is not. What would you do if you were this person's adviser?

Dr Joseph: From a clinician's point of view, the way I view the individual funding request is not on the basis of accessibility in terms of time. It is not a question of, "You get to jump the queue and get something sooner." That is not the purpose as far as I am concerned. The purpose is: is it something that routinely I could not do? Is it an exceptional case, or something that has not been tried and tested as much? There is only a glimmer of hope, and therefore that is what I have to do.

That is how I see the role. As a clinician, I would find a way of squeezing somebody in somehow, somewhere. If you were unable to do that, the resource needs to be looked at. That is the issue.

Chair: We are, coincidentally, about to come to the same sort of point.

Q183 Mr Williams: In a slightly different context. I want to ask about access to specialist cancer drugs. First, in practice, how do the divergent systems in Wales and England work? Could you outline briefly how the two systems work?

Dr Rees: There are two systems. Devolution has been here for 15 years. All clinicians want to do the best for their patients, whether they are working in one system or the other. It is not the system that you could comment on but the practicalities of getting the best care for patients. If a cancer drug has a technical appraisal by NICE, it is mandatory that that drug is available to all patients throughout the NHS. The whole essence of the NICE appraisal—I have sat on two NICE committees myself—is that it is a forensic assessment not only of the efficacy of that drug but, crucially, its cost-effectiveness. There are two issues. Does the drug work? Is it good value to the NHS? If NICE says yes, that drug is available. There are no issues regarding the unavailability of NICE-approved cancer drugs in Wales or in England.

England has a separate system with a separate fund. Certain drugs that have not been approved may be funded through the English system, for which we do not have an equivalent in Wales. I and the college are not persuaded that this disadvantages individual cancer patients in Wales. Velindre is one of the best centres in the UK. A lot of clinical trials take place in Wales which are funded by the pharmaceutical companies, so paradoxically you can get access to new and innovative drugs if you take part in clinical trials. Talking to our oncology colleagues, I do not see this as a big issue in terms of standard NICE-approved drugs for the treatment of cancer.

Q184 Mr Williams: In your written submission to the Committee you said there was a lot of confusion on the part of patients. Quite obviously, that is a frustration.

Dr Rees: I think that is a valid point. Patients do not quite understand the complexities of the different health care systems between England and Wales, and they need to be better informed that we work within two systems. As devolution goes on, there are more differences. The obvious one is free drugs in Wales.

Q185 Mr Williams: When you say it is about devolution, do you defer to the Assembly's right to go along whatever route Mr Drakeford chooses to go on this? Practically, what are the time considerations for patients under the two different systems in terms of accessing those drugs?

Dr Rees: I do not have any experience of that, not being an oncologist. All I can tell you is that I have spent 26 years as a consultant at the University hospital of Wales. I also share an interest in diabetes and lipidology. There are some things done in Wales which I think we are very proud of. We have a genetic familial hypercholesterolemia register, which is considered a worldwide exemplar. We have the largest unit for LDL apheresis, which is a kind of filtering of the blood. We have patients from the west country coming with their funding to Cardiff for that. I do not recognise some of the criticisms of the NHS in Wales from my clinical experience. I understand that there are complexities if you are on the border between one side and the other.

Coming back to shared patient data and IT systems, it is a generic problem throughout the UK. You are aware that £9 billion was wasted, for want of a better word, in trying to develop a comprehensive IT system in the NHS throughout the UK. There is a clear need for better information sharing, but it applies between the north of England and the south of England, as between the north of Wales and the north-west of England. It is a generic problem.

Q186 Mr Williams: We have seen various press reports recently—the point referred to by Mr Glyn Davies—talking about people moving to England to receive cancer drugs that are not perceived to be available in Wales. Notwithstanding what you have said, and probably what we agree on in terms of devolution, should there be a single system across England and Wales? Would that not remedy the frustration, worry and anxiety that we have talked about?

Dr Rees: Cancer is a very emotive subject. Patients sometimes read about new drugs that come along and all the rest of it. I can say only that my experience from my oncology colleagues in Velindre in Cardiff is that they will get the best treatment for those individual patients, according to the opinion of their consultant oncologists. That is all I can say.

Q187 Mr Williams: As constituency MPs we would attest to that frustration and that perception in the media and elsewhere.

Dr Rees: I am not denying there are individual frustrations. All I am saying to you is that I am very reluctant to accept that they get second-class care in Wales. I think they get first-class cancer care.

Q188 Jonathan Edwards: You mentioned earlier trying to explain to patients the complexities of the health systems in England and Wales. We have had some very high-level political statements over recent months. For example, Offa's Dyke has been seen as a line between life and death. I believe that comment was made in the context of cancer treatment. Do you think those sorts of statements are helpful, or not?

Dr Rees: No. They demoralise NHS staff. We are here to comment on clinical issues, but I leave the politics of it to the politicians. I do not think those comments are in any way helpful. They could be construed as inflammatory.

Q189 Geraint Davies: There is an objective reality, and there are differences and so on. Is there a danger that, when these things are exaggerated, it undermines confidence and causes people to behave in such a way that is not helpful to their own interests, and indeed the delivery of systems both in England and Wales?

Dr Rees: I would accept that but, as clinicians, our obligation is to do the very best for our patients, whichever system we happen to work in. I am fortunate that, working in Cardiff, I do not have much personal experience of these cross-border issues. I am also quite proud of the service that we do provide in the NHS. The NHS generally is underfunded and under-resourced. There has been an exponential increase in demand; relatively flat-lining of the budget; we have an inherent inflation of 6% to 7% in the NHS. If you do the maths, you can see that we are generally under-resourced, whether you are in the north of England, the Shetland islands or mid-Wales.

Q190 Geraint Davies: You mentioned NICE's criteria for drug prescription and the combination of efficacy and value for money but, in England, a portfolio of drugs outside that regime is being offered. Given we have limited resources, would it be better for the English system if they did not provide those and provided them within a strict regime of efficacy and value for money? There isn't a limitless amount of money, and therefore we are using our money more effectively in Wales.

Chair: We had better have a very brief answer to this.

Dr Rees: I think evidence-based medicine is the way forward. That is as brief as I can be.

Q191 Simon Hart: You said that you did not do politics and then you very neatly did politics, which I actually think is a good thing. I think the Church and health should be welcome to do politics. You talked about the inflammatory nature of comments. When any comparison is made between the English and Welsh service, somebody, somewhere, puts up their hand and says it is either unhelpful

or inflammatory. They might be right. Does this not cast quite a lot of doubt on the devolved nature of health? How do we avoid making these comparisons when the service is devolved?

Dr Rees: It depends on what metric you use to measure: the exceptional or the generality. In most of the surveys done within Wales in the NHS there are over 90% approval rates. You have to compare apples with apples, not apples with pears. If you look at the demographics of south Wales, they are elderly and socio-economically deprived, and there is industrial legacy. If you are going to compare the health outcomes in that area, you should have an equivalent—say, Lancashire or Yorkshire off the top of my head. Health care is a very complex issue. If you are comparing outcomes and metrics in one part of the country with another, you must make sure it is not apples and pears but apples and apples.

Dr Kelly: A brief point from my specialty—I am a respiratory doctor looking after people with lung cancer. In the last 10-plus years that I have been in post, I have not perceived any blocks to any treatment we want to give. There was a brief period a few years ago when a drug was available in England but not in Wales. We had an arrangement with a hospital just across the border where we could refer people easily, so access was available. I have not see any blocks in my specialty to people getting the best treatment we think they need. Yes, there was a small technical issue, but it was easily resolved. It may be the exception rather than the rule.

Q192 Jessica Morden: You talked earlier about making sure patients were aware of the complexities of different health care systems. How do we make sure that patients know when they join a GP practice what system they are joining, and what more can we do to raise people's awareness? People who came to give evidence at the public evidence sessions said they just joined a GP practice because they had no choice; it was the only one, and it was not until further down the line they understood what that meant in terms of referrals.

Dr Horvarth-Howard: When we sat down with the Welsh Government last year to formulate the Welsh response to the border protocol, there was talk of a website, which I think would have been accessible to professionals. A lot of professionals do not understand how it works either. In fairness, it is immensely complicated and convoluted. There is already a lot of information out there. For a lot of the areas that I cover, the internet is not functioning much at all. Most of it tends to come through the media. It is often distorted, and then there is a discussion with the GP. For instance, a patient registered with me might say, "Can I choose to go to such and such a hospital?" I have to explain, "No. Choose and book isn't available in Wales; that is an English prerogative." That is the way most of it happens. Most people are aware of prescriptions and car parking charges because they have had a lot of publicity.

In terms of the fundamental responsibilities of health boards and governments, that is difficult for all of us to understand. That is going to be very hard to put out into the public sector without confusing people.

When push comes to shove, my impression is that most of the public who stay registered with Welsh GPs do so because, as Dr Rees said, they have been happy with the service, and we have had good validation scores on our performance as far as they are concerned; otherwise, they would probably move. Possibly, there could be a website or something in practice leaflets. I do not know, but there can be too much information.

Dr Joseph: To push back on that a little, human nature wants things to be equitable and similar. No matter how hard we try to change people's perception and keep that message going, our aim, as Dr Rees said, when it comes to health care, is that the outcomes, targets and what we do need to be standardised across the board. If we can get to that point, the message to people is very simple: you get the same. How you achieve the same may be different, but what you get at the end is the same

no matter where you are and where you are registered. That is where the patient would want it to go.

Q193 Chair: There has been a bit of controversy about different waiting times on different sides of the border. Is there an argument for making providers meet standards based on patient residency—in other words, somebody in England will get the English standard, even if their GP is a Welsh-registered GP?

Dr Kelly: I would not necessarily be terribly keen on that. We treat people the best way we can. We want to see people immediately. Our wait times have slid and we do not like that. We know that we have almost two speeds: we have got very quick in respect of cancer and some urgent slots, and quite slow in other cases. You worry about those; some people need to be somewhere in the middle. I understand why the targets and waiting times are there, but as a clinician you just want to see the time being shorter for everybody. I do not think you want to treat people differently based on where they live; you want to treat them based on what they need. It does not sit easily as a clinician.

Q194 Chair: Turning the question around a bit, do you think the standard should be the same on both sides of the border?

Dr Kelly: We treat people in the same way, so it would be helpful to us to have things the same. To have two different standards when you are doing one thing is not that helpful to me.

Chair: Thank you very much indeed. I am sorry we are running a little late, but I appreciate your patience. There are a lot of important questions there.

Examination of Witnesses

Witnesses: **Andrew Wilson-Webb**, Chief Executive, Rarer Cancers Foundation, and **Emma Hughes**, Development Officer for Wales, Genetic Alliance UK, gave evidence.

Q195 Chair: Mr Wilson-Webb and Ms Hughes, thank you very much indeed for coming along today to give evidence to us. Can I start off by asking you both to give a very brief description of the sorts of rare cancers or conditions for which you provide support to people?

Emma Hughes: There is a range of conditions. There are about 6,000 to 8,000 rare conditions. I will just give you a flavour of some of them. Tuberous sclerosis complex is one of the conditions. Patients with this condition will access services in Bath hospital, often through referrals, and they need treatment through everolimus, which often cannot be got through normal routes. It has not been appraised and does not have a formal stamping from NICE. For patients suffering from vasculitis, who often receive care at Addenbrooke's hospital in Cambridge, there is a drug called Rituximab. Some patients with vasculitis will need that.

Q196 Chair: Is that a NICE-approved drug?

Emma Hughes: Rituximab is not. For alkaptonuria, people go to Liverpool for treatment, and the drugs they need are Nitisinone, and currently patients in Wales do not have access to that drug.

Q197 Chair: Is that a NICE-approved drug?

Emma Hughes: No. For ataxia, patients will go to Sheffield. There is no treatment for ataxia in terms of the other conditions.

Andrew Wilson-Webb: The Rarer Cancers Foundation deals effectively with all cancers, with the exception of the big four. That is approximately 230 different types of cancer. In terms of drug use,

there may be licensed drugs, licensed drugs being used off label, or drugs that are completely unlicensed in the UK.

The patients come to us usually through our helplines. Patients are referred to us either through Macmillan or NHS Direct directly, or alternatively by other charities. The majority of the patients who come to us through our helplines are generally at an advanced stage of cancer and thus need perhaps end-of-life drugs; or they are on long-term therapy; or they are on drugs which perhaps have stopped working, and they need one of the newer drugs which may not be readily available, or available to all.

Q198 Nia Griffith: Could you explain a little about the foundation and how it is funded?

Andrew Wilson-Webb: The foundation is funded effectively through the pharmaceutical industry, which represents about 40% of our turnover. The industry itself has no say in any of the work we do. That is very clear; everything is absolutely transparent. At the moment we are in the process of producing around 230 different fact sheets on different cancers. It helps to fund the helpline. It also does fund some of the policy work. Where it does that, on any of the reports we produce, we will always show where pharma is involved. Pharma has absolutely no editorial control over anything we do. It does not see any of the work we do until we publish. More importantly, over the years we have produced a lot of work which pharma has not particularly liked. We call for good value to the NHS. We feel that drugs should be affordable for all, but we also feel that they should be available. Therefore, the interest of both the patient and pharma in that respect is very similar.

Q199 Nia Griffith: You mentioned that there were four big cancers you do not deal with. Which are they?

Andrew Wilson-Webb: Breast, prostate, lung effectively and liver.

Q200 Nia Griffith: You mentioned the cost of some of these drugs. We know that the cancer drugs fund started off with just £50 million; it is now £280 million.

Andrew Wilson-Webb: We started off with £200 million.

Q201 Nia Griffith: I believe it is £280 million this year.

Andrew Wilson-Webb: That is correct.

Q202 Nia Griffith: It seems an awful lot of money. Is it really well spent?

Andrew Wilson-Webb: It probably is well spent. Since its inception in 2010, it has assisted 60,000 patients, but it deals with a variety. About 10% of that is off-label use. This may be for use of medicines which have been licensed by NICE but are being used for a different indication—in other words, where the biology may be very similar from one cancer to another. Therefore, the clinician will use it for that particular treatment, but it is not necessarily licensed. It is also used for new drugs coming on to the market which are going through the NICE process. The NICE process takes about 18 months now, which in our opinion is excessive. We have been calling for a long time for that to be reduced to six months. That gives early access to those patients. It also gives access to drugs which have not been licensed in this country but are licensed elsewhere, or in the States. More importantly, there are a number of drugs which will never be licensed by NICE because the patient numbers are too small and, therefore, the clinical trial data will not be available. In that respect, we think it has certainly done a job.

Q203 Chair: I have just been doing a back-of-the-envelope calculation. If you divide £280 million by 60,000 people, it comes to about £4,500 per person. Is that about right?

Andrew Wilson-Webb: That is probably about right.

Q204 Geraint Davies: With respect, the £280 million is an annual figure; the 60,000 is the cumulative figure, so the unit cost per patient is much higher. What is it?

Andrew Wilson-Webb: You are absolutely right. It about 10,000 to 15,000 patients per annum. Since its inception in 2010, it has treated approximately 60,000 patients. For the first three years, the budget was £200 million, although there was an underspend in the first two years. It has now been increased to £260 million.

Q205 Geraint Davies: If it was 10,000, obviously it would be £28,000 per patient. We heard at a previous hearing that the justification for using NICE drugs was efficacy and value for money. You are saying that money should be taken out of that £280 million for drugs that are not tested, or are not as efficient or give the same value for money. You are saying that from the perspective of an organisation funded by the pharmaceutical companies wanting to try to test and sell their new drugs. Is that correct?

Andrew Wilson-Webb: That is not the case. The problem here is that you have quite a number of drugs, for example, which are treating very small patient populations. Those patient populations will never ever have a drug which has been approved by NICE, because the trial data are just not available. If you use that argument, you are saying that that group of patients—maybe 5% to 10% of all of the patients within the cancer drugs fund—should not be allowed to have those drugs.

Q206 Geraint Davies: You are saying that the public should have access to drugs that do not have trial data.

Andrew Wilson-Webb: It is absolutely correct that it has limited trial data, but the basic reason for this is that you may have a tumour type which has exactly the same biology; in other words, it is a drug that has been licensed for prostate cancer. You can take anything really.

Q207 Geraint Davies: You do not do prostate cancer.

Andrew Wilson-Webb: The biology of that tumour is similar to another type of cancer where the patient number would be less than, say, 500 people per annum maybe worldwide. Therefore, that particular drug will never ever go through NICE because the patient numbers are just too small to meet the current NICE appraisals.

Interestingly enough, there is discussion at the moment about looking at the NICE appraisals and maybe at a methodology which will encompass this type of drug—in other words, they would use real-world data, as opposed to trial data, over maybe a three to five-year period.

Q208 Glyn Davies: Is not colorectal cancer one of the major cancers? You mentioned the four major cancers but you did not include colorectal cancer. I thought it was one of the major ones.

Andrew Wilson-Webb: It is a major cancer. There are lots of major cancers but effectively there are four which have the largest number.

Q209 Glyn Davies: I will have to check up on that. I am sure you are right. I am sorry that I have a questioning look on my face. I accept that rarer cancers don't have the access to treatments that they should have. It is a very important issue, particularly when, in terms of charitable work, the major ones take nearly all the money that is available. The way you secure access to a drug is through either a programme that has already been agreed with the deliverers of the treatment or the individual patient funding request.

Andrew Wilson-Webb: Indeed.

Q210 Glyn Davies: Can you explain how those two separate systems work and complement each other?

Andrew Wilson-Webb: If we start in England—this is fairly relevant—in 2008, we realised that there was a postcode lottery with regard to cancer treatment. This was caused basically because for every cancer drug an individual funding request had to be made. Within that funding request, there is an exceptionality clause. The exceptionality clause means basically that that particular patient has to prove exceptionality. The original IFR agreement was set up not for cancer but for things like tattoo removal. For example, if somebody wanted to have a tattoo removed and made an application to the NHS, effectively that would not have a material effect on their life. However, in the event that the tattoo is located in such an area that it gives them mental problems, they could possibly prove exceptionality. Because the word "exceptionality" is included within an IFR application, it has been extended, or enveloped if you like, into cancer.

It has always been accepted that the exceptionality rule is unfair and is not fit for purpose for cancer. This was part and parcel of the reason why the cancer drugs fund was started in the first place to do this.

If we look across the border at Scotland, Scotland has accepted that the exceptionality clause is not fit for purpose. It has introduced a new pack system which still has IFR but removes that clause and the word "exceptionality". That is a much fairer way of dealing with cancer, because then a clinician will apply for a drug that he wants to provide to his patient. On the other side, the IFR board will look at its effective use for that patient. Cost, as you rightly mentioned, does come into it.

Chair: I know you are passionate about this, but I am a bit worried about the time.

Q211 Mr Williams: You stated in your submission that patients had particular difficulty in securing referrals for treatment outside Wales. I think you alluded to that in your answer just now. Why is that so? Why are there particular problems? Do you think there are particular problems in the relationship between Welsh patients and English treatment?

Andrew Wilson-Webb: There are certainly some problems. For example, we know that under this process—this comes from the leading Welsh cancer hospital—90% of all IFRs are refused. That is a very big percentage.

Q212 Mr Williams: How do you react to the questioning in the previous session when we heard from the physicians who seemed to be suggesting there were not such big problems?

Andrew Wilson-Webb: I disagree. In terms of cancer patient care, from the most recent surveys that have been carried out, care in Wales is excellent, but access to drugs is not. That is where the problem arises.

Q213 Mr Williams: In your submission, you said that "such restrictions on out-of-country referrals are clearly inappropriate"—we would all agree on that—"and should be stopped." What is your solution to this problem?

Andrew Wilson-Webb: It is a solution that, essentially, Wales has to make for itself. If these drugs were made available in Wales, or if the exceptionality rule was omitted from the IFR process, this would make a huge difference. Interestingly enough, of the four most-used drugs, or applied-for drugs, within the cancer drugs fund, none is routinely available in Wales.

Q214 Mr Williams: Maybe we can broaden it out to Emma Hughes as well. Without referring to specialist centres in England, how confident are you that there is sufficient knowledge of rare conditions and necessary treatments within Wales now? Have you got that base?

Emma Hughes: We have done some reports and work on this. Knowledge is quite limited in Wales in terms of rare conditions and a broader understanding, as well as specialist understanding. There are three specialist centres in Wales, but where the patient cannot go to, say, Cardiff where the centres are, they will need to be referred out of area to English or other UK centres. The issue lies in the breakdown in those pathways. The gentlemen before us spoke about secondary care referrals and the fact there were not many issues there, but, in terms of specialised pathways, they do break down. I put in my submission that there are two types of referral. You have the prior approval referral where there are clinical gatekeepers, so a specialist in a service will say whether or not they are going to authorise that referral to a centre. Where that is not approved by the clinical gatekeeper, they will go through a process of applying under exceptionality for an IPFR application.

Q215 Mr Williams: Can you explain what that process involves in terms of the time frame? How long a time are we talking about?

Emma Hughes: It has been up to years for some patients where their application has been stuck in this process. They are not really communicated with about the application or process. I have a quote here from a patient. She said that, on her last clinical visit in September to a consultant in Cambridge, he said that he doubted that he had the time to complete the 12 pages of paperwork for each of his patients. There is real concern among clinicians as well as the patient community that these pathways are not working. The problem is the paperwork as well as the process.

Q216 Mr Williams: That is the experience of a constituent of mine as well. When approval for a treatment did come, it was a week after the lady died. That is anecdotal, but you are suggesting it is more widespread.

Emma Hughes: A timely letter is really key, and having timely processes, as well as ones that are robust, is really important. For a lot of patients, the sooner they get access to treatment, the better they may react to it. In terms of enzyme replacement therapies, the sooner you get that treatment, the better the response usually.

Q217 Nia Griffith: We have here a copy of the IPFR process. It seems to be set out very clearly, and commissioners will be familiar with it. Do you find that they are familiar with it and use it? At the end of the day, it seems to point to clinicians making the judgment.

Andrew Wilson-Webb: If the clinicians were allowed to make the judgment, the system would work. We hear differently from clinicians in Wales. Quite a number of clinicians we have spoken to will not make an application under the IFR process and will not discuss certain drugs with their patients because they know they are going to be refused. That is a huge problem. There is disillusionment with some clinicians; we know of clinicians who have left.

Q218 Nia Griffith: How can a system work if people will not use it? Would not the first step be at least to try it?

Andrew Wilson-Webb: You also have to look from the clinician's point of view. They are dealing with a patient who is seriously ill. If they know that that drug is perhaps not available to them, or not going to be available to them in Wales, it is a little pointless, and they do not want to give them false hope. Therefore, the drug is just not mentioned. A lot of patients are very well educated and will go to the clinician and say, "I would like this drug." In some of those cases, they will go cross-border. It would be very easy for them, but not for all patients, because some are too ill to do it. We know that quite a large number of patients have crossed the border because they know the drug will be available. We have one particular situation where a patient waited for about three months for a response to an IFR and during that time he was deteriorating very rapidly. He then went to Bristol. He registered with a GP in England and effectively had the drug in about 72 hours.

Q219 Nia Griffith: Are you saying you do not think there should be this process at all? Are you saying you think there should be free rein to prescribe these drugs?

Andrew Wilson-Webb: There are several ways of doing it. You could, for example, have a cancer drugs fund in Wales. The cost would be about £10 million.

Q220 Chair: How do you make that estimate? If it is £280 million for the UK, Wales is about 5%, so it would be about £14 million, would it not?

Andrew Wilson-Webb: We think it is probably a little less than that, because we can base it more or less on the number of patients. We know that over the last five years about 230 patients have been turned down, but, give or take, yes. There is that alternative.

The other alternative is to look at the Scottish new pack system which is being introduced. Effectively, it includes the IFR process but excludes the exceptionality clause. That is one of the big problems.

The other point is that access to drugs for off-label purposes is much easier in England than in Wales, with or without the IPFR process. That is a matter that perhaps the All Wales Medicines Strategy Group should look at.

Q221 Nia Griffith: We have heard that Professor Peter Clark has said that some of the drugs do not have much of an effect. You would, therefore, be funding something that is a false hope for the patient anyway.

Andrew Wilson-Webb: No. I am sorry, but I disagree with that completely. Peter Clark is saying that there are some drugs that do not perform particularly well. The way that the system works in the UK is that you have a fast-track list, with a number of drugs that the clinician can effectively prescribe as soon as you apply for them. One or two of those drugs may not be that effective. A lot of new drugs are coming through the pipeline at the moment. There are new immunotherapy drugs that they want to include in the CDF. The idea is to de-list the drugs that have a poorer response rate and to introduce the new drugs.

Q222 Nia Griffith: But those are currently being funded.

Andrew Wilson-Webb: Some of them are currently being funded. Then again, the way in which the system works has matured quite a lot over the years from its early days. You are seeing the benefit of that now. It is absolutely incorrect to say that the drugs do not work. We have been contacted by patients from 2010 who accessed drugs through the cancer drugs fund and are still alive today. They would not have been alive today had it not been for the CDF. At the moment, I think there are 71 drugs available in England that are not readily available in Wales.

Emma Hughes: Can I just add something to that? Last year, the All Wales Medicines Strategy Group introduced a new process. If a drug is included in the cancer drugs fund in England, they will reappraise it through their appraisal body in Wales. That is a new system. A number of companies have been approached by the All Wales Medicines Strategy Group to go through that process, but there is a lack of engagement at the moment. They are trying to encourage companies to go down those appraisal routes again. It is an evidence-based national appraisal.

Q223 Jessica Morden: What do you think will happen to the cancer drugs fund in the long term? As Nia Griffith said, it was initially a temporary measure.

Andrew Wilson-Webb: It was always meant to be a sticking plaster until value-based pricing was introduced.

Q224 Jessica Morden: Nia Griffith referred to Professor Peter Clark; you have now dealt with some of those criticisms. There is an evaluation going on at the moment. How many drugs are being evaluated?

Andrew Wilson-Webb: There are currently 71 drugs available through the CDF; I think that that is the correct figure. Some of those may well be de-listed, but new drugs will be introduced over a period of time.

To answer your question about what happens in the long term, the cancer drugs fund was only ever meant to be a short-term solution. There are alternatives to the CDF. There is one thing we have been looking at for quite some time. In 2013, the pharmaceutical industry entered into a contract with the PPRS in respect of pricing, where there was a cap on the total budget for cancer drugs in the UK. Any spend over and above that effects a rebate back to the Government. Sadly, although those rebates are being repaid to the Government, they are not going back into cancer, which was the original intention. If they were going back to the right place, in the longer term, effectively, you would not need a cancer drugs fund.

Q225 Geraint Davies: You heard me talk earlier about a fund of something like £280 million spread among 10,000 people, which is about £28,000 a head. Obviously, some patients will consume much more money, because that is the average.

Andrew Wilson-Webb: Or much less.

Q226 Geraint Davies: Or much less. I was talking about the distribution. The other thing that strikes me is that a lot of people who have severe cancer and whose life expectancy may be only a few weeks are desperate to try any drugs that may save their lives. Can you give any examples of where patients have been prescribed very expensive drugs and have simply died a couple of weeks later?

Andrew Wilson-Webb: You have to look at it from a clinician's point of view.

Q227 Geraint Davies: Yes, but are there examples of that?

Andrew Wilson-Webb: Not that I know of.

Q228 Geraint Davies: None?

Andrew Wilson-Webb: No. You have to understand that a clinician will not prescribe a drug that he does not feel will work for a specific patient. In answer to your question, there may be one or two, but I think that there are very few.

I would also make a point about expenditure per patient. When the cancer drugs fund was originally formed, it was based on the assumption of £19,800 per patient. In 2012-13, the London cancer new drugs group carried out an audit of the cancer drugs fund. The actual average cost per patient was around £9,400. The reason for that was, obviously, that, if a drug does not work for a patient, it is discontinued. If you take it as an average, it was under £10,000 per patient.

Geraint Davies: Is there a danger—

Chair: Geraint, I know that this is an important issue, but I put you in as a supplementary. We have quite a few more to get through in nine minutes, if that is all right. If it is a very quick question—

Q229 Geraint Davies: It is. If big pharmaceutical companies do a lot of marketing on the internet, do you have situations where patients are demanding drugs available in America that are not tested, and putting pressure on GPs to prescribe them?

Andrew Wilson-Webb: Of course, GPs do not prescribe—it is the oncologists who prescribe. They are not allowed to advertise the drugs.

Q230 Jonathan Edwards: I have a question for Emma Hughes. You state in your evidence that IPFRs can be delayed by funding issues between LHBs and the Welsh Health Specialised Services Committee. Could you expand a little on that statement?

Emma Hughes: That is no problem at all. We have spoken to patients who have experienced really long delays in getting access to drugs because they have been pushed between the local health board and the Welsh Health Specialised Services Committee for funding. There are two types of prior approval. I described one earlier, which is for specialised services, but there is also a local health board prior approval process, which is for non-specialised services. Often, there will be a discrepancy and the funding will be bounced between each board, to say that they are responsible for funding. The patients believe that it is really a delaying tactic, so that they do not have to make available the funding for the service or the treatment.

Chair: Simon seems to have disappeared. Geraint, would you like to ask the last question? I will see whether there is time to ask Simon's for him.

Q231 Geraint Davies: You are suggesting that the current system is somehow failing, aren't you? What sort of changes would you like to see? How would you guard against opening a doorway when more and more people see things on American internet sites that make out that there is some sort of magic cure and keep demanding drugs that have not had proper trials, as you have said, at great expense and at the cost of not having NICE approve drugs for other people? How do you see things going ahead to improve the system?

Emma Hughes: For cancer drugs or just for any drugs?

Q232 Geraint Davies: For drugs you are aware of—NICE and non-NICE drugs for cancer.

Emma Hughes: We do not deal that much with cancer in Wales, but for the rarer conditions they are developing a process for appraising orphan medicines. That will be a national process and will look at wider perspectives—societal perspectives and the impact of the condition on the family. Having that broader scope for appraising medicines is the way forward for the more specialised drugs.

Q233 Nia Griffith: Obviously, it is very important that these orphan drugs are looked at. No drugs company will look at them, because they are already freely available and licensed for some condition, even if not for all. Are you saying that some special work is being done now by the Welsh Government to try to make those orphan drugs available to you?

Emma Hughes: Yes. We had a review of the appraisal process last year and work is under way at the moment. There has been a £1 million investment to develop a new process for appraising orphan medicines, to be undertaken by Professor Routledge from the All Wales Medicines Strategy Group. That is starting imminently, to be finished by September 2015, for a new process for appraising orphan medicines.

Q234 Geraint Davies: Pharmaceutical companies will try to promote the most profitable drugs, as opposed to the most efficacious drugs. If consumers of drugs—namely, patients—can demand drugs that do not work but make lots of money, and NICE is not imposing clinical standards, is there a problem that we end up wasting lots of money in the NHS just to fund pharmaceutical companies,

instead of providing the best care? Is that an intrinsic risk, Mr Wilson-Webb? I know that you are funded by the pharmaceutical companies.

Chair: What do you think, Mr Wilson-Webb?

Andrew Wilson-Webb: I take offence at that. We receive donations from the pharmaceutical companies, but we are completely independent and they have no say in any of the work that we do. You can check that on our website, if you like; it is very clear on exactly what we do.

I do not agree with your comment concerning the fact that a patient can insist on a drug to their GP or oncologist. That just does not happen. The oncologist will advise as to whether or not it is a drug that they wish to prescribe. I also disagree with the comment that you made concerning the fact that people can go on the internet and look up these drugs. All of these drugs, even if they are not licensed over here, will have gone through some clinical trials in order to become licensed. They may not have sufficient numbers to satisfy NICE under the current scheme, but that does not mean that they are any less effective or do not work for small patient populations. You have to be very careful—

Geraint Davies: But there are miracle cures with no evidence, aren't there?

Q235 Chair: Order. We have one final question; we have gone over this a fair bit now. You mentioned in your evidence that people have moved to England. That has certainly been highlighted in recent press articles. Would you both, therefore, like to see a similar system working in England and Wales—or perhaps even the same system?

Andrew Wilson-Webb: It would make sense—not just in England and Wales, but in Northern Ireland and Scotland as well.

Emma Hughes: In terms of better collaboration between the two countries, it would be sufficient if clinical reference groups in England and the All Wales Medicines Strategy Group could commission services and treatments so that they were more in line with each other, as long as they have been through a robust process and there is timely access.

Chair: We have managed to stick to time. I thank you both very much for coming.

Examination of Witnesses

Witnesses: **Jane Ellison MP**, Parliamentary Under-Secretary of State, Department of Health, **Ben Dyson**, Director of NHS Group, Department of Health, and **Ian Dodge**, National Director for Commissioning Strategy, NHS England, gave evidence.

Q236 Chair: Good morning. I can see that you are still getting ready, but I will gently start now, if I may, as we are running out of time. Thank you very much for coming along today. In starting, could you tell me whether you agree that it is very important that patients are able to cross borders freely in order to get the best possible health care? If so, how does the Department of Health keep track of them?

Jane Ellison: Yes, we do think that it is important that patients should move across the border if it is in their best interests. Clearly, different procedures are put in place by the two different Governments to track that; we have some detail around that, which I am sure we will get to. Welsh patients are important to some of the hospitals close to the border, but in England we have a clear policy of patient choice. We want to make sure that patients can move across the border, but we acknowledge that the way in which that is handled and the protocols and policies in place to do that can be quite complicated and have perhaps become a little more so over many years. We are

seeking to bring some clarity to that. We will welcome the Committee's report and advice in that respect.

Q237 Chair: Do you have a good personal relationship with the Welsh Health Minister?

Jane Ellison: I do have a good working relationship with him. Health Ministers across the four nations are working together closely on Ebola, for example, to make sure that the UK is prepared. I chair a four-nations Health Ministers meeting. At the most recent meeting, which was last week, we did some work looking at preparedness across the UK.

Q238 Chair: How often do you meet him face to face?

Jane Ellison: Unless you count video conferencing, which I suppose I would, we do not meet very often face to face in the same room. I have phone calls and video conferencing with him not frequently, but reasonably regularly.

Q239 Chair: Once a month.

Jane Ellison: At the moment that is true. In recent months, because of Ebola, we have increased the number of contacts.

Q240 Chair: When did you last meet him face to face?

Jane Ellison: I would count a video conference in that regard, so it would be last week. I do not think we have ever met in the same room. I have been Public Health Minister since last October. I cannot be sure whether any of my predecessors did.

Q241 Jonathan Edwards: We have had some very inflammatory political statements over recent months in relation to the Welsh health service. How has that impacted on your relationship with your counterparts in the Welsh Government?

Jane Ellison: Discussion of comparative health systems is a key part of political debate. That is entirely legitimate, but my relationship with the Welsh Health Minister remains a good working relationship. We have spoken about a number of different issues, not just the UK's preparedness for Ebola. From my point of view—obviously I cannot speak for Mark—it is a perfectly civil and sound working relationship.

Q242 Jonathan Edwards: We have received some evidence today that those statements have been demoralising for senior Welsh health professionals. Are you comfortable with those sorts of statements being made by the Prime Minister?

Jane Ellison: I entirely support what the Prime Minister, the Secretary of State and other Ministers have said about this. It is in the nature of our political debate that shadow spokespeople have made criticisms of the English NHS, so it is entirely reasonable and legitimate to make comparisons with Wales, where Labour is running the NHS. That is the stuff of politics.

Chair: It is an interesting area, but I am not sure that it is entirely relevant to our inquiry.

Geraint Davies: May I—

Chair: You may, but other people may then want to start talking about the English NHS.

Q243 Geraint Davies: It is relevant. If there is a distinction across Offa's Dyke as to whether or not you live, does that help integrated services across the border? We are investigating integration across borders. If the Prime Minister says that there is a straight line and you live or you die, surely that does not help integration, does it?

Jane Ellison: The Labour Front Bench, the Labour health spokesman and Labour MPs regularly attack performance by the English NHS. It is entirely legitimate that we as Ministers should draw attention to comparative health performance between the two systems, particularly where Labour is running the NHS. That is the nature of political debate, but it does not necessarily impact on having sensible collaboration at both official and ministerial level. That has always been the case.

Chair: With due respect to all members, this is the sort of thing that all members suggested we wanted to try to avoid, if possible.

Geraint Davies: Yes. We should not have had this hearing until after the election.

Q244 Glyn Davies: Can I get back to what I think we should be talking about? We have taken a lot of evidence on the way in which the cross-border protocol operates. At the moment, commissioning works on the basis of the GP practice, so sometimes you have people in one country being commissioned by a group in another country. How do you think that protocol is working when it is based on the GP practice, rather than on where the patient actually lives? What are the benefits and disbenefits of that?

Jane Ellison: Patients should be treated on the basis of residence, but, operationally, historically it has been on the basis of GP registration. We have now clarified the legal position in England. The next stage is to work with the Welsh Government and the NHS to ensure that there is English-commissioned secondary care for English patients. Clearly, it is a matter for the Welsh Government what services they want for Welsh residents. I do not know whether Ben or Ian would like to comment on the operational aspects of the protocol, at a detailed basis.

Ben Dyson: To the best of our knowledge, the protocol worked well for a number of years. During 2013, we became aware of concerns about the way in which it was operating. At that point, we established that there was an inconsistency between the protocol and the legislative position. We have been working since then to resolve that inconsistency.

Q245 Glyn Davies: You have just talked about the systems in England and Wales not being the same. Is work in development on the Welsh side in terms of how the protocol works? What is the ideal position that you would like to have? Would it be for treatment to be commissioned on the basis of where people live, rather than the practice they belong to? Is that where we would like to get to?

Ben Dyson: That is the legislative position. That is what we want to achieve in England.

Q246 Glyn Davies: Would the position be the same in Wales?

Jane Ellison: It is a matter for the Welsh Government.

Q247 Glyn Davies: I accept that. I was asking only whether you knew what the Welsh Government's position was. We do not know; we will have to ask them when we meet Mark Drakeford.

Jane Ellison: It is not something I have had a detailed discussion about. Obviously, I am answerable for the position in England. On a week-to-week, day-to-day basis, there clearly needs to be some collaborative working across the border. We have evidence of where that is happening, but we have clarified the position in England. I have now written to Mark Drakeford to say that to move to the next stage, in terms of getting clarity, we need to have a conversation and to work with the Welsh Government, but it is for the Welsh Government to define what is right for Welsh patients. This is not a recent thing. Health has been devolved for a long time, in effect, and has obviously been much more devolved since 1999, so it is something that has built up over a long time. We have tried to bring clarity to the English situation and are now working to find a way through.

Q248 Glyn Davies: There is one other point I would like to bring in on this. We have had the factual figures, in terms of the number of Welsh people who are treated in England and the number of English people who are treated in Wales. Those are different—20,000 go one way and 15,000 go the other. For the life of me, I have not been able to find out—even though I have asked the Library—what the cost of that is. The implication when the Welsh NHS gave us evidence was that there was a cost associated with that, which fell on the Welsh NHS in some way unfairly. I do not expect you to be able to give me the detail of that now, but can you make certain that we as a Committee have the information on whether there are any cost implications in that at all?

Ben Dyson: There may have been some confusion in some of the discussion of this thus far. It is absolutely right to say that the costs of the primary care itself—of providing general practice services—are borne by the Welsh or the English system, regardless of where a patient lives, but the costs of secondary care associated with those patients are ultimately met by the country in which they are resident. Although, in the first instance, a Welsh local health board will meet the secondary care cost for an English resident who is registered with a GP practice, there is then a reconciliation between the two countries. We can provide figures to indicate that cost. It is perhaps worth saying that the principle of providing primary care services on a knock-for-knock basis also applies across a broader range of services, including dental services, optical services and community pharmacy services.

Glyn Davies: The question that I asked was about primary care. I have had a reply telling me about the position in relation to secondary care, which is not what I asked about. I am interested in the position in relation to primary care, in terms of what costs might fall—

Q249 Chair: Broadly speaking, you seem to be confirming our impression, which is that Wales is not compensated for the extra 5,000 patients from England whom it treats.

Ben Dyson: Yes. The arrangements for primary care itself are dealt with on a knock-for-knock basis, but it is worth bearing in mind that there are other primary care services that operate on the same basis. For instance, the number of Welsh patients who receive dental services in England is greater than—

Q250 Glyn Davies: That is helpful.

Ben Dyson: If we were to look across the border at all of those services, we would be surprised if there were a significant difference between them.

Q251 Geraint Davies: I want to be crystal clear on this. We have heard that 20,000 people from England are registered with Welsh GPs and 15,000 from Wales are registered with English GPs. If an English person registered with a Wales GP is referred to a Welsh hospital for treatment, the cost of that is borne by the English NHS, not the Welsh NHS.

Ben Dyson: In the first instance, the Welsh local health board would meet that cost, but there is a subsequent process whereby the Department of Health recompenses the excess costs on an aggregate basis.

Q252 Geraint Davies: And the drug costs. Is the cost of the free prescriptions borne by the English NHS? If I register with a Welsh GP because I want free drugs and do not want to pay for them, is that cost borne by the English NHS?

Ben Dyson: As I understand it—I would need to double-check—the prescription costs would be met by the Welsh local health board, on the basis that that represents a primary care cost.

Q253 Geraint Davies: I see. These drugs could be quite expensive. Earlier, we were talking about cancer drugs, which cost thousands of pounds. If I were a cancer patient and I registered in Wales, the

cost of the NICE drugs that I would get—tested drugs, rather than magic drugs—would be borne by Wales, even though I was an English resident. That is true, isn't it?

Ben Dyson: It depends on whether those drugs are supplied by virtue of a GP prescription or whether they are provided as part of a hospital service. The more expensive drugs, like the cancer drugs to which you refer, would form part of a hospital service. The cost of that would be—

Q254 Geraint Davies: The cost of that would be borne by England, wouldn't it?

Ian Dodge: That is right; that is my understanding. In England, chemotherapy services are deemed to be specialist services, so they would be part of the package of secondary care costs.

Q255 Geraint Davies: Maybe we could have a note on the net costs of all of this.

Ian Dodge: Ben alluded to dental services. The figures that I have in front of me are that in 2013-14 there were 47,655 courses of dental treatment delivered in England for patients from Wales and 28,318 courses delivered in Wales for patients from England.

Q256 Chair: It sounds like we are losing out on the dentistry as well.

Ben Dyson: No, it is the other way round.

Q257 Chair: I see.

Ian Dodge: Hence the knock-for-knock arrangements.

Jane Ellison: It is also worth saying that £6 million goes to Wales each year for primary care. We can clarify all of this in writing.

Q258 Chair: If we could have that in a note, it would be very helpful.

Jane Ellison: That is an annual payment, precisely to cover some of this area.

Chair: We have had a lot of contradictory evidence on this.

Geraint Davies: So the English are removing Welsh teeth.

Q259 Nia Griffith: Thank you for clarifying that £6 million is paid for primary care as a block grant to the Welsh health service. Is that correct?

Jane Ellison: No. Apologies—the £6 million is just a general health grant, not for primary care.

Q260 Nia Griffith: Right. It is not related to the excess of 5,000 patients who are registered with GPs in Wales but come from England.

Ben Dyson: I think that I can clarify this. It goes back to my initial comments; apologies if those have caused some confusion. When an English resident registers with a practice in Wales, the secondary care that they receive by virtue of that is more expensive than that for Welsh residents registered with practices in England. It is the excess secondary care costs that the Department pays to the Welsh Government.

Q261 Nia Griffith: To clarify this, at the initial registration stage, 15,000 Welsh people are registered in England and 20,000 English people are registered in Wales. You are saying that no specific money is given to the Welsh Government in respect of the primary care stage for that initial excess of 5,000.

Ben Dyson: Correct.

Q262 Nia Griffith: Are you also saying that at secondary stage those who are resident in England will have their care funded by NHS England or their local commissioning group and that often comes in at a higher cost than care provided in Wales at secondary level?

Ben Dyson: Yes. Because, as you have said, a slightly greater number of English patients are registered with Welsh practices than vice versa, it is not surprising that the secondary care costs associated with those patients are higher. For that reason, the Department of Health meets the excess cost by paying a block grant to the Welsh Government.

Ian Dodge: From the information that is available, it is not apparent to me that either the Welsh NHS is subsidising the English NHS in aggregate or vice versa. There is clearly a transfer in relation to secondary care, to which Ben has alluded. In primary care, you have touched on the difference in the number of patients registered on each side of the border. For a number of other services, including dental care, pharmacy care and services such as open-access sexual health services, there are potentially commensurate flows the other way. I do not think that there has been any published study that calculates the aggregate effect of this and works out whether the English NHS or the Welsh NHS is losing out.

Glyn Davies: A note would be very helpful.

Q263 Nia Griffith: Traditionally, in the border areas many Welsh patients have gone for secondary care to hospitals in England. How do you find that the arrangements for payment for that treatment in England by local health boards in Wales are working? Are they working satisfactorily?

Ian Dodge: This is very much a matter for the local commissioners and providers of services. They are in discussion, as they are with other commissioners of services, including English commissioners. This is a continuation of practice for many years—for English hospitals, since the creation of the internal market in 1990. Generally, I would characterise relations between Welsh commissioners and English providers as not obviously worse than those between English commissioners and English providers. They will have discussions—

Q264 Nia Griffith: You are saying that the same sort of administrative issues arise, whether it is Welsh-English or English-English.

Ian Dodge: Absolutely so. They have local resolution procedures in the event of disputes.

Q265 Nia Griffith: Can you tell us whether there are any specific advantages to the payment by results system or the block grant system—that is to say, the system used in England and the system used in Wales?

Ian Dodge: Gosh—that is a very big question. NHS England, with Monitor, has been reviewing the future direction of financial flows and payment systems in England. Recently, we published a long-term strategy, which I will be very happy to forward to the Committee. There have been a number of issues associated with different forms of payment systems. In relation to block funding, there can be challenges in relation to unfairness, supporting patient choice and getting the incentives right to provide timely care. There are issues in relation to capitated payments as well. There is further work to do to continue to evolve the payment systems in England. We are making some progress along those lines.

Q266 Nia Griffith: What would happen if there were a disagreement between a provider in England and an LHB in Wales about how much should be paid? What processes exist for resolution of those sorts of disagreements?

Ian Dodge: My understanding is that the providers and commissioners would go through a dispute resolution process, which would be set out in the agreement between the commissioner and the provider.

Q267 Nia Griffith: And there is such an agreement between Welsh LHBs and providers in England.

Ian Dodge: Absolutely so.

Q268 Geraint Davies: I know that we have spoken at some length about the 20,000 people who are English and are registered in Wales and the 15,000 who are Welsh and are registered in England. It seems to me that the 20,000 from England registered in Wales can have free drugs. If they have expensive drugs, they are likely to choose that. The 15,000 who are registered in England have to pay for their own drugs, because the prescriptions are not free. Just so that I am clear on this, do you have any figures on the overall cost to the Welsh NHS of having to pay for 20,000 people's drugs? As I said, the 15,000 going the other way pay for their own.

Ian Dodge: No, I do not think that we do, nor do I believe that we have the converse figures for the Welsh residents who are registered with English practices who would have access to, for example, the cancer drugs fund in England.

Q269 Geraint Davies: But some of the drugs that people get are for chronic conditions—Crohn's and that sort of thing. In England, those patients have to pay for their own drugs; in Wales, they do not. If you had Crohn's disease, for instance, and you registered in Wales, the Welsh NHS would pick it up. If you registered in England, you would have to pay yourself. Can you provide us with those figures?

Ian Dodge: I do not know whether they are collected centrally.

Q270 Geraint Davies: This is a huge amount of money.

Ian Dodge: Nor am I am aware of whether there is an aggregate net benefit across drug costs, bearing in mind the differential arrangements for secondary care. One of the 15,000 Welsh residents who are registered with an English practice would have access to the English NHS in relation to arrangements such as the cancer drugs fund that may not be available in Wales.

Geraint Davies: I was thinking of general drugs, not just cancer drugs. If you have 20,000 people getting free drugs—

Nia Griffith: Can we be absolutely clear about this? A Welsh patient registered with an English GP, even though they were living in Wales, would have the same access as a patient in England. That contradicts slightly what we have heard in some of our previous evidence sessions.

Q271 Chair: It does a little. Does anyone know for certain about that? Maybe you could write to us.

Ian Dodge: My understanding—we will check this—is that if you are registered with a—

Jane Ellison: It might be better for us just to write to you on it. There is no doubt that this is quite a complicated area of policy. We want to assist the Committee with the most accurate information possible, so I suggest that we write to you on that point.

Q272 Jonathan Edwards: In the past there have been high-profile occurrences of English hospitals refusing to treat Welsh patients because of a shortfall of money from Wales. Could that happen again?

Jane Ellison: I have not had those examples brought to my attention in the time that I have been the Minister. I would be concerned about that. That does not ring quite true. I do not know whether Ian can comment on it.

Ian Dodge: In relation to emergency care—both ambulance services and urgent and emergency care services—the arrangements are very clear: patient safety is paramount. That has been a long-standing principle. I am not aware of any examples where there has been a problem in relation to urgent and emergency care. I have not had brought to my attention examples in relation to planned care. It may be that as part of the local discussions we alluded to earlier there have been conversations between commissioners and providers around fair reimbursement for the work that is being completed by a provider.

Ben Dyson: For planned care, we would expect commissioners and providers to have contracts in place, as Ian has mentioned, that set out in advance what payment can be expected. There should not then be questions raised in relation to specific patients.

Jane Ellison: We are quite clear in relation to emergency care. Ambulance services in Wales and England work together to ensure that there is an immediate response where life is in danger and that patients are taken to the nearest appropriately equipped A and E.

Q273 Jonathan Edwards: Are you aware of any examples of Welsh LHBs owing money to English providers, and vice versa?

Ben Dyson: At the moment, we do not have central information on any money owed by Welsh local health boards, although we would expect, by virtue of the accounting requirements that are now placed on us by the Treasury, to have information on that in due course.

Jane Ellison: It should be in the 2014-15 accounts.

Ben Dyson: I apologise to the Committee. We do not have it in the 2013-14 accounts.

Ian Dodge: Clearly, there will be moneys owed by Welsh commissioners to English providers, just as there will be moneys owed by English commissioners to Welsh providers. Within the information that we will get, we will not necessarily see whether or not there is a differential position between the amount of debt provided by Welsh commissioners and the amount provided by English commissioners.

Jane Ellison: Exactly. As an English Health Minister, I would expect English providers to pursue money that they are owed. If any Member of Parliament is concerned because their local trust has spoken to them about that sort of issue, my door is open to hear from them. No English Members of Parliament have met me specifically to say that that is an acute problem in their area. Some concerns have been expressed in Parliament about those sorts of pressures, but no one has specifically come and said that there is a major problem of non-payment to an English provider. If there were, we would expect that to be pursued vigorously.

Q274 Glyn Davies: This is a very significant issue in my constituency, in terms of what people believe. Huge numbers of people still write to me on a regular basis on the assumption that the Welsh NHS is not paying the Shropshire hospitals for treatment. That used to be the case. I remember that there was an arbitration case; I think that £1 million passed between the Powys local health board and the Robert Jones and Agnes Hunt hospital.

Several years ago, before a new protocol came in, there were regularly such issues, but it is still a huge issue in terms of public perception. Anything that you can do to provide assurances to this Committee will be helpful. I tell people that it is no longer an issue, because I am asked about it regularly, but there is a real challenge for both sides of the border to remove the perception that Welsh LHBs are not paying for emergency treatment, in particular, that runs rather larger than the contract agreed before the year started. It is still a really big issue in public perception.

Jane Ellison: It is useful to know that from your constituents' point of view. The new position in the 2014-15 accounts will be considerably more helpful in terms of greater transparency. We are clearly moving towards that. We have not been in a position to offer that in the past, but there will be a clearer picture going forward.

Ben Dyson: Some of the confusion may arise from the fact that some activity, like A and E, has been provided on the same knock-for-knock basis that we described earlier. There will always be some categories of hospital expenditure that are not covered by cross-charging arrangements.

Q275 Jonathan Edwards: I have one quick question. How important are Welsh patients to ensure that English hospitals are viable? We have had evidence that the Cheshire hospitals are reliant on Wales for 20% of their footfall. How vital are those patients?

Ben Dyson: The way in which we would see this is that those hospitals have evolved their services over time to reflect their natural catchment areas. It is not surprising that the Countess of Chester has developed its services to meet the needs of patients living in the catchment area covered by Powys health board, where there is not a local DGH.

Q276 Geraint Davies: There have been suggestions that Welsh patients receive second-class treatment in English hospitals, because they are pushed further down the waiting lists for financial reasons and decisions about when they are seen are made not on a clinical basis but on a financial basis. How would you respond to those?

Jane Ellison: I will let Ben or Ian come in on the detail, but it is important to make the point that they are treated to the standards commissioned by the Welsh health service. We would not want to see any patient treated as a second-class citizen. What you are describing is merely the difference between two different levels of provision that are being given as commissioned.

Ben Dyson: I cannot see any reason in principle why an English provider would be unwilling to enter into a contract with a Welsh commissioner to enable a patient to be treated to the same standards as apply in England. It is very much a choice for the local health board and the Welsh Government.

Q277 Geraint Davies: But if an evaluation of a Welsh patient and an English patient were done by an English consultant—by which I mean a consultant living and practising in England—one would be treated more quickly than the other, wouldn't they?

Ben Dyson: Not necessarily. The key difference is in the maximum waiting time. There will inevitably be some cases where people are approaching the maximum 18-week period in England. At that point, the hospital will make strides to make sure that they are treated within that period. Clearly, there will be large numbers of people who are treated well before that maximum period arises.

Q278 Geraint Davies: In your view, a clinician working in England and seeing two patients, both of whom were acute, would treat them on the basis that they were acute, rather than think, "The Welsh one can wait a bit longer."

Jane Ellison: Can I be very clear? No one is saying, "The Welshman can wait a bit longer," in the sense in which you have presented it. The Welsh have set a 26-week waiting time standard. The Welsh Government can decide to set a different waiting time standard. In England, we have set it, in that equivalent example, at 18 weeks. That is a decision for the Welsh Government.

Q279 Geraint Davies: As Mr Dyson mentioned, those are maximums, which are very important. I was asking whether, in practice, people who presented with acute conditions would have the same treatment. Mr Dyson suggested that they would.

Ben Dyson: For urgent and emergency care, certainly, one would not distinguish. The sorts of elective cases covered by the 18-week or the 26-week wait, as the case may be, are for planned care that is not as urgent.

Jane Ellison: We know that in England, very sadly, roughly 25% of cancers are still diagnosed in A and E. Were that diagnosed in an urgent or emergency setting, it would be treated appropriately.

Q280 Chair: That leads on neatly to my next question. There have been suggestions in the press—in fact, I have met people who say that they have done this—that people have moved from Wales to England to receive cancer drugs that are not available in Wales. Are you aware of numbers of Welsh patients doing that? If so, what is your opinion on that movement?

Ben Dyson: I am not aware of any information that would enable us to quantify the number of cancer patients—

Q281 Chair: Presumably, because they have already moved to England so they will not show up as being different from anyone else.

Ben Dyson: It is very difficult to distinguish between what may be a number of potential reasons why somebody has moved from one place to another.

Q282 Chair: This is a political question, I suppose, so it is really for the Minister. Do you think that there should be a single system across Wales and England with regard to treatment that has been approved by NICE?

Jane Ellison: If we are talking about something like the cancer drugs fund, setting up a fund in Wales is a matter for the Welsh Government. I know that there has been considerable discussion of this recently and that the Welsh Secretary has urged the Welsh Labour Government to go in that direction. We would like Welsh residents to be able to access life-prolonging cancer drugs, for example, but it is a matter for the Welsh Government. There is no cancer drugs fund in Wales. We are very proud of what has been achieved by the cancer drugs fund in England in terms of the many thousands of people whose life it has enhanced.

Q283 Geraint Davies: We have heard different evidence on this. One position has been that just to have NICE drugs is in the interests of efficacy and value for money. On non-NICE-approved, non-trialled drugs, there is expenditure of something like £280 million across 10,000 to 15,000 people—an average of £28,000. It may be the case that in the English system we are spending a lot of money on drugs that are not properly tested, for people who do not live very long, at the expense of drugs that are NICE approved, efficacious and value for money. You cannot have it both ways, can you?

Jane Ellison: We are quite clear that the cancer drugs fund has significantly enhanced the lives of 55,000 cancer sufferers. It is something that the Government have said is important for the English NHS. We see in our constituencies, and people write to me all the time about, people who have had extremely significant life-enhancing treatment because of the cancer drugs fund. It is something that we regard as very important in the English system. As I said, it is up to the Welsh Government to decide whether to do something equivalent. I am sure that any points such as the ones you have just made would be relevant for you to discuss with the Welsh Government.

Q284 Geraint Davies: Do you have data on people for whom a lot of money has been spent on these drugs and who have lived only another couple of weeks? Are there examples of that?

Chair: We are straying off the subject a little.

Q285 Geraint Davies: Who knows whether it is a waste of money?

Ben Dyson: I am not sure that I can answer that question directly, but NHS England operates a very careful prioritisation process. Indeed, recently it consulted publicly on some changes to the operation of the cancer drugs fund to make sure that the treatments that it offers are prioritised effectively.

Jane Ellison: I am quite surprised to hear somebody call the cancer drugs fund a waste of money.

Geraint Davies: No. I was—

Chair: Order.

Geraint Davies: I asked whether you knew of individual cases—

Chair: Order.

Geraint Davies: Hold on, Chair. I asked whether there were people who did not live long on whom we had spent tens of thousands of pounds. That is a waste of money.

Chair: Geraint, this is not about the cancer drugs fund in England. The reality of a Committee discussion is that the witnesses will usually end up having the last word. That is the just the way it is in any Committee.

Q286 Nia Griffith: I am sure that we all want to continue to try to make improvements in services. The chair of the cancer drugs fund, Professor Peter Clark, has admitted that some drugs that have been provided have not been of particular value and have not delivered particular benefit to patients. Minister, I am sure that you will be reviewing the whole way in which the fund operates. Are there any particular bits of advice that you might give to the Welsh Government if they were going to set up something similar? Do you think that there would be advantage to joint, cross-border working, for the sake of having greater efficiency at national level, or that there should be separate paths?

Jane Ellison: On the first point, as Ben Dyson has made clear, there are processes in place to ensure that there is some rigour and a process around the cancer drugs fund and that all of those things are able to be reviewed. We all have an obligation to make sensible use of money, in the context of the policy decision to have the cancer drugs fund.

With regard to advice to Welsh Ministers, it is up to the Welsh Government to decide to go down that path and to have a cancer drugs fund. Some people have called for it. If they were to decide to do that, I am sure that Ministers in England, equivalent officials and NHS England would be willing to have discussions about their experience of the policy. Our doors are always open. We are one United Kingdom. In the same way as much research and good practice is shared between our nations, I am sure that we would be willing to do that.

We have made that offer on the urgent and emergency care review, which in England was led by Sir Bruce Keogh. I have made the point personally a couple of times during Health oral questions that we would be willing, were the Welsh Government to decide to do a similar review, to share the learning from Sir Bruce Keogh's work in England. If a policy decision were made to go in that direction, we would want to be helpful.

Chair: With all due respect to both you and Geraint, we are not going to discuss the English cancer drugs fund; it is not relevant to us.

Q287 Jessica Morden: This morning, we have again had various examples of frustrations with IT compatibility, including people talking about real delays that affect day-to-day patient care. How much have you discussed whether you could have a similar, compatible IT system between the two areas?

Ian Dodge: My first observation is that the issue of IT inter-compatibility is not simply a cross-border issue—it is a wider issue across the NHS and, indeed, other health care systems. We are looking to address that in England by building on the use of the NHS number as a single unique identifier. I understand that that number applies also in relation to Welsh patients.

We have been developing standards for inter-operability for local IT systems in England. Locally, we would expect local commissioners and providers to be discussing how, in relation to cross-border flows, they can look to join up information flows in the best interests of patients. At the moment, there is not a joint programme of work between NHS England and the Welsh Government around central IT arrangements. We are entirely open to further conversations with the Welsh Government, should that be an area of mutual interest.

Q288 Jessica Morden: That is good to hear. Realistically, how difficult do you think it would be to sort out some of these problems?

Ian Dodge: Historically, it has been a difficult issue to tackle within England alone. Across the border, if the Welsh Government wanted to introduce the same inter-operable standards as are being introduced in England, that would clearly help from an English perspective, but that would be a matter for the Welsh Government to consider.

Ben Dyson: It is worth emphasising that the key aspect of the work that NHS England is doing here is to develop those standards that allow for inter-operability of different systems, rather than putting all of one's eggs in one basket and thereby relying on a single national IT system. In principle, I cannot foresee a reason why the Welsh health system could not take advantage of those standards to achieve inter-operability, where it made sense in the interests of patients.

Q289 Jessica Morden: Do you appreciate that it is a real problem? Have you seen some of the evidence that we have had on the lengthy delays in getting people's test results?

Ben Dyson: A key feature of many discussions that are going on in England at the moment to understand how we can better integrate care is the provision of consistent information along a patient pathway, with IT systems supporting those information flows. That is at the heart of a number of new care models that are being developed.

Q290 Glyn Davies: Again, the basis of my question is the relationship between the Department and the Welsh Government in relation to health matters. We are facing a position in mid-Wales—I represent Montgomeryshire, but it is a bit wider than that, certainly towards the west—where both in Shropshire and in Wales the health service is not sustainable; it cannot carry on. There is major change—future fit—in Shropshire. In Wales, there is Marcus Longley's report on the west coast and the future of Bronglais. These are huge issues. The decision taken in one of those places has a major impact on the other. For Bronglais to survive, it needs Newtown, which is an important part of Shropshire's current treatments.

The Shropshire services are so important. Telford and Shrewsbury are the two existing hospitals; there is a possibility of having one emergency care centre in between them. What really worries me is that in a year's time, probably, the biggest issue for the Montgomeryshire MP, whoever that is, will be maintaining reasonable access to secondary care treatment for the people of Montgomeryshire. At the moment, it is hugely confused. The only reassurance that I want is that the Welsh Government and the Department will speak to each other, so that if a decision is taken in relation to Bronglais we will understand what the impacts of that are in Shropshire, and vice versa. That is the basis of my question.

Chair: Can I chip in and add to that? A very similar situation is happening in Monmouthshire with the Aneurin Bevan health board. It has contributed to a discussion about development in the Forest of Dean, but a lot of people feel that it is not being properly listened to, although it will become

responsible for providing primary care services to Forest of Dean residents. It happens the other way round as well. Do you think that there needs to be much more consultation on both sides?

Jane Ellison: It is clearly an important issue. There is a slight challenge for me, as a Minister for England. My door is open to English MPs who want to come and talk to me about issues similar to those that are being described; indeed, I have had meetings with several of the most affected English MPs, some of whom the Committee has taken evidence from. I can appreciate that it may be more difficult—I do not know whether it is—for a Welsh MP to go and see the person who may be making those key decisions, but if Mark Drakeford rang me and said, "I have had people come to see me who are concerned about how this will work in the future. Is this something we can talk about?" I would say, "Of course we can talk about it." That is not an issue that he has raised with me, but that would be the order.

I have raised with him the issues that I am tasked with trying to resolve on behalf of English MPs and English patients. My letter to him last week, ahead of this Committee meeting, said that we would like to talk about the next stage of work through the post-protocol world, but the equivalent conversation needs to happen in reverse. If he were to say to me, "Can I talk to you about this and the consequences going forward?" of course I would be happy to do so. It would not be for me to raise the specific example that you have given, but the equivalent example for English MPs is something I am engaged with and have met with him on.

Ian Dodge: Could I add to that? In NHS England, we want to see that patient interests are put paramount and that commissioners and providers, as they are designing and delivering services, are engaging effectively with the users of those services. That means the natural communities, irrespective of whether someone is a Welsh or an English resident. That is the critical principle. That is how the system has developed in practice.

It is worth mentioning that the local NHS in England has a duty to co-operate with other statutory bodies, including its Welsh partners. Through the consultation processes that it has, involving not just local Healthwatch but having public meetings and engaging with users of services, including people who are resident in Wales, it will be looking to do that. I have heard a number of leaders of English providers say that they will not distinguish in practice between a Welsh citizen and an English citizen as they are thinking about the design of those new services. It is very important that those arrangements around community engagement work as effectively as possible.

Q291 Glyn Davies: The point that I was making is that there is a reorganisation of services in Shropshire, which is part of the English NHS, that is hugely important and will have a huge impact on Montgomeryshire. There is a similar exercise taking place in Wales, which involves the building up of the hospital in Aberystwyth to serve the whole of the population of mid-Wales. What I am seeing is that the underlying principles of both are contradictory. At that level, we need to have a serious debate about what is the right thing for patients in future. At the moment, my constituents are in the middle of this. There is a real worry that their interests will not be taken seriously when decisions are made in England—and perhaps in Wales.

Jane Ellison: Can I make a quick point? If you wanted to come and see me with the English MPs who would be similarly affected by the particular arrangement that you have just described, I would be very happy to have a conversation and to listen to those concerns. As Ian has outlined, there is not just an expectation but a requirement for English providers to co-operate, where appropriate, taking into account the historical actual distributions of population and leaving aside where the border is.

Q292 Jessica Morden: You alluded earlier to the complexities of the two health systems. This morning, we had witnesses who said that they thought that some GPs and clinicians were not aware of the cross-border protocol. We have certainly had patients give evidence to us on their choice of GP and not being aware of what that means in terms of future treatments and referral. What more do you think we ought to do to raise awareness both among GPs and clinicians and among patients about what these decisions could mean?

Ben Dyson: This will need to be a key feature of the work that we are doing with the Welsh Government and the Welsh NHS to review the operation of the protocol. We have to do that anyway, for the reasons that we have mentioned earlier, as it has become clear that it does not support the legislation in England. Once we have settled upon a way of giving effect to that legislation that works for patients and in the best interests of those who wish to register on the other side of the border, an essential part of what follows will be to engage with local communities to make sure that they understand the effects of the protocol. We will do that in partnership with NHS England, the Welsh NHS and the Welsh Government.

Q293 Jessica Morden: What practical measures could that include?

Ian Dodge: At the moment, if you look on NHS England's website, we have frequently asked questions for patients—for example, what does it mean in terms of waiting time standards if I register with a practice in Wales? That material is there and up to date.

As part of the work that we are taking forward with the Welsh Government, we want to resolve the problem around the rights of English residents. I can see three theoretical scenarios here. The first is that one attempts to close the border and accepts that the two systems are totally separate. It seems to me that that runs contrary to the whole spirit of the conversation that we have been having here this morning and to putting the interests of patients and communities paramount, so I do not think that that is the right solution.

The second approach is simply to recognise that English patients who are registered with Welsh practices do not receive their NHS constitution rights in relation to either a legal entitlement to choice or maximum waiting times. Clearly, that is very problematic and is not something that we can duck. We need to find a way of addressing that.

The third option is that those patients who are registered with Welsh practices receive English standards and entitlements. That contrasts with policies of the Welsh Government as to the equal treatment of Welsh-resident and English-resident patients on a GP's list. We are working with the Welsh Government to try to resolve that conundrum.

Q294 Chair: Can I finish by asking one last question, on the issue of redress? The Welsh Assembly Government have a system for allowing redress for English or Welsh patients being treated in Wales. As I understand it, there is a system of redress for English patients being treated in England but not for Welsh patients being treated in England. Is that the case? Is something being done to address that inequality?

Jane Ellison: Welsh patients receiving care in England are entitled to redress.

Q295 Geraint Davies: Mr Dodge seemed to be suggesting that we wanted to move towards a situation where English patients with a Welsh GP sustained their English rights. Would that mean that they would be denied the right to have free prescriptions? I presume that it would, because that would not be an English right. Are you saying that you think we should move to a system where English people resident with Welsh GPs should not have free prescriptions?

Ben Dyson: In the protocol that we are reviewing, we are looking essentially at what happens in terms of secondary care when somebody registers with a practice on the other side of the border.

Geraint Davies: I was wondering whether it was a case of wanting to have your cake and eat it.

Q296 Chair: Brecknock and Radnor community health council has said that England does not operate a redress system. Would you disagree with the evidence that it gave?

> ***Ben Dyson***: The position is exactly as the Minister has described. If a Welsh patient receives services commissioned by the Welsh NHS in England, they are entitled to redress under the relevant Welsh regulations.

Chair: In that case, thank you very much, Minister.