HOUSE OF LORDS

Select Committee on the European Union

Home Affairs Sub-Committee

Corrected oral evidence
Brexit: Reciprocal Healthcare

Wednesday 1 November 2017

10.30 am

Watch the meeting

Members present: Lord Jay of Ewelme (The Chairman); Lord Crisp; Lord Kirkhope of Harrogate; Baroness Massey of Darwen; Lord O'Neill of Clackmannan; Lord Ribeiro; Lord Soley; Lord Watts.

Evidence Session No. 9 Heard in Public Questions 68 - 76

Witnesses

I: Fiona Loud, Policy Director, Kidney Care UK; Robin Hewings, Head of Policy, Knowledge and Insight, Diabetes UK.

Examination of witnesses

Fiona Loud and Robin Hewings.

Q68 **The Chairman:** A very warm welcome to you both. Thank you very much for coming to give evidence to us for this inquiry. We are very grateful to you and looking forward to hearing what you have to say. We regard this as an important session.

The meeting is in public and is being webcast. The proceedings are recorded in the usual way by *Hansard* and we will send you a transcript after the session so you can send back any corrections you might have.

It would be helpful for us if you could introduce yourselves and the organisations for which you work. If either or both of you want to say anything initially before we move on to the questions, that would be fine, too. Who would like to go first?

Fiona Loud: Good morning, Lord Chairman. Thank you very much indeed for inviting Kidney Care UK to come and talk about how this issue may affect kidney patients, specifically those on dialysis. Kidney Care UK is a national patient support charity. We give advocacy, counselling and grants to kidney patients who are in difficulties because their kidneys have failed. Their income will be low, so we pay for people's funerals. We also give grants for people to go on holiday, which is relevant to what I will say later. We work with hospitals and fund some posts in hospitals, too. I am policy director of the charity.

My main thrust today will be about those kidney patients—29,000 people in the UK—who depend on dialysis to stay alive. Of those, only 5,000 are even well enough to be on a transplant list to get an organ donation. So you can see that a fair group of people could be affected by the inability to receive reciprocal healthcare in other countries.

I will explain about dialysis. The majority of dialysis is called haemodialysis: there are two needles in the arm which take the blood out, cleanse it through a machine and filter off the fluid that your natural kidneys—which are no longer working—would remove, and then put it back into your body. That must be done three times a week for four or five hours a time, and that gives you about 10% of your normal kidney function. You can see that it is very important to be able to receive regular dialysis wherever you go.

At the moment, patients who wish to travel in the EU can use their EHIC card to receive treatment at the same rate as residents of that country; in other words, free of charge. The ability of people who are tied down by dialysis in the way I have just described to travel and of their families to get out and about is of course incredibly important, whether it is for work, as for some of the younger patients, or to take a holiday, which of course applies to everybody. I am sure everybody here appreciates the right to be able to travel. But without that EHIC card and without being able to do that easily—in terms of how the process works; there are always issues with capacity, of course, and I may discuss those later on—

we have heard from a lot of patients who are really worried about the impact of that.

The Chairman: Thank you. You have raised a number of points there, some of which we will come on to in the discussion. Mr Hewings, do you want to say a little bit about your organisation?

Robin Hewings: Would you like me to introduce the condition in a similar way?

The Chairman: That would be helpful.

Robin Hewings: I am head of policy, knowledge and insight at Diabetes UK. I work with a team of people focused on thinking about how we can improve the lot of people with diabetes through better health services and less discrimination. Diabetes UK is just over 80 years old. It brings together healthcare professionals and people with diabetes to do research, to better understand how we can have better health services for people with diabetes, and to counteract the discrimination that people with diabetes might face at school, in the workplace or in other parts of their lives, such as driving. We also provide lots of direct support for people with diabetes. We help bring them together in local groups. We provide telephone support and even children's holidays so that children with type 1 diabetes can connect with other children with type 1 diabetes and learn more about their condition.

On the condition itself, we estimate that around 4.5 million people live with diabetes in the UK, of whom about 3.5 million are diagnosed with diabetes. That 1 million gap is overwhelmingly people with undiagnosed type 2 diabetes. The issue is the definition of whether you have type 2 diabetes. There is a long-term measure. The problem that diabetes causes is that you have too much glucose in your bloodstream and that can do long-term damage to your microvascular and macrovascular system, putting you at risk of all kinds of complications to your eyes, kidneys and feet, and more macrovascular complications such as heart attacks and strokes.

There are two main types of diabetes. Type 1 is an autoimmune condition, which can come on at any time in a person's life. Usually the onset is quite severe. Essentially, with type 1 diabetes the cells that produce insulin, which enables people to convert glucose in their bloodstream to energy, are attacked through an autoimmune response which we do not really understand. That means that essentially you have to manage your insulin through injections or the newer pump devices, which can do it in a better way. That is something that you are managing all the time.

Type 2 diabetes tends to come on in later life, really quite slowly, which is why many people do not realise that they have it. Among people in their 20s, really quite small numbers have it. Among people in their 60s or 70s, around 25% have type 2 diabetes.

That is a quick tour d'horizon of what diabetes is and a little bit about what the organisation does for people with diabetes.

Q69 **The Chairman:** Thank you very much indeed. That is a very helpful introduction from both of you. I will move on to the questions. The first question, which I think Fiona Loud touched on, is: do you have any data on how many British citizens require treatment for kidney conditions or diabetes when they travel to the European Union or the EEA, and how often they access that treatment? Do you have any idea of how much that costs? Who wants to go first?

Fiona Loud: There is a range of answers to that. NHS England has a specific policy covering reciprocal healthcare, which covers what we call dialysis away from base. If a patient goes away, whether in the UK or the EU, there is a policy called the dialysis away from base policy so there is the opportunity to collect those figures, but we understand they are not collected across the EU.

The Chairman: No other country collects them?

Fiona Loud: These are the inquiries that I have made. The NHS Business Services Authority helpline stated that it does not keep a record of the number of people who dialyse in Europe. The DWP oversees a department helpline and says it is not aware of whether the numbers are collected and it does not think it has the resources to differentiate between the different uses of the EHIC card. I have the overall EHIC numbers. I can refer to them later. There are millions of those given out every single year. The DWP referred us to NHS England and the Department of Health, which also do not collect those numbers. I can offer figures based on our work, which are really estimates, if that is helpful.

Kidney Care UK, as I said, gives grants so that patients can travel. In January to June 2017, we gave £250,000 for 291 patients on dialysis to take a holiday break and 115 of those went to an EEA country. We do not pay for the dialysis treatment; this is money to go away.

We work with a partner organisation, Kidney Care Dialysis Freedom. We sponsor it in the UK to run a dialysis swap service, but it also has a foreign travel advice service. It tells us that in the last two years it has arranged for 1,704 patients to travel to the EU. It says that after people have been away the first time they may build their confidence and are likely to do their own thing the next time round. So we think that that 850 is significant underreporting; it is likely to be more than double that. Of all dialysis patients, it is not a huge number, but even if it is 2,000 or 2,500, that is still a group of people who will be directly and severely impacted by this.

You ask about costs. If people were to go privately, EU dialysis units charge between €250 and €450 per session. Remember that there are three sessions every week, which is why it becomes so difficult for

dialysis patients to travel if they have to pay it for themselves. Units in the Canaries charge between €200 and €300 a session.

To mention a couple of other points on that, the EHIC card specifically states that for "treatment for long-term (chronic) conditions and existing illnesses, such as kidney (renal) dialysis treatment", it allows access to state-provided healthcare in all EEA countries, but each country's health system is slightly different. With your EHIC, you should be able to get the same treatment as a resident of the country you are visiting. In some countries, you might have to pay a patient contribution, which is known as a co-payment. Some providers require a co-payment of up to 20%, so there can be a payment to be made in some countries.

The Chairman: That will depend on the National Health Service requirement of that country.

Fiona Loud: That is absolutely right.

To add a little more to that, if the renal unit to be used within the EEA is not a state-provided renal unit, the patient will need to pay for the treatment themselves and can then apply for a refund through the cross-border team of NHS England, so they need to get approval before they go. That is done under a European directive called Article 56. This refunds the cost of what the NHS would have paid for dialysis, so we always advise people to get their arrangements sorted out in advance, so they can be sure of getting their refund when they come back.

Finally, I have something on dialysis on a cruise ship, if that is of interest. Subject to clinical approval, if the cruise—that is, river or ocean-going cruises—is within the boundaries of, or the majority of the cruise ports of call are to, an EEA country, you can be reimbursed in the same way up to the cost of the tariff. Again, it is about getting the approval in advance and being able to give receipts back when you go.

Is that comprehensive enough?

The Chairman: That is very helpful. Thank you.

Lord Ribeiro: I am slightly confused. I started off with the belief that the EHIC card provides you with urgent and emergency care. You have been talking a lot about what I would call preplanned care, which is S2.

Fiona Loud: That is right. The quote I read is from the EHIC website, which specifically says that it will cover "treatment for long-term (chronic) conditions and existing illnesses, such as … dialysis".

Lord Ribeiro: So, that is separate from the S2 arrangement, which is preplanned?

Fiona Loud: Yes, this is a specific arrangement that covers dialysis patients.

The Chairman: Do you know whether that exemption or arrangement is

specifically for dialysis or for any other long-term health condition?

Fiona Loud: I cannot advise on that. I can only tell you about dialysis coverage, but it does refer to "long-term (chronic) conditions and existing illnesses", so other conditions may also be covered by it. The only example I have been given was from some inquiries from the Scottish Government about people who need oxygen, but that is not my area of expertise.

The Chairman: That is very helpful. Thank you.

Robin Hewings: Similarly, diabetes is quite a data-light area. It is likely that the numbers are significant, particularly if one thinks of people retiring to France or Spain, given that, as I said earlier, about a quarter of people in those age groups have type 2 diabetes, but we do not have figures for the overall number of people with diabetes who are resident in other European countries, or vice versa—those from other EU countries who are resident here.

The Chairman: That is very helpful

Q70 **Lord O'Neill of Clackmannan:** You have given us very helpful figures for UK citizens going to EU and EEA countries. Do you have any stats on people coming into the UK and getting treatment under the reciprocal arrangements?

Fiona Loud: We do not have those stats, but I have done some investigation, so I can offer you what I have. As I said, we do not know how many EU or EEA citizens access dialysis treatment in the UK. We understand that it is quite difficult for EU patients to obtain spaces for dialysis at NHS units because of capacity issues, as you can imagine, but we also understand that private units in London provide that service. We have been told, for example, that some patients from Germany can access them because they have a different public healthcare insurance system, so they can obtain that private dialysis.

The Chairman: So they can get private dialysis because of insurance.

Fiona Loud: That is right, because of the insurance they have in their country.

The Chairman: They are not paying for that.

Fiona Loud: That is right. Those private units charge about £300 a session, so people coming from non-EU countries—from the East or wherever—would be paying £300 per session. We do not have those figures. You also asked about costs. The NHS tariff is about £30,000 a year for someone on dialysis. That includes the dialysis sessions, the supporting drugs and transport.

If I may, I will add one other thing. We have been in touch with a group called the European Kidney Health Alliance. It said that it has not had any specific comments back from its members—who are, obviously, kidney

patient associations from the different countries in the EU—about kidney dialysis itself. Its comments went wider than that, and I can expand on that later, if you wish, but it is more to do with clinical research, clinical trials and rare diseases—that side of things.

Lord O'Neill of Clackmannan: From what you have said, the dialysis treatment is by way of using machines. Is there any evidence that these machines are being taken up by people coming to the UK at the expense of UK patients?

Fiona Loud: We have no evidence of that nature.

Lord O'Neill of Clackmannan: How many hours a day are these machines in use? Is it just from nine till five?

Fiona Loud: No. Depending on the unit or hospital, they will often run three shifts a day, so they may start at seven in the morning, run another at lunchtime and many of them will also run twilight sessions, so NHS staff will be dialysing patients— including any visiting patients, if there is a slot—at any of those times. UK patients will be given a slot, so they know that they can regularly turn up on Monday, Wednesday and Friday at 7 am.

There is a smaller group of patients who can using that method at home, or a different method, which is called peritoneal dialysis, which uses the process of osmosis through a port in the stomach instead. That uses a machine as well. Both of those are smaller machines, and those patients will still need to be able to carry their machines with them when they travel, but I will talk about them later on because of the rules that cover their ability to carry that equipment.

Robin Hewings: We have no real data on the extent to which EU citizens use diabetes services in the UK. Having said that, I have never heard of someone moving to the UK from another European country to use diabetes services, because basic diabetes care is not very expensive.

Q71 **Baroness Massey of Darwen:** Thank you for coming. I assume that EU member states vary somewhat in their approach to long-term effects. Is it easier for the people you represent to access treatment, for a start, in certain EU member states?

Fiona Loud: I do not know whether it is easier but I know that it is working well at the moment. Certainly, there is a well-established and well-understood process for patients to book their dialysis in those EU countries, particularly the holiday-type destinations.

Baroness Massey of Darwen: Is this all EU countries?

Fiona Loud: No. I have particular data on that. For example, in southern Ireland it is almost impossible to get dialysis through a state unit because there is a capacity issue, which we share here; whereas in places such as Spain or the Algarve, which are popular holiday destinations, capacity has grown because of demand. I may not have mentioned earlier that

although some of our patients are younger, the majority of people on dialysis tend to be slightly older, which relates to the diabetes comments we heard earlier. So if you are going to those holiday-type destinations, you are more likely to be able to access your treatment. That is because they are the more popular places. In the places that are not so much holiday destinations, where people may be travelling for different reasons, I understand that it is quite easy to obtain dialysis.

Baroness Massey of Darwen: Can you give examples of countries that are less well equipped to do this?

Fiona Loud: It is not that it is less easy, it is just that there is more capacity in other countries. I have mentioned southern Ireland. You need to book quite a long time in advance. You can get dialysis in places such as Greece, France, Switzerland, Spain and Portugal—all those countries will be familiar with providing dialysis to visitors. Equally, in Germany and some other countries, dialysis provision is available through the EHIC card.

My main source of knowledge is those grants we give to kidney patients and those tend to be the countries that they visit. We hear from people that sometimes they have to compromise and choose a different destination, but people are advised to get their dialysis booked before they actually put money down on going somewhere.

I can quote from the husband of a patient, Steven, whose wife Amanda has had a transplant in the past but is unlikely to be able to have another because for some people it is very hard to obtain a transplant because of issues with previous transplants. In his blog he describes feeling trapped because of his wife's dialysis treatment, but that nevertheless she has a terrific attitude to life and wants new experiences, and that the ability to travel and see things without the tethering of dialysis or being tied to the UK is incredibly important. He says it gives them the sense of freedom that they feel is lost to them. It is that spirit that I am—I hope not going over the top about—really passionate about being able to preserve, whatever happens in the future with reciprocal healthcare arrangements.

Lord Watts: You mentioned Ireland. Is it difficult there because it is not state-funded?

Fiona Loud: There is state funding; the issue is capacity. There is absolutely state-funded dialysis there. It can be more difficult. It is not impossible, it is just that we have had feedback that it is more difficult to achieve there.

The Chairman: Do you have anything to add to that, Mr Hewings?

Robin Hewings: No. The issues with diabetes are quite different because the general style of diabetes treatment is that people need medications but they do not need treatment three times a week. For short-term holidays, they would stock up on medications before they go. If they are going somewhere for two weeks, they can easily make sure that they

have that quantity of medication. Then they need to think about refrigeration if they treat their diabetes with insulin, as do all people with type 1 and about 25% of people with type 2. But you do not need to worry about booking a holiday in advance in the same way.

Q72 **Lord Crisp:** On kidney patients at least, you have given us a clear view that most of your people access healthcare through the EHIC scheme. Do you have any sense of the numbers of people who might be accessing it through S1, S2 or the patients' rights directive?

Fiona Loud: We do not have a clear sense of that, but we always tell patients that in case something else happens to them while they are away, they should take out insurance anyway. It is more likely, unfortunately, that if you are on dialysis—or, indeed, if you have had a transplant—other incidents will occur that will require visits to hospital, et cetera, which may need some other cover.

On expats—which is probably what you are getting at—particularly in places such as Spain, we do not have those figures. Of course, we are aware that there are people in those countries who will be using the S1, for example, to access local dialysis services. I have already referred to the fact that people may retire to those countries. We do not collect those numbers. We tend to support patients living in the UK. It is not that we would not support others, but they would not necessarily come to us for that level of support. Of course, there are people for whom it is incredibly important to be able to receive those services in the countries where they reside. We just do not have those numbers.

Lord Crisp: We will stick with kidneys and come to diabetes in a moment. The other question—which I think you will tell me you do not have figures for either—is: are there any British citizens resident in one country in Europe who actually receive services in another country?

Fiona Loud: From the point of view of dialysis, that is not that likely, but I suppose it is possible in somewhere such as Switzerland, on the border with France. Typically people would want to be within half an hour of their dialysis unit, simply because of travel, but we do not have those numbers.

Lord Crisp: May I ask the same question about diabetes? How many British pensioners in Spain have diabetes—do you know?

Robin Hewings: No. I think we can say that S1 is likely to be particularly important because diabetes is a condition that is associated with being older. You will access treatment like a resident and it is a condition, particularly type 2, which is looked after mainly in primary care. My sense is that S1 is particularly important and that the numbers would be, as a proportion, fairly similar to British pensioners here, but that is an educated guess, really.

Q73 **Lord Watts:** I think I know the answer to this question, but just to clarify: what reciprocal healthcare priorities would your stakeholders hope to see reflected in any potential withdrawal agreement and what sort of

transitional arrangement would they like to see? I gather they probably want what they have now. Is that right?

Fiona Loud: Absolutely. What we have now—whether it is the EHIC, which I have been particularly talking about, or the S1—for the sake of all patients, we would want those arrangements to continue. If they were not able to continue, we would want to see similar arrangements being made with each individual state. But of course, the preference is to keep a system that is working in the way we have described to enable people to receive their care and to give them the ability to travel, because trying to pay for it in another way is prohibitive to most people, as I hope you will understand.

Lord Watts: So the model that we have now is the one that you want to see in total, and, if that cannot be achieved, individually negotiated with each member state?

Fiona Loud: We would have to agree with that. We would hope that each individual state would think, "That is fine. It works well enough for us at the moment and we want to see it continue working".

The Chairman: Are the people you look after showing anxiety or concern at the moment about what the prospects might be when we leave the European Union? Are people nervous about what might happen to them in the future?

Fiona Loud: Absolutely. I quoted one partner of a patient. We have numerous testimonies from other patients. One, Nicola, says: "If I can go away on holiday periodically, then I'm good. I can cope with my life on dialysis and I can live a life that is all the happier for it, but only if I can go away".

That summarises the situation. People are incredibly worried about that precious ability to travel with their families, and to do so without the fear of having to pay £1,000 a week to go away. As I have already explained, travel insurance in the UK will not cover that for people. That covers a range of people. The lady I just referred to is one of the people who has been waiting a very long time for a transplant, even though she is in only her 40s. For her, and her young daughter, travel is incredibly important. There are many other patients behind her who are older, and perhaps not as articulate in expressing their fears; we hear from them and we support them through our different services. That is a real concern for people at the moment, absolutely.

The Chairman: What about diabetes? Will people be able to take whatever they need to take to other parts of the EU after we have left? Is that a concern for you?

Robin Hewings: For short-term holidays, it is less of an immediate worry. That is more for people who would be living in other countries for a longer period. It would become quite a big problem for them if it became much harder for them to access basic primary care.

I want to underline that we have made a lot of progress on good diabetes care in this country over the past 15 years. It is about reaching the millions of people who have diabetes with some relatively inexpensive checks, helping them either to manage their type 2 diabetes through diet and lifestyle or to go on to some relatively inexpensive drugs, in the first instance. That helps them to avoid the much more serious implications of diabetes that are devastating to the individual but very expensive for the NHS, such as end-stage renal failure, heart attacks, strokes, foot amputations and blindness. All of those are really costly conditions. Work done on this a few years ago found that the primary treatment of diabetes costs the UK about £2 billion, but the complications of diabetes cost us about £8 billion.

If we put a system in place where it is harder for people to access basic primary care, the risk is that we store up serious complications for the future. That goes for both UK citizens in EU countries and vice versa; it is really important that EU citizens living here are accessing basic primary care, and that they are being diagnosed earlier. I said earlier that there are around 1 million people living with type 2 diabetes who do not yet know it; that is a lot better than it used to be. Also, people used to be diagnosed with serious complications already apparent. People who work in the service would say that is now much less common and that people are being picked up before they develop too many problems, through things such as the NHS health check. If you had such a system, from both sides of the fence, you would have big problems. We did some work on that over the summer, which showed that people who receive the basic checks on how their diabetes is being looked after—blood pressure, cholesterol and a long-term measure of glucose levels—were half as likely to die than people who had not received all the checks, but only a few of them, over a period of seven years. This is basic stuff: getting to people early really works. Anything that puts that in danger is likely to be a much more expensive system for people on both sides of the fence.

Lord Kirkhope of Harrogate: You mentioned travel insurance a few moments ago. Can you confirm to us what the current position regarding obtaining insurance for these two conditions is when you travel? Is it very expensive? Is it difficult to get it at all? In the event of there being no reciprocal healthcare arrangement that is satisfactory from your point of view, what would that do, if anything, to the insurability of the people you represent when travelling in the EU?

Fiona Loud: As you know, travel insurance does not like pre-existing conditions. I am sure we have all seen that before. Travel insurance does not cover dialysis, so you cannot receive cover for it.

Lord Kirkhope of Harrogate: You cannot get it.

Fiona Loud: No. In this country, at the moment, travel insurance will not pay for dialysis in another country. However, we always recommend that patients take out travel insurance because of other issues that may happen to them. They will pay a very high premium because of the pre-existing condition, which opens you up to many of the things Robin

described. Of course, we share so many things; diabetes is one of the key causes of kidney failure. To be clear, at the moment, travel insurance does not cover dialysis treatment. I cannot predict what will happen in the future, apart from the fact that it would be incredibly expensive if it ever became available. We just do not know what will happen in the future.

Lord Kirkhope of Harrogate: I know about diabetes. My wife is diabetic. Whenever she travels in Europe and so on, although she has cover, she has to give an indication of her condition. She has to notify people that she is diabetic to see if there is any loading, as it were, on the costs. I wonder, in the case of diabetes, how would companies look if there were no reciprocal contribution?

Robin Hewings: I looked into this before giving evidence. It is difficult because if you have just been diagnosed with diabetes, have not developed any complications and have all the medication with you, then that kind of insurance is likely to be a little more expensive than what you would normally pay for, but nothing like what Fiona has been talking about. However, if your diabetes has developed complications, or you have had problems, then the costs will mount up.

I was trying to work out a way of answering your question, to be frank. In a way, because diabetes is so heterogeneous, trying to give an overall response is quite hard. If you have diabetes and have developed end-stage renal failure, then you are in exactly the same situation as the one Fiona described. If you have type 2 diabetes and manage to control it with diet and exercise, when I looked into it, you would pay about 50% more, but you would not pay loads to start off with. I was looking at a European country that did not have EHIC membership; two weeks was £12, but if you had type 2 diabetes and no other problems, it was £15. I think it is something like that, for an S1.

Lord Kirkhope of Harrogate: Do you think, if there was no reciprocal arrangement for the contribution made currently, that would be the sort of percentage, in terms of normal diabetes, that would increase premiums?

Robin Hewings: Yes. I looked at a European country that was not a member of EHIC—Serbia. It is not a million miles away from other European countries, and all the rest of it, so it felt like a reasonable comparator. It was about 50% more expensive there, but it was not as expensive in the first place. Short-term holidays are not the big problem for people with relatively straightforward diabetes; it is with longer-term residents that the risks of their not accessing treatment would mount.

Lord Ribeiro: On the question of travel insurance, it is clear from the briefing document you sent us from Kidney Care UK that the Government get it. You made the point about point 49 in the government position paper, "Safeguarding the position of EU citizens in the UK and UK nationals in the EU to ensure people on dialysis can continue to travel". Clearly, there is a strong government position on that.

Fiona Loud: We hope so, yes.

Lord Ribeiro: Have you received anything else from them directly as to how that would be achieved?

Fiona Loud: No. We have written, but we have merely had an acknowledgment of our letter. We have not heard anything more than that, but we believe it is important to make sure, as I am doing today, that it does not get forgotten in the larger picture. That is the problem: in a very large picture with many other things going on, the importance of this type of issue is in danger of being lost.

Lord Ribeiro: That seems to be a commitment.

Fiona Loud: I hope so.

Q74 **Lord Ribeiro:** Can you tell us how non-residents of the EU 27, when visiting the UK, can access healthcare for long-term conditions, such as the S2 arrangement, post Brexit? Might those groups need to fall back on private insurance, because you recommended even to your own people when going overseas, to Europe, to get private cover?

Fiona Loud: We simply do not have that information. It would be hard to suggest what might happen. We would hope that if a reciprocal arrangement was put in place, it would continue to work both ways, as it should. That is all we can say at the moment. We would hope that would continue, and continue both ways.

Lord Ribeiro: I am talking about the Europeans coming over here. Many things can be accessed on the NHS by virtue of the fact that they are considered urgent. As you know, you can turn up to A&E, even with a dialysis problem, and probably have a substantial amount of your initial management free on the NHS, because it is an acute problem. Do you know whether the diabetes or renal groups in Europe are considering the sort of cover they should provide for their patients, should we leave the EU? Do you have any feedback from any groups?

Fiona Loud: No. I will just look at what the European Health Alliance told us when I made some inquiries prior to this committee. It said that it has not directly received kidney patient testimonies about the impact of Brexit on access to dialysis care, but it has heard other concerns about the regulation of medicines, patient access to medicines, patient involvement in clinical trials, research collaboration and general healthcare access. Again, as you say, it is about the acute admissions and unplanned ones, on the other side of travel. That is all the information it has provided to us.

Lord Kirkhope of Harrogate: May I ask about the table, as it were, in terms of health? Some people here argue that the Europeans need us more than we need them. Those are some of the arguments that float around in this place; perhaps not in this place, but along the corridor quite a lot. Some of my colleagues will probably know the answer to this, but in terms of diabetes and kidneys, where are we in the European table

of illnesses, on the numbers and percentages of those with diabetes and those who need dialysis? Are we high up? Are we low down? Or is there no difference between European countries?

Robin Hewings: This is where I do have some data. The International Diabetes Federation has compiled research; obviously there are slight differences between definitions and coverage and so on. We are in a broadly similar position to countries such as Germany and France. The prevalence of diabetes is somewhat higher in southern European countries.

Lord Kirkhope of Harrogate: Higher?

Robin Hewings: It is a lot higher. We are in a broadly similar position. Diabetes prevalence varies a lot. If you go to the UAE, for example, it is many times more. In the US, it is double what it is here.

Lord Ribeiro: I know we will come back to this on supplementaries, but would it be possible to have that data? One of the indicators of diabetic management in different countries is amputation rates. If you have a country with higher such rates, the management of diabetes may not be as good. If you have some data on that and could let us have it, it would be helpful.

Robin Hewings: I will ask and find that out.

Lord Ribeiro: How healthy are our kidneys compared with the kidneys of Greece and Germany?

Fiona Loud: In terms of data, there was a *Lancet* study earlier this year, which I can supply you with.

Lord Ribeiro: That would be very helpful.

Fiona Loud: It looked at the incidence of chronic kidney disease, the precursor to kidney failure, but part of the diabetes spectrum. Again, that can affect between 4% and 6% of people in our country.

The Chairman: 4% and 6%?

Fiona Loud: Yes. Between 4% and 6% of people in this country will have some form of chronic kidney disease, many of them as a result of ageing, which will go nowhere near kidney failure. The information Robin has given about annual checks—blood pressure, renal function et cetera—to make sure that your risk of diabetes is going down and being appropriately managed with the right drugs is incredibly important. We echo all those comments about prevention.

The *Lancet* has done an international study. I can provide figures, but not off the top of my head. I remember that, from the numbers on dialysis, the prevalence in Germany was higher. There are 29,000 people on dialysis in this country. There are 60,000 people who have had kidney failure; the other half have had kidney transplants. In Germany, there

are 100,000 on dialysis. That is echoed by the higher prevalence of CKD there as well.

In Spain, fewer people are on dialysis because, as you may be aware, it has a different consent system for organ donation, which we will not go into today. They achieve about double the rates of organ donation that we do in this country at the moment. So, there will be slightly fewer people on dialysis, partly to do with that. I can give you that data on different countries in detail as part of the submission we make after this meeting.

Lord Crisp: May I come in on that interesting data? Presumably, the demographics and the ageing are bigger issues than the differences between countries. Is it right that there are more older people from the UK living in Spain than younger people from Spain living here?

Fiona Loud: Yes—absolutely. That would be entirely logical.

Lord Soley: Are there other ways in which people you represent may be affected by potential changes in reciprocal healthcare that we have not looked at or considered?

Robin Hewings: I cannot think of any.

Fiona Loud: We have a couple of examples. I have already mentioned the first, but I want to be clear, because it was part of something else. It is the ability of people who dialyse themselves at home to take those machines with them, if they use small machines—some people use big machines and it is not practical to take those with them—along with some of their kit. Under EC regulation 1107/2006, people have the right to carry their equipment and anything associated with it on a plane, free of charge. There is a regulatory guarantee there. We would want that to continue, because it prevents unfair treatment—that is, refusal of carriage on the basis of reduced mobility. The second thing is guaranteeing provision of assistance, free of charge, that passengers need for air travel. That is the first area to highlight.

The second, which is worth mentioning, concerns donated organs for transplant. We have an arrangement, regulated by our competent authority, the Human Tissue Authority, between EU members. So, if an organ—it applies to other organs, but really it is the kidneys and lungs that are affected—is given for donation and cannot be used in this country, we rightly have reciprocal arrangements across the EU and the Republic of Ireland to export it for use by another patient. Of course, that works the other way as well. It is highly regulated, because of the rules on organ trafficking. We have some very good regulations.

The Chairman: Who regulates that?

Fiona Loud: It is regulated here by the Human Tissue Authority. There is a whole EU set of policies around that as well. The figures are quite small. I can supply them in evidence if you want. The figures we have from an NHS blood and transport report say that over the past three years, 50

organs from deceased UK donors were transplanted into Republic of Ireland or other EU residents, and 74 came back the other way, which were all kidneys. It is important to remember that issue as well.

Lord Soley: Those are both areas where you might need a special arrangement, particularly on organ transplants, because of the dangers of trafficking. Presumably you can do that separately from the health card system.

Fiona Loud: Yes, it is covered by completely different regulations. It was a European Parliament body that set these arrangements up, in conjunction with all the EU member states, in order to make that work.

Q75 **Lord Soley:** What about people travelling to non-EU or EEA countries? Do they just not go? With diabetes we are thinking about long-term care, the equivalent of S1. If you go to the States or Canada, for example, presumably they have to make some special arrangement.

Fiona Loud: With dialysis patients, there is a reciprocal arrangement with Australia as well, but it depends on capacity down there. But if people go to other countries—for example, quite a large proportion of dialysis patients may be black or from Asian countries, because diabetes affects those ethnicities particularly—they will pay.

Lord Soley: Wherever they went, they would have to pay?

Fiona Loud: They would have to pay or make their own arrangements. For example, if you travel to the States, you need to pay the local dialysis provider. Again, you have to book it in advance but you would need to pay. It would be $200 or whatever per session, depending on the part of America you went to. Of course, insurance for going to the States is especially high, as you can imagine, compared with other countries.

Lord Soley: Presumably in both cases, if you went as an employee of a company, the company might make the arrangements. Does that happen very much?

Robin Hewings: Yes. You would join the local private or social insurance system in the normal way.

Fiona Loud: We are aware of people—not kidney patients but cancer patients—whose companies pay for their long-term care. But eventually they had to return to the UK because the insurance policy would not pay after a period of time, because these conditions are incredibly expensive.

Lord Soley: What I am driving at here is that in both cases, but particularly with kidneys, it is very difficult for people if they go anywhere other than an EU country or one which has special reciprocal arrangements.

Fiona Loud: It is an additional obstacle for people. But some people do travel because it is really important to go back to your homeland. I gave

the example of America, where obviously it is pretty expensive, but in some countries it may not be anything like as expensive.

Lord Soley: Finally, what about countries where there has been a special relationship and where there are particular health problems, such as Caribbean countries?

Fiona Loud: People do travel to the Caribbean for their dialysis.

Lord Soley: Is that relatively easy to arrange for them or not?

Fiona Loud: They have to make their own arrangements for that.

Lord Soley: And for diabetes?

Robin Hewings: Similarly.

Q76 **Lord O'Neill of Clackmannan:** You are both UK organisations. In the event of us finally getting to the leaving point, do you anticipate the negotiation of arrangements being different between Wales, Scotland, Northern Ireland and England, each of which has different health jurisdictions? You have negotiated these arrangements with other countries in the past. Do you anticipate this being a big problem, or do you think it should be able to be handled by our negotiators without too much difficulty? We could be looking at 108 different sets of negotiations, if we took one from each jurisdiction and then all 27 members. Have you had any assurances from the Government that this will be all for the best in all possible worlds, or will it be a very difficult thing to transact?

Fiona Loud: I am just looking for some correspondence we had from the Scottish Government. I cannot find it. I will have to provide it subsequently. We wrote to the health departments in each of the four nations and we have not received anything back that says that that would be a problem. What we have received—for example, from the Scottish Government—was a commitment that they absolutely understand the need. I have not received anything that has indicated that it would be a problem. That does not mean it is not the case, but I can only tell you about what we have received. We have not received anything indicating that each of the four nations wishes to do something separately. My understanding is that the UK Government made those original arrangements, although I have been quoting from the NHS England policies because I know them best; it is not because other policies do not exist. We really hope that that will be the case, because it would be a little easier that way.

Lord Ribeiro: One thing you said earlier about the number of organ donations or transplantations suggested that we were the net beneficiary of organs.

Fiona Loud: We are. That is what the numbers show.

Lord Ribeiro: There has been a debate in the media recently about the whole question of consent. How much of this is due to presumed consent,

particularly in Spain, where people are obliged to allow their organs to be used for transplantation?

Fiona Loud: We could have a very long conversation about consent. I do not have any evidence to support that. But there are of course 27 of them and one of us, so it is more to do with the balance of numbers than anything else, but that is just my assumption. I do not have any evidence.

Lord Ribeiro: It has implications for the UK when we leave: the pool of organs will be considerably reduced.

Fiona Loud: If that were not addressed, it would. I noticed that yesterday there was a Written Question from Vince Cable on just that matter, so we might want to look out for the Answer to that.

The Chairman: Thank you very much indeed. Is there anything that we have not asked that you think we ought to have done, or that you would like to tell us that we have not given you the opportunity to do?

Robin Hewings: No.

Fiona Loud: I would just like to thank you very much for the opportunity to explain what the impact of this will be on kidney patients, and to say that there are lots of kidney patients anxiously awaiting the outcome of the negotiations. I hope that if there are any further questions, we will be able to answer those satisfactorily. Thank you very much.

Robin Hewings: For diabetes, this is less imminent in people's lives. There are not lots of people with diabetes very worried about this in the same way as kidney patients, but the long-term dangers of a breakdown in reciprocal arrangements would also be very severe for people with diabetes.

The Chairman: Thank you very much indeed, both of you. You have been extremely helpful to our inquiry and we are very grateful to you. As I said at the beginning, we will send you a transcript of the hearing for you to make the necessary corrections. Thank you very much.