

# Public Accounts Committee

## Oral evidence: Services to people with neurological conditions, HC 502

Monday 14<sup>th</sup> December 2015

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Members present: Meg Hillier (Chair); Mr Richard Bacon; Deidre Brock; Kevin Foster; Mr Stewart Jackson; Nigel Mills; Stephen Phillips; John Pugh; Karin Smyth; Mrs Anne-Marie Trevelyan.

Sir Amyas Morse, Comptroller and Auditor General, Adrian Jenner, Director of Parliamentary Relations, Laura Brackwell, Director, National Audit Office, and Marius Gallaher, Alternative Treasury Officer of Accounts, were in attendance.

*Witnesses:* Arlene Wilkie, Chief Executive, Neurological Alliance, Dr Paul Morrish, Consultant Neurologist and adviser to the National Neurology Intelligence Network, and Geraint Fuller, former President of the Association of British Neurologists, gave evidence.

**Chair:** Good afternoon, everybody, and welcome to the Public Accounts Committee. We are here today to consider the progress in implementing recommendations that the previous Committee made to improve services for people with neurological conditions.

Over 4 million people suffer from neurological conditions, and these can have a very severe impact on their health and quality of life. What is clear from the NAO Report is that progress in the last three years has been mixed at best. Good progress has been made against only one of the six recommendations that the previous Committee made. This raises for us the wider question of how seriously the Department and NHS England are taking forward recommendations made by the Committee. There have been some good steps—the appointment of a National Clinical Director for neurology, Dr David Bateman, the setting up of strategic clinical networks and some improvements in data—but we are concerned. We recently looked at diabetes and there are some parallels with that Report in the way that the system is dealing with people with long-term conditions.

We have two panels today. The first, which will last for about half an hour, includes Dr Paul Morrish, a consultant neurologist and adviser to the national Neurology Intelligence Network. Dr Morrish, you wrote an interesting article in *The British Medical Journal*, which we have been reading,

along with all the responses. I think Dr Fuller also responded to that, so we have been watching the debate through the pages of that magazine. We also have Arlene Wilkie, the chief executive of the Neurological Alliance—you can explain a bit more about that if you need to in your answers—and Dr Geraint Fuller, who is the former president of the Association of British Neurologists.

I should declare that my brother, Dr Charles Hillier, is a consultant neurologist at the Poole Hospital NHS Foundation Trust. I will hand over to Anne-Marie Trevelyan, who will lead off our questioning.

**Q1 Mrs Trevelyan:** I will begin with a question to all of you: how would you describe the experience of people with neurological conditions in terms of their relationship with health and social care services?

**Arlene Wilkie:** Thank you very much for inviting us to give evidence today. First, as the Chair outlined, an awful lot has been done by NHS England and Public Health England since your review in 2012. Leadership, data and so on have all been announced and awarded, but these things have only just happened in the past two years or 18 months, so we have not had much time to show the real impact on patients and their experience.

We did a survey on patient experience just a couple of years ago, and it is interesting that the service experience is very similar to what you announced in your Report of 2012. Diagnosis is still taking too long: the services in hospitals are variable across the country and there are not enough services—there are not enough neurologists and assessing teams to help with getting a quick diagnosis. When patients are out in the community, because they do not have care plans and there is a lack of co-ordinators and co-ordinated care, they do not have that key co-ordination of their care, and quite often that can result in those individuals going back into hospital, which costs the NHS money. Although a lot has been done—we must commend NHS England and Public Health England on what they have done—we have not been able to demonstrate improvements in the patient experience thus far.

**Dr Geraint Fuller:** I think “mixed” is probably the summary. Patients with neurological diseases, compared with patients with cancer and heart disease, for example, have really been left out. We are very much the Cinderella, partly because it is not one thing, but lots of things. We have a large group of people with lots of different types of illnesses—acute, chronic, and relapsing, a whole range—and it has almost been put in the “too difficult” box by a lot of people because there is no straightforward, formulaic way to evaluate it.

If we just look at it from the medical perspective—how we see patients and how patients are able to see us—for a new patient across most of England the out-patient wait is actually reasonable. It is not as good as one would like, and a lot of the time getting people to be seen quickly enough is a problem, but that has been a real focus for a lot of the reforms and targets that we have had—seeing the new patients relatively quickly. I use the word “relatively” advisedly.

The second group of patients are those who turn up to the hospital with an acute neurological problem. They have a very ropey set of services. In some places, particularly the neuroscience centres, they get a very good service because neurologists will pick them up and see them straight away. In neurology centres where the neurologist is based, they get a better service than they might—they will be seen, perhaps, four or five days in a week. That is quite a way from the seven-day service to which we are aspiring, but they still see them. If you are in a DGH—a district

general hospital—where the neurologists are visiting, it could be once or twice a week. Across the whole country, the median is three and a half days a weeks. In fact, in a lot of hospitals, if your constituents are admitted, on only three or four days of the week would they be able to see a neurologist. These are the sickest patients, so perhaps we have been focusing on the wrong end.

The other group of patients is those who have established neurological disease. Their problem is that they cannot get back in to see us. We will say, “Come back and see us in three months, four months, six months or whatever,” but because the pressure is on seeing new patients, the trusts do not have an incentive to allow us to see those patients as easily. That group has got squeezed, and they get a worse service than they deserve and require.

**Dr Paul Morrish:** There is something to add to that, which is that neurology is something that primary care is not very comfortable with. In surveys of GPs, it is always the one that they find most difficult, so patients go to their GP and the GP says, “Ah—neurology. Bit difficult. I need to find a specialist.” Of course, the specialist can be miles away, or can simply have a long waiting list, so patients fall into a very awkward gap.

**Q2 Mrs Trevelyan:** Thank you, that is very helpful. Why is it that so few of these patients have a written care plan once they are in the system? Why is that not working?

**Dr Geraint Fuller:** As is often the case, a care plan sounds like a really simple thing to describe, but is actually an extraordinarily variable thing. For patients who have limited capacity—patients with learning disabilities and epilepsy and so on—probably a very high proportion of them will have a care plan. However, other patients—for example, someone with reasonably well controlled epilepsy—will have a plan, but it will not be written in the form of a care plan. There has been some uncertainty about applying one model across all patients with neurological disease. We would like a plan for everyone, and we would like to engage with people, but we have not worked out exactly how that should be used.

**Q3 Chair:** Arlene Wilkie, you probably have more to say on this. I think you did some research on this showing that 11% of people had a care plan.

**Arlene Wilkie:** There is a real lack of care plans. I think there is possibly a problem with understanding what a care plan is and what it should contain. There are no incentives for CCGs to ensure that their population has a care plan, and we do not have the specialists in the community to help drive those care plans—nurses or co-ordinators. It is absolutely key that neurological patients get care plans, because once they have been diagnosed and they have a treatment plan from the hospital, they are then living in the community for a very long time with their condition, which can fluctuate or progress very quickly. As Geraint was saying, there is not one clear pathway for individuals, but our needs are very similar. We still need specialists. I think there is a lack of CCGs making it happen and a lack of specialists within the community to control, co-ordinate and implement plans for individuals.

**Chair:** Dr Morrish, do you have anything to add to that?

**Dr Paul Morrish:** I would add that you have only 15 minutes with a follow-up patient. Somebody who has Parkinson’s disease will come every four months or maybe six months, and in that 15 minutes, a care plan is not actually a priority for most of us. I think it could be.

**Q4 Chair:** But should the care plan be down to the consultant in the hospital, or should it be at an earlier level?

**Dr Paul Morrish:** I think it should be a joint plan.

**Q5 Mrs Trevelyan:** Do you think that not having that structured support for them—partly to empower patients themselves, but also for the different medical groups that might interact with the patient—is having a genuine detrimental impact on their long-term health, or is it just making it chaotic?

**Arlene Wilkie:** There is evidence from the MS Society and Parkinson’s UK—it was in your previous Report—that if there is a nurse or co-ordinator, they can identify individuals’ risk of developing, for example, the urinary tract infection or respiratory problems that would mean they would end up going back into hospital. I don’t have statistics, but I think if you had those individuals co-ordinating, you would prevent a large proportion of those readmissions to hospital, because they would be doing better and being kept well in the community.

**Dr Geraint Fuller:** I am not sure the care plan is necessarily the instrument by which that outcome would be achieved. To a certain extent, co-ordinators and specialist nurses, particularly for MS, Parkinson’s, epilepsy and MND, make a dramatic difference. They are very patchy as to how well and how widely they are provided. Some areas have them.

**Arlene Wilkie:** It also comes back to your point about self-management and independent living. When you have a plan, you are then able to live your life long-term in the community.

**Q6 Mrs Trevelyan:** Dr Morrish, do you think there is an impact in terms of having less structure?

**Dr Paul Morrish:** Care plans work in other conditions, so maybe we should be adopting them. I would say that we should, but as I said, it is another thing in the 15 minutes.

**Q7 Mrs Trevelyan:** Yes, you make a very clear point there. In your experience, what is the variation in service provision across England? There is some data on epilepsy.

**Dr Paul Morrish:** You know the waiting list figures. Something that we can do through the Intelligence Network is to look at the chance that an individual within a population gets to see a neurologist. In Camden, it was something like 2,470 in every 100,000 one year, whereas in Doncaster I think it was 190, so you are looking at a thirteen-fold difference in the availability of out-patients.<sup>1</sup> If you take that further and look at local out-patients, some CCGs offer no neurology out-patients in their area, so it is a huge variation, and that is just in the first step. When you come on to things such as what drugs are used, we know from intelligence that that varies up and down the country. We have even got things such as survival in epilepsy, which is probably the most useful statistic. If you

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<sup>1</sup> Figures clarified by witness after session

have epilepsy, your chance of dying of that condition varies 49% up and down the country.<sup>2</sup> There are huge differences and huge impacts.

**Q8 Mrs Trevelyan:** With epilepsy actually being given as an indicator to CCGs, are we seeing any improvement yet?

**Dr Paul Morrish:** Unfortunately, the one we did have that was very useful was 12 months seizure-free survival, and that varied—I think 46.5% was about the worst, and 87.1% was the best.<sup>3</sup> If you have good epilepsy seizure-free time, you are more likely to have a job, more likely to have a relationship and more likely to have a decent life. If you go down into the 40% side of things, it is pretty difficult. Added to that is that, actually, people who are more likely to be seizure-free are less likely to die from their epilepsy.

**Q9 Mrs Trevelyan:** So there is a continuing and compounding impact?

**Dr Paul Morrish:** Absolutely.

**Q10 Mrs Trevelyan:** And epilepsy is the only one that we are even looking at?

**Dr Paul Morrish:** Quite. We now have very good information on epilepsy—we have prevalence and we have seizure-freedom, although that has been taken away. We only had one year of QOF with that. Epilepsy is very good and, actually, in time we could do the same thing for the others, but epilepsy is one of our big illnesses, and if we could—I won't say crack it, but if we could start to get at it, we can apply those lessons elsewhere.

**Q11 Mrs Trevelyan:** In an ideal world, what one thing should NHS England do that would genuinely take us up a level in terms of supporting sufferers?

**Dr Paul Morrish:** I think, actually, the Intelligence Network is the key to finding out the difference in care in the different parts of the country. Far more than any drug or anything like that, learning what is happening with care in one CCG and applying it to another would make a huge difference.

**Q12 Mrs Trevelyan:** So data?

**Dr Paul Morrish:** Data—and ongoing data, so that when we intervene—put in a new consultant, perhaps—you can see whether things are changing.

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<sup>2</sup> Figure clarified by witness after session

<sup>3</sup> Figure clarified by witness after session

**Arlene Wilkie:** I think data is absolutely key to giving a national picture, as well as a local picture, so that CCGs and commissioners actually understand who is in their patch, who they are commissioning for and what they should be commissioning so that they can improve the services. Data is key. Again, as you picked up in your original review, clinical leadership at national level is absolutely key. You identified it as a problem before saying that local determination and local commissioning did not work in the NSF, so you identified clinical leadership as key. We are unsure as to the future of the clinical director position of the Intelligence Network. Of all the things that you recommended three years ago, we are unclear of the future beyond March. We believe that these must maintain, stay and develop, so I think that clinical leadership and data are key.

**Dr Geraint Fuller:** I endorse everything that has been said about data. We look at what the cancer networks have done, and it has all been data-driven. You discover that this is a bad area and you do things differently. Clearly, the data is going to be very important. Looking at the funding mechanisms could also be interesting. At the moment, people are paid to see a new patient, and they are paid a certain amount to see a follow-up patient. If you see a sick patient on the ward, there is no money in the system for that, so a trust has no particular incentive to get neurologists to see the sickest of the patients. There is no mechanism in place to do that. It might be that it doesn't need to be done with a specific mechanism, but you need something to make it a higher priority for the trusts to enable people with the most severe and acute neurological illnesses to see neurologists at an appropriate time.

**Q13 Chair:** Can I chip in on that? I think that in your article, Dr Morrish, you talked about “bizarre tariffs”. Am I quoting you right, or was it one of your respondents? Do you want to explain what you mean by that and what you want the NHS to do?

**Dr Paul Morrish:** Yes. A few years ago, I wanted to know how much each hospital was being paid for each patient it saw. There was no central store of that, with neurology having locally agreed tariffs, so I did a freedom of information request and got back all the tariffs. Seeing a patient in one hospital is £67 and in another it is £592, so the hospital is earning three times as much—they are bizarre tariffs.<sup>4</sup>

**Q14 Chair:** Really bizarre. It is interesting that you had to do an FOI request, as a working neurologist. I find that amazing. Do you have any understanding of why those differences were in place?

**Dr Paul Morrish:** I think it is long standing. There were local agreements, and it was never really looked at.

**Dr Geraint Fuller:** I think each tariff was derived on the basis of “How many patients do you see? How much money do you get? Let's divide one by the other, and that's the number.” That's where they started, because most of these things were introduced, effectively, as a way of allocating resource, rather than with a market-type philosophy in place.

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<sup>4</sup> Figures clarified by witness after session

**Q15 Karin Smyth:** Can I come back on a previous point about data and QOF? Dr Morrish, I think you were saying that QOF is picking up some of the epilepsy cases. I missed the point in relation to data. Can you expand on QOF and whether the change has been helpful?

**Dr Paul Morrish:** Sure. General practitioners earn QOF points, and various things are included in the QOF each year. One year, we had the percentage of their patients who were seizure-free, which was terribly useful. The next year that was dropped, so that very good measure of how well epilepsy is being managed disappeared.

**Q16 Karin Smyth:** So in relation to your wider data point, that is something to be regretted.

**Dr Paul Morrish:** Absolutely. It is the loss of a key figure on how well you are managing your patients' epilepsy.

**Q17 Karin Smyth:** Do you have any figures measuring how those conditions are being supported in primary care?

**Dr Geraint Fuller:** If you've got a patient who has epilepsy—we can all imagine this quite easily—and has had a couple of blackouts, and all of a sudden they can't drive, how much does that mess up their life? They can't get to work and all kinds of different stuff, so getting their driving licence back is a really big deal. You had a very simple and relatively robust measure, and it has been taken away. That seems very sad.

**Arlene Wilkie:** One of the things that you recommended was more indicators within the system to allow commissioners to understand what they can and should be doing. That hasn't been progressed at all for neurology. Again, if we look at priorities for DH and NHS England, we should think about indicators and how we can better measure improvements and services in neurology.

**Q18 Mrs Trevelyan:** Are there specific ones? As you say, it is not one disease but lots of diseases. Are there specific indicators that you, the specialists, would recommend because they have a high impact and therefore a high value?

**Dr Geraint Fuller:** There are some surrogate measures. Disease modifying therapy in MS is a wide range of different things, which are quite expensive drugs. We don't really know how many patients are getting which drugs where. We don't necessarily know what the perfect answer is, but if you had some notion of the distribution of funding, that wouldn't be a bad outcome. The proportion of your patients with MS who are receiving disease modifying therapy would not be a bad measure of MS therapies.

**Arlene Wilkie:** Understanding prevalence, I think. From the numbers we have, we can't tell you exactly how many people have a neurological condition.

**Mrs Trevelyan:** Fundamental data records.

**Dr Geraint Fuller:** Yes, really simple things.

**Q19 Chair:** Arlene, through the alliance, do you pick up any resistance from GPs to collecting that data, or any practical issues that we should be aware of and putting to the NHS?

**Arlene Wilkie:** I suppose it is an additional thing for them to do, and I suppose it is about what you would do with that information. That is why the Intelligence Network—if it is able to pull in GP data and match it up with hospital data, and we are able to give that information back—would show that it is being used. It is about incentives; they are not incentivised to do it.

**Chair:** Data is a bit of a theme in this Committee, whatever the subject—the NHS or anything else.

**Q20 Stephen Phillips:** Ms Wilkie, you made a reference to the recommendations of the predecessor Committee, and this is not for you, but it is for the witnesses who come after you. We made a specific recommendation, as you know, that neurological indicators should be included in the NHS outcomes framework and the adult social care outcomes framework. That has not happened, even though that recommendation was accepted. I am giving advance notice to Dame Una, whom I can see, of one of the questions that she is going to be asked: what has been the effect of that recommendation, which was accepted, not being followed up by NHS England and the Department of Health? What has it meant for patients?

**Arlene Wilkie:** What it means is that commissioners, at the end of the day, are not recognising neurology as a priority and something they have to look at. Because it is not filtering down from NHS England to say, “These are the things that you have got to look at and to measure,” they are not doing it. They are not seeing neurology as an issue. The data is not feeding into the Intelligence Network, so they are not then able to get the data back out to commissioners to let them know what is happening.

**Q21 Stephen Phillips:** Has the fact that that has not been done led to poorer outcomes for patients, even though we recommended it and it was accepted that it would be done by NHS England?

**Arlene Wilkie:** It comes back to the commissioning issue. Commissioners are commissioning neurology services, but the research that we did—we did an FOI survey—showed that commissioners do not know the population, do not know the service needs and do not know if services are actually improving outcomes. It is a bit of a cyclical thing: unless they start to measure it, they will not actually be able to demonstrate improvement.

**Q22 Stephen Phillips:** I think the fact of that answer—I will ask Dr Morrish and Dr Fuller as well—is that it has led to poorer outcomes for patients. Is that right?

**Arlene Wilkie:** Our survey, which was the very first survey of patient experience that we did—

**Q23 Chair:** Was this the August survey?



**Arlene Wilkie:** We launched it in July this year. It was the Neurological Alliance patient experience survey.

**Chair:** Sorry, I read it as dated August, but that would be the same one.

**Arlene Wilkie:** It is showing that services are not integrated or co-ordinated, and that they are poor for patients.

**Q24 Stephen Phillips:** Can I ask the same question to Dr Morrish and Dr Fuller? What does the fact that that recommendation has not been implemented mean for patients?

**Dr Paul Morrish:** I think it means that they have a disease that is considered a Cinderella disease, and the CCG does not take responsibility for it. I spoke to a CCG commissioner yesterday and said, "Tell me: in neurology, what are the barriers?" and he said, "It is not on our radar." I think that is the problem.

**Dr Geraint Fuller:** It is the same point. If it is not visible and if it is not counted, you can ignore it—broadly speaking, that is the process. We have not touched on the commissioning issues. Arlene, would you like to say anything?

**Q25 Stephen Phillips:** If it makes commissioning more difficult or less effective, I would like to know that before the next panel gives its evidence.

**Dr Geraint Fuller:** Within neurology, there has been a huge problem with the nature of commissioning because of internal confusion in terms of varying sets of rules. One set of rules said that all neurology is specialised. Obviously, specialised commissioning is low population, high expenditure and low-prevalence diseases, so paediatric pancreatic replacement—really rare and expensive and unusual diseases. All neurology got swept up—all of neurology, but only in about 31 centres, I think, not in the other places—and we then basically had NHS England to talk to, for the most part. The CCGs were saying, "It is not us."

All of a sudden, they changed the rules so that now it is mainly CCG commissioning, with only in-patients and consultant-to-consultant referrals going into specialised commissioning, so the CCGs are having to take on more responsibility across the country. You can see the picture I am painting is one of confusion, and if I have conveyed confusion, you have caught it beautifully.

**Arlene Wilkie:** Our services are split between NHS England-funded and CCG-funded, and there is no clarity as to who is supposed to do what. Commissioners—again, our freedom of information survey showed this—just do not think that it is their responsibility. So, a lack of indicators and a lack of commissioning clarification mean that they think it is someone else and they think it is NHS England's responsibility.

**Dr Geraint Fuller:** For the most part, I do not think it has got to the point where a large gap has appeared and everything has fallen through it, but it is not through want of trying.

**Q26 Mr Bacon:** Dr Fuller, you said something that I thought quite striking earlier: on only three or four days a week would one be able to see a neurologist. How many neurologists are there in England, and how many do we need?

**Dr Geraint Fuller:** At the moment, there are about 750, which is about 650 full-time equivalents.<sup>5</sup>

**Q27 Mr Bacon:** Right, so 750, of whom some are working part time.

**Dr Geraint Fuller:** They are working as academics and so on.

**Mr Bacon:** Oh, I see. So 650 full-time equivalents. How many do you estimate that we need?

**Dr Geraint Fuller:** It depends what service we are aiming to provide. If we are trying to provide the kind of service that we are looking for, we would probably need about another 50%.

**Q28 Mr Bacon:** Another 50%, so another 300.

**Dr Geraint Fuller:** Yes, to around 1,000. As always, there are additional complexities. For example, stroke is a neurological disease—the rest of the world sees it as a neurological disease. In parts of the UK and parts of England, it is a neurological disease. In London, the hyper-acute stroke services are largely run by neurologists, and they interact with their colleagues in geriatrics and stroke medicine. In other parts of the country, they are entirely separate. There clearly needs to be some level of integration. The way that runs may have impact as to the number of people who are neurologists, or neurologists and strokeologists. There are opportunities for working more intelligently.

**Q29 Mr Bacon:** Does your 50% increase from 650 to 1,000 or so full-time equivalents include or not include the stroke element you are talking about?

**Dr Geraint Fuller:** That would not include the stroke element.

**Q30 Mr Bacon:** So how many strokeologists, as you call them, are there?

**Dr Geraint Fuller:** I cannot give you the numbers for stroke.

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<sup>5</sup> Subsequent written clarification by witness: “The [RCP Annual census 2013/14](#) indicates that the number of consultant neurologists in the UK is as follows: England – 640, NI – 16, Scotland – 75, Wales – 25, Total - 756 (cf 716 in 2012/13).

*It notes that the apparent increase of 5.6% since 2012/13 will be offset by those new posts with a significant number of PAs devoted to stroke services.”*

**Dr Paul Morrish:** One hundred and seventy nine.<sup>6</sup>

**Q31 Mr Bacon:** Who just do stroke. From when the Committee looked specifically at strokes, which was after we had previously looked at cancer and cardiac services, 11% of deaths in this country—I remember the number—were caused by stroke. At more than one in 10, it would seem to be a rather important area for the NHS, and neurology as part of that. Does it surprise you that so little emphasis has been placed on it that, to use Dr Morrish’s phrase, it is not even on the radar for some people?

**Dr Geraint Fuller:** I think that, historically, neurology as a whole has been something of a Cinderella because most doctors will have experienced only a small amount of it as medical students. In the past, there were relatively few things that we could do for most patients with neurological diseases. There was a sort of nihilism about the whole thing. Now there are huge opportunities. There are lots of things that we can do to improve the quality of life and, indeed, the outcomes—not by as much as one would like, but it is changing all the time.

**Q32 Mr Bacon:** Is the message that it is one of the most exciting areas percolating through to medical schools and to career choices?

**Dr Geraint Fuller:** Interestingly, medical students tend to find it interesting and hard, so quite a lot of people are frightened of it and therefore tend to try to avoid it. Nevertheless, the ones who are interested are often very enthusiastic. We talk about neurophobia—doctors having a fear of neurology. We have also described a condition called neurophilia, which is when you really love neurology.

**Chair:** So you’re neurophilic.

**Dr Geraint Fuller:** We’re neurophilic, yes.

**Q33 Chair:** Okay, on that point, the figures we have for the UK—not England and Wales—are that there is one consultant per 90,000 of the population. In the Report it says that there is one per 15,000 in the European Union and one per 19,000 in the USA. If those figures are right, that is a big variation. Does that accord with your knowledge of this? Do you know of any good reason for that difference?

**Dr Paul Morrish:** I think it comes from history, actually. I have a series of reports going back to 1945 and they all say the same thing: there aren’t enough neurologists in this country and the ones we have are not very well distributed. That was pretty much what I said in my editorial. If you look at how neurology is distributed, it does tend to be stuck to the major centres. London has one neurologist per 40,000; the rest of the country has probably one per 90,000. If you go to somewhere like Liverpool, as Geraint said, they tend to be in one central hospital and they visit district general hospitals, rather than being based in a DGH and popping into the central hospital.

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<sup>6</sup> Figure clarified by witness after session

**Q34 Chair:** Dr Fuller reacted to that point in your article by suggesting that it was perhaps unrealistic. I am paraphrasing, but maybe you can explain, Dr Fuller.

**Dr Geraint Fuller:** We are in a time of really quite dramatic change. We can see that there is change, and changes bring opportunities, one of which is getting more neurology to patients across the whole country and hopefully going some way towards remedying this iniquity. One thing you do not want that change to do is to lose some of the really excellent things we currently have. A lot of the time at the centres, because of their organisation, you have really expert and really valuable resources in MND centres and a whole range of different things that are there at the centre. We want to try to keep the really good things in the centre, but provide everyone with a better deal elsewhere, if that is feasible. There is that tension, to a certain extent.

**Q35 Chair:** We touched earlier on the role of the CCGs, which is very varied from all the figures that we have seen and that the NAO has picked up on. Do any of you have any good examples of the best-performing commissioning in the country? Dr Morrish, I guess we should start with you, and perhaps Arlene Wilkie will have something to contribute as well, through the Intelligence Network.

**Dr Paul Morrish:** Off the top of my head, I cannot name—

**Chair:** If you think of one afterwards, do drop us a note, because we like to highlight best practice. We often get a reputation for attacking the worst.

**Dr Paul Morrish:** I will. You hear about things all over the country, such as a headache service in one CCG, which seems to me to make fantastic sense because a lot of what we do is to see headaches and that can be done by other people, actually. There are good examples dotted around.

**Q36 Chair:** If any occur to any of you afterwards, please let us know. Arlene Wilkie, are there any good examples you can highlight?

**Arlene Wilkie:** The SCNs have been doing quite a lot of good work with their CCGs. For example, the London SCN produced CCG data packs—

**Chair:** Sorry, what's an SCN?

**Arlene Wilkie:** A strategic clinical network for neurology. The SCNs have produced neurology data packs for their CCGs, which is quite unique for a lot of the SCNs. They should be encouraged. We need the data from the Intelligence Network to turn into CCG packs, which will allow the CCGs to review and transform their services.

**Dr Geraint Fuller:** The lack of engagement of CCGs means that none of these things has actually filtered through. The very valuable and informative data that Paul has been producing is only just coming out, so it has not really had any time to make the kinds of changes that one would hope it would.

**Q37 Chair:** A couple of quick questions from me before I hand over to Karin Smyth.

There is obviously a five-year forward view now in NHS England. Do you think that that will help neurology services? Do you think that there are any questions that we should be asking the next panel to make sure that that five-year forward view reflects some of the concerns that you have highlighted?

**Arlene Wilkie:** There are many positive things in the five-year forward view—very general positive things that will be coming out from that—but there is no specific neurology focus. They should be side by side. The five-year forward view, the models of care and the vanguards will work for neurology, but I think they need a side-by-side, strong clinical leadership to ensure that these new models of care work for neurology. So, yes, but I still think we need to have a neurology focus within NHS England.

**Dr Geraint Fuller:** If every time people mention cancer they add “and neurological services”, all of a sudden people will be thinking about neurological problems in the same sort of way. If we can pick up on that, that would be great.

**Dr Paul Morrish:** My concern is that the five-year forward view talks about being closer to the community, but neurology at the moment is a long way off. It is not in the DGHs properly yet, so the step from there into the community is a very long way away.

**Q38 Chair:** So is there another area or long-term condition—we have touched on cancer, and we looked at diabetes a month or so ago—or any other models that are working well on which neurology services should be modelled?

**Dr Paul Morrish:** I have looked at mental health, which starts as a community service—dementia starts as a community service and works back the other way. Neurology is really coming in the other direction, from academic centres outwards, but maybe we should be starting further out. That sort of brings me back to CCG-led commissioning. The CCGs have to see their responsibility to the neurological problems in their area and to react accordingly.

**Arlene Wilkie:** We should probably acknowledge that NHS England has a new project. It is looking at community care for neurological patients, which is great, because they can do better in the community, with less of the hospital care, but we need to know the long-term commitment to this beyond March from NHS England. For everything that is in place, what is the long-term commitment to this to ensure that when you review services again in three years’ time, we can actually demonstrate to you improvement in the patient experience.

**Chair:** There’s a question we will be coming back to in about three years’ time, probably. Dr Fuller, a last quick point on this and I will hand over to Karin Smyth.

**Dr Geraint Fuller:** I have nothing to add.

**Q39 Karin Smyth:** You have been quite critical about commissioning generally, and talking about the gaps in commissioning as well as the actual approach. NHS England and CCGs both have a link with commissioning support units. Have you had to get lots of data, information, intelligence, quality information and all the rest of it? It would be interesting if you had had any involvement with the large resource that is currently in the commissioning support units.

**Chair:** I think that is a no from all three witnesses, just for the record. The very last question is from Stewart Jackson.

**Q40 Mr Jackson:** I was one of the few people, and I think the only person in the last Parliament, who took any interest in—

**Chair:** Sorry to interrupt, Mr Jackson. You need to declare an interest.

**Q41 Mr Jackson:** Yes. My brother is a professor of cognitive neuropsychology at Nottingham University and has worked on some of these areas, particularly Parkinson's.

Tourette's has not got much of a mention, unfortunately. Unless I have missed something, evidence has not been submitted to us. Can you give me a brief estimate of where we are on Tourette's? One of the problems in the last Parliament was that it fell between education and health and, I think, is still very much a Cinderella service, particularly in delivering for schoolchildren and young people with Tourette's. I'll put this on the record: it is not a joke; it is a very serious condition that affects many thousands of families. What is your view of the current situation with regard to Tourette's?

**Dr Paul Morrish:** It is representative of a lot of neurological conditions. The GPs do not know whether it is neurological or psychiatric. The patient meets the GP, and neither really knows; and then the GP does not know who the local person with an interest in it is. It doesn't happen. The patients do get to us, and when they get to us, we can do useful things, but quite often there is a bit of a gap before they get to us.

**Dr Geraint Fuller:** A large chunk of it is actually paediatric neurology, which astonishingly is an entirely separate specialty. We start at 16 or maybe 18, and while we will see adults with Tourette's, a large chunk of the problems run into the interface that you hinted at, between education and medicine. As Paul says, it is a good example of a rare—well, it's not that rare—a relatively uncommon neurological disease where patients do not get on to any map; there will be no CCG commissioning. We would like to be able to keep the specialist clinics and things, where there is a particular interest, at different centres and allow all the patients to have access to them. Working out a commissioning strategy to allow that is actually quite tricky.

**Q42 Mr Jackson:** The problem is that they get excluded from school. That knocks them off track and puts them back practically forever.

**Dr Geraint Fuller:** That would be a paediatric neurological issue, which we would not tend to—

**Q43 Chair:** Just to be clear, neither of you is a paediatric neurologist; you are adult neurologists. Do you have anything to add, Arlene Wilkie?

**Arlene Wilkie:** Just to what Paul said. With most neurological conditions, it takes too long for the GPs to recognise that it is a neurological condition. People can see GPs four or five times and

maybe it takes a year for them to be referred to a neurologist. It is just taking too long for people to get into the system. I appreciate the issue with Tourette's; it is very, very similar to many other neurological conditions.

**Chair:** I thank you all very much both for your time and for the submissions that you sent in. You are very welcome to stay for the next panel. The transcript of this hearing should be available, uncorrected, on the website in the next couple of days. You will get the chance to correct anything factual. If you said something and you didn't want to, it's too late, but factual things or mistakes in the transcript you are very welcome to correct. If you swap with the next witnesses, you should be able to find a seat even if it's not a very comfortable one.

### Examination of Witnesses

*Witnesses:* **Dame Una O'Brien**, Permanent Secretary, Department of Health, **Simon Stevens**, Chief Executive, NHS England, **Professor Sir Bruce Keogh**, National Medical Director, NHS England, **Dr David Bateman**, National Clinical Director for Adult Neurological Conditions, NHS England, gave evidence.

**Chair:** Good afternoon. This is our second panel—the people who are responsible for ensuring the delivery of neurological services in the UK. I will not repeat my preamble—I think all of you but Simon Stevens were in the room—but I am delighted to welcome our second panel. Sir Bruce Keogh, the National Medical Director for NHS England, is a reasonably regular visitor, although not as regular as some of your colleagues on the panel. Simon Stevens is the chief executive of NHS England; welcome back, Mr Stevens. Dame Una O'Brien is from the Department of Health. Dame Una, we have learned today that you will be moving on in April, so you will be losing your frequent flier points at the PAC, depending on where you go. We may see you again—we don't know yet—in another role, but it's up to you to tell us that in due course. We are delighted to welcome Dr David Bateman, who is the National Clinical Director for Adult Neurology Conditions for NHS England. We are really pleased to have you here, Dr Bateman; we were particularly keen to have you as a witness. I think you heard from the pre-panel that we have a lot of questions for you this afternoon.

I need to declare again for the record that I have an interest, in that my brother, Dr Charles Hillier, is a consultant neurologist at Poole Hospital NHS Foundation Trust. I am going to hand straight over to Anne-Marie Trevelyan, who is leading our questioning.

**Q44 Mrs Trevelyan:** I am new here so I have been quite intrigued to discover, from looking at a progress report, that although some of the PAC's recommendations following the 2011 NAO Report were rejected by the Department, you have moved ahead with some of them, which is good news—but not necessarily particularly good progress—on the specific issue of appointing a clinical lead for neurology, which was not supported by the Department at the time, and establishing local neurological networks. I am really pleased to welcome Dr David Bateman. It struck me just from reading the Report, not having followed earlier ones, that this was an obvious and important part of the process of improving neurological services for patients.



May I start with you, Dr Bateman? How do you think the support for those suffering from motor neurone disease, MS, Parkinson's and other less well known neurological conditions is improving and what support are you getting from NHS England to make that happen?

**Dr David Bateman:** I have been in post for only two years, so we have obviously had to do quite a lot of groundwork to begin the improvement. The clinical networks—or strategic clinical networks, as they were previously called—have been fundamental and I think they are critical for dealing with quite a lot of the problems that have bedevilled neurology services from the start, really, because patients do cross a lot of boundaries, from a neuroscience centre to a DGH to the community. For neurology services, clinical networks are probably the most fundamental and most important way of trying to establish care pathways for those patients across all these health boundaries.

What I have been doing with the clinical networks is helping form them and helping to set them up. We have managed to appoint clinical leads in all the clinical networks now and their work programmes have been determined by my leadership and my priorities and the national agenda, and also, to some degree, by local priorities. Now they are really beginning to bear fruit. All the neurology clinical needs have got some very supportive, very hard-working clinical managers, and they are beginning to develop programmes that, as I say, are making a difference.

Just to give some simple examples, in the Thames valley, there is a fantastic clinical network that has been looking at headache out-patient referrals and trying to think about how we can improve access for patients with chronic daily headaches of various kinds, how we can improve their care, and how we can try to transform the waiting times for patients—for neurology out-patients—by seeing if that kind of work can be done in another way. They have managed to think up a potential model with GPs with a special interest who are not new and they have been able to demonstrate that there is quite a lot of interest from GPs and quite a lot of uptake of that kind of model. They have been able to see patients earlier, have reduced the follow-up, have reduced the investigation rate and have improved the outcomes—so much so, that Oxfordshire CCG now wants to commission that kind of service. When you think that 20% of out-patient referrals to a consultant neurologist are probably for headache disorders, if they were all removed, we would have some opportunity both to shorten the waiting times and to see if we can actually begin to reconfigure what neurologists do to do other kinds of work.

Another colleague is looking at headache in a slightly different way—at giving GPs protocols for diagnosing and managing headache and giving them access to scans. That is under way at the moment. They have also looked at data again to see how patients are being looked after in their particular group of CCGs in the clinical network so that they can actually begin to understand what is happening and who is getting treated where. Most of the clinical networks, in fact, have got programmes around headache in one way or another, so they are copying that kind of work, and that is being rolled out.

Other clinical networks have begun to look at what we can do about the care of patients who are being seen in seizure clinics and in the acute emergency departments. That is fairly critical if you have epilepsy, because if you have a new epilepsy, you will probably be taken to the emergency department, and if you have existing epilepsy that is poorly controlled, you will go to the emergency department, so it is a critical part of the care pathway. We had two previous big audits called the national audit of seizure management in hospitals, which demonstrated that we were not doing well so quite a lot of the clinical networks have been looking at that pathway to see if they can put more resources into it, identify these patients and make arrangements to ensure that they are being seen.



Only about 25% of new patients with epilepsy were actually being seen, so we wanted to see if we could significantly improve that.

The other thing about these acute neurological conditions is that a lot of patients with acute headaches and seizures get admitted to hospital because of the difficulties for people in the emergency department knowing the cause and whether it is serious. If you look at the length of stay—this is where data are really helpful—it is 1.7 days for those patients, so they have a short stay until they are better and then they go home. It is not actually a very effective way of dealing with it. Looking at the data, it costs us £70 million a year to look after epilepsy emergency admissions of people who already have a diagnosis. We are thinking about ways in which we can significantly improve that care pathway. The clinical networks are also looking at those across the whole country.

NHS England has very kindly taken up my cause, which was trying to improve community care of long-term neurological conditions. From my perspective as an adult neurologist of 25 years, once you get a neurological diagnosis, the less you see of hospitals and the more you are managed as a normal person looking after your own condition, the better. I am very concerned that patients do not get access to the right care at the right time and that we do not prevent the deterioration that has unfortunate consequences. With NHS England, we are looking at commissioning person-centred, co-ordinated care of patients with all neurological long-term conditions. That work has only just started but if it is successful, it could make a huge and critical difference.

**Chair:** Dr Bateman, we very much welcome your expertise but we have quite a lot to get through. That is fine for the first answer but all panel members need to keep answers a little bit shorter. Anne-Marie and I have a lot to get through.

**Q45 Mrs Trevelyan:** Thank you. Mr Stevens, we heard from the pre-panel—and I certainly found out in my research into this—that Dr Bateman is a bit of a hero in the neurological world. His arrival has been greatly welcomed. There is some talk of changing that. Can you confirm that you will not get rid of the national clinical director for neurology? He is obviously adding value.

**Simon Stevens:** Yes. I am sure Sir Bruce will want to come in there because these are his shock troops. The fact is that when NHS England was set up, as I understand it, a large number of appointments were made for a period that initially takes place until March next year. At that point, a review has been undertaken to consider how the role of the national clinical directors relates to the strategic clinical networks, the clinical senates and the clinical reference groups. There is quite a labyrinthine structure of clinical advice nationally, even before you get to the leadership that local CCGs are bringing to the party. Sir Bruce, rightly, is looking at that and may want to say a bit more.

**Q46 Chair:** Yes. Sir Bruce, are you reviewing it now or in March?

**Sir Bruce Keogh:** No, we are reviewing now with the intention of trying to have a slightly more coherent structure in March. The issue that we are trying to address is that we probably have more clinical leadership in the NHS now than we have ever had.

**Q47 Chair:** Anne-Marie Trevelyan's point is about the clinical lead—Dr David Bateman's position and the equivalent position.

**Sir Bruce Keogh:** I need to explain how we get there, sorry. We have CCGs, clinical reference groups that oversee specialised commissioning, and the strategic clinical networks, which you have heard about and are also clinically-led. We are also trying to encourage local leadership through the CCGs and the strategic clinical networks. We currently have 24 national clinical directors. We are trying to focus those on three areas: our corporate priorities; life course things such as maternity, children, and frailty and end-of-life care; and the big killers. At the moment, we do not see that neurology fits specifically into that, but what we do see is a groundswell of support among the strategic clinical networks and the leadership there for promoting the development of neurological services. In fact, David has explained that.

**Q48 Chair:** Sorry, I am not quite clear. Can you give us a hint where you are going with this? You talk about the need for this network. Does that mean individuals' needs?

**Sir Bruce Keogh:** At the moment, a hint is that we are not intending to replace the national clinical director for neurology.

**Q49 Mr Bacon:** You say "at the moment". There is a review going on. Are you saying that next March it might be something different?

**Sir Bruce Keogh:** Yes.

**Q50 Mr Bacon:** It might. So you might scrap the national clinical directors?

**Sir Bruce Keogh:** Yes.

**Mr Bacon:** And do what instead?

**Q51 Chair:** That is what I am not clear about. You have all these various structures. Which one would be the predominant structure?

**Sir Bruce Keogh:** The strategic clinical networks.

**Q52 Mr Bacon:** But will they have someone in charge of them?

**Sir Bruce Keogh:** Yes, they do.

**Q53 Mr Bacon:** Who is in charge of them at the moment?

**Sir Bruce Keogh:** Well, they have come together as a collaborative.

**Q54 Chair:** So all the different strategic clinical networks have come together?

**Sir Bruce Keogh:** Yes, they have. So we would see the leadership coming through that. We would also see a—

**Q55 Mr Bacon:** I didn't ask you to describe the leadership; I asked who was in charge.

**Sir Bruce Keogh:** The collaborative will come together—

**Q56 Mr Bacon:** So there are lots of people in charge. The trouble is, we have found on this Committee in lots of different domains for many years that when lots of people are in charge, it turns out that no one is in charge. The great thing about national clinical directors is that there is a visible person in charge, the emblematic example being Sir Mike Richards, who did a brilliant job. We recommended that you introduce a national clinical director in this area. You refused our recommendation and then did it. It sounds like you are now threatening the future of the national clinical director, without saying clearly what you are going to do instead or who will be in charge.

**Sir Bruce Keogh:** As the person responsible for bringing in more clinical directors than we have ever had in the NHS, I am not aware of having refused a national clinical director for neurology.

**Q57 Mr Bacon:** You should read the Treasury minute in response to our previous report. We recommended the introduction of a national clinical director for neurology, and the recommendation was turned down by the Government—you obviously didn't read the Treasury minute. What we are interested in is what you are going to do instead.

**Sir Bruce Keogh:** Our review is taking place and I will send you a note.

**Q58 Chair:** You talked about bringing everyone together as a collaborative. Does that mean across the different clinical areas?

**Sir Bruce Keogh:** Yes. Well, there will be a neurology collaborative. They will be specifically focused.

**Q59 Mrs Trevelyan:** This was raised by the pre-panel, and it struck me enormously in the Report: what there is not in neurology is any decent data. It is very, very difficult to get a handle on just how many people suffer from each disease, how it is monitored and how it links through. That was raised in the previous Report, and it would be helpful if you could explain why you have not developed a comprehensive dataset across neurology using, as was indicated, the patient's unique NHS number, for instance, which tracks them in the many areas of the medical framework that they hit.

**Simon Stevens:** There is a programme to do exactly that; it's called care.data. This Committee is very familiar with the troubled birth of that programme, but at the point that care.data comes into being, it will do precisely what you say: it will enable data linkage across settings and enable information for planning and for quality improvement purposes that, at the moment, requires a series of one-off, rather laborious and expensive efforts, which is not a sustainable way of

generating good insight into not only these important neurological conditions but a range of other patterns of care as well.

We have to get away from the idea that the only way in which we generate information to drive improvement is through these one-off, bespoke exercises. We have had an overly fragmented set of responsibilities between NHS England, the Health and Social Care Information Centre and Public Health England, which is the host body for neurology data and the equivalent cancer data. We have talked in this Committee about the issues with cancer data as well.

One of the things we are doing across the NLBs—the national leadership bodies of the NHS—with the Department over the next several months is looking at how to streamline and harmonise that source of intelligence for the health system as a whole. We need to make sure that the benefits are felt for neurology, just as they will be for cancer and other conditions.

**Dr David Bateman:** I would really welcome and agree with that, but you need to have a Neurology Intelligence Network, because someone needs to understand the data and needs to know how to interpret it and what could be done about it. If you do not have those things, it is not going to mean very much. That is what the Neurology Intelligence Network is about. We had a neurology compendium of data—a big dump of data, the first ever—but it is slowly being turned into intelligence at the moment. Given the resources that we have had, I think we have done pretty well in terms of the kind of data that we have got. We would not want to repeat that one-off data dump. We want to be savvy about what data we get and why, and get some data on a regular basis so that we can see changes and some new data based on what we think is important, but I think if we do not have expertise and intelligence—

**Chair:** Sorry. I apologise for the funny noise and feedback. It is distracting. It is the ghost of Committee Room 15. Perhaps William Gladstone has risen from the grave.

**Dr David Bateman:** Can I just make one point? We have appointed a number of new analysts at the Neurology Intelligence Network. It has taken them a long time to understand the neurology framework and the neurology data.

**Q60 Chair:** You say “a long time”. How long?

**Dr David Bateman:** Well, I don’t know.

**Q61 Chair:** Months or years?

**Dr David Bateman:** Six months or so. Understanding the neurology domain and the playing field, how neurology services are organised and how to get the right sort of data—

**Q62 Chair:** The problem for us is that we have heard this before.

**Dr David Bateman:** I look after Michael Jackson, the senior analyst, because I live in Sunderland and he lives in Durham. We work very closely together, and that has been a very fruitful relationship. He has done some fantastic work.

**Q63 Mrs Trevelyan:** Dame Una, perhaps you could expand for us how care.data is going to work and what its time frame is, realistically. I am new here, as I keep saying, but I am rapidly learning that anything to do with IT systems usually falls off a cliff. In the meantime, we have 4 million patients out there with neurological conditions who need looking after and better care, so it would really help if you could explain how it will work and what the time frames look like, so we have some idea of whether this is a realistic proposition in the short term.

**Dame Una O'Brien:** If I might say so, you are sitting next to one of the country's experts on this entire matter. There is much that could be said about it. The crucial thing is that we have got to solve this problem generically. What I mean by that is that we have to solve it for all people with all conditions—this ability to link data—so that if you are sitting in a GP's surgery or a CCG, you can see the totality of the patient population and who is building up risk. Just the other week I had a discussion about diabetes and trying to get people who are pre-diabetic. It is exactly the same issue.

To your point about when this will be solved, as you know, the Secretary of State has asked Dame Fiona Caldicott to look independently at the fundamental issue of where the proper arrangement sits for people's ability to opt out. She is now looking at all the matters related to that, and her report is due at the end of January or early February, I think. We have to get to a proper settled position about how the different elements of data law come together. It is not just health law that applies here; it is also the Data Protection Act.

I think we have now understood at a very deep level, following findings from this Committee and the NAO and the work that we have been doing with the Department, what we need to do to solve it. We are determined to solve it, because one of the good outcomes from the spending review is that we now have investment in technology which will enable more effort to go into building the digital framework for this information to be properly exchanged. So I cannot give you precise dates as such, but what I can tell you is that the components are now in place, and we are very determined that we will deliver those changes in this Parliament.

**Q64 Mrs Trevelyan:** In this Parliament—that is, within the next four years. Patients who have motor neurone disease at the moment and have very little support are not going to see the benefit of that. Because you have not yet got it in place, what are we going to do in the near future to make sure that our neurologists out there on the ground have better data, so that they can better support and assess what they are doing to get the best for those patients?

**Dame Una O'Brien:** If anything, our problem is that we are awash with data, but it is not actually joining up. We have to find a once-and-for-all solution that can do this, legally and technologically. Hopefully, we will do it before 2020—that would be our ambition—but I stress the scale at which we are trying to address this.

In respect of what is going on right at the moment—my colleagues in NHS England know more of the detail about this than I do—we have made very good progress on the summary care record at the level of the GP. I think this starts to open up the possibility of greater clarity about people having access to their own record—that is No. 1. Secondly, we might be able to leapfrog this confusion about care plans because, in the summary care record, we now have the ability to assemble the elements of a person's individual plan. From the point of view of what people actually want—

**Q65 Chair:** When you say “we,” what do you mean?

**Dame Una O'Brien:** The system.

**Q66 Chair:** So the clinician on the ground can do that?

**Dame Una O'Brien:** Yes. What that actually means is that, for people with any long-term condition based in the community, you want to be able to see the elements of your plan and your care record. We already have some much nearer term progress on that than this ultimate data linkage, which has to happen and has to be done once and done legally.

**Q67 Chair:** I want to bring in the Comptroller and Auditor General now.

**Sir Amyas Morse:** Just to go back a little bit. One of the things that is clear is that information and the organisational maturity around it can be very difficult. It sounds that, in the case of neurological conditions, it is considerably worse than for any other conditions. We know that, unfortunately, the systems do not always develop in time; while we are waiting, what is going to be put in place to support people with this condition? At the very least, the paper says that supporting information is needed. Are you any further along on that?

**Simon Stevens:** Absolutely. Public Health England have not said that they will not continue with an information network for neurology; what they have said is that, given the overall need to generate efficiencies across their own running costs and those of the national leadership bodies as a whole, we have to answer the question of how we get more coherence between the value added that Dr Bateman rightly described as a kind of extra intelligence that comes from people who know the world of neurology and neurological conditions and the fantastic work that the patient groups do versus the grunt labour of assembling routine datasets to answer exam questions that should be generated automatically off the back of the administrative datasets at our disposal. It is about how we keep the value-added piece with a proper neurology focus while standardising and systematising the underlying routine analytical production. That is the question that we want to solve not just in the case of neurology but for other conditions, too, and I think we will get there.

**Sir Amyas Morse:** The only thing that is absolutely clear is that you are not going to have a clinical lead.

**Simon Stevens:** As far as the information is concerned, we want something that is at least as good as what we have, and over time is better. If you look at the much-heralded data that is being produced by the Neurology Intelligence Network, a lot of it is pretty exciting, but it is not that exciting. We ought to have at our fingertips the age and each standardised utilisation rates for different neurological conditions. We have some of this coming out of the Intelligence Network, and we have some of this coming out of the NHS atlas of variation, which is a separate but related product. We have the commissioning for value exercise, which is also being done through PHE and NHS England. We have the Right Care process. Frankly, we have too many different—

**Chair:** A smorgasbord.

**Simon Stevens:** Yes, and it is time to produce a fixed menu with some à la carte options that are genuine upgrades.

**Chair:** It sounds as though you have just written the recommendation for our Report.

**Q68 Mrs Trevelyan:** I am looking forward to this magical data world, but in the meantime we have to look after patients. There is one indicator that has been used but, as has been mentioned, it has stopped—the monitoring of epilepsy and patients who have been 12 months without a seizure. That was a really useful indicator, and it helped neurologists to do well, and it helped those patients. Are there other indicators that would be genuinely useful to help improve outcomes and care for sufferers? Why do we not have them?

**Dr David Bateman:** We are getting them. We have data on emergency admissions for existing long-term neurological conditions, so we know the rates of emergency admissions for epilepsy, for Parkinson's disease, for motor neurone disease, and for multiple sclerosis. These are for conditions that are already known about, and we would hope to prevent those emergency conditions if we had better care pathways and better support. So we know that for epilepsy, for instance, we are spending £70 million a year on those admissions, which are a very poor utility.

**Q69 Mrs Trevelyan:** But you can tell the differences across England in terms of the better and less good care that is available.

**Dr David Bateman:** As Simon Stevens has said, if we use the commissioning for value, which I have been supporting enormously, hopefully they are going to produce some CCG neurology packs early next year on their outcomes and costs and various indicators for the emergency admissions for epilepsy and other long-term neurological conditions. They will have their out-patient activity and costs compared with the best and the worst in the country and with their peers. That will give a real opportunity for CCGs to look at their own care pathways and to begin to think how they can improve these care pathways. That will be of great importance, but critical to that is a message that the CCGs hopefully will get with those packages that this is a real opportunity; we can commission these care pathways on our local population base and we can try and improve them. That has been the major problem with neurology services. There has not been a lever and there has not been the data to enable that process to happen. We have had a problem with commissioning responsibilities that hopefully NHS England are involved in addressing.

**Q70 Mrs Trevelyan:** Sir Bruce, with that information, who will have oversight to look at this and make sure that if there is poor practice, the CCGs will be asked to improve what they do if they are not focusing on the neurological illnesses?

**Sir Bruce Keogh:** I think that there will be a variety of places where that sort of information will get some oxygen. The first is the strategic clinical networks. The second, which we have quite a lot of hope for, is in the programme called Right Care where we look at variation across CCGs in a number of different areas. We identify those that are performing well and less well. We develop specialised admission packs for them. We go in and help the CCGs that are not performing well. That programme is just starting. It is going to be put in place in other areas. It is all very promising. I think they are starting on neurology at the beginning of April.



**Dr David Bateman:** Yes, as I was saying, that is the commissioning for value packs that I am keen on and supportive of. I am optimistic that that is going to be of enormous help.

**Q71 Chair:** Can I just be clear, before Anne-Marie carries on, about where responsibility lies. Sir Bruce, when you talk about “we”, are you talking about the Department of Health?

**Sir Bruce Keogh:** No, NHS England.

**Q72 Chair:** So if we come back to this, Simon Stevens, it is you and your team that will be responsible for making sure there is more clarity and common practice across CCGs.

**Simon Stevens:** Yes.

**Chair:** We just like to know who is in charge. It is you; that is all I need to know.

**Simon Stevens:** I said that without moving my lips.

**Q73 Mrs Trevelyan:** This is most encouraging, but my cynicism is starting to kick in on a regular basis with all big new projects. One of the problems that has been highlighted not only by our pre-panel but by a variety of people in the profession is that there just are not enough neurologists to pick up the workload. Is there anything going on to encourage more young medical students to go into neurology across the piece, so that the CCG cannot say, “The nearest neurological centre is 50 miles away, so realistically we cannot access that for our patients”? What are you doing to improve that outcome so that you can support this excellent-sounding work?

**Simon Stevens:** The first thing to say is that, over the course of the past decade, there has been an increase of about 60% in the number of whole-time equivalent neurologists in the NHS. This is a growing specialty that has coincided with a substantial increase in the investment that the National Health Service has been making in those neurological conditions. It is up by over 4% in cash terms since 2006-07. The proportion of CCG spending on neurological conditions has gone up by a quarter over the past several years.

**Chair:** Sorry, when you say several years—

**Simon Stevens:** It is in the NAO Report. From 2009 to 2012-13, there was an increase of a quarter in the share of their spending on such conditions.

Looking out over the next five years, the number of new neurologists that there will be is a function of those who are already in the training pipeline, given the length of time it takes to produce extra neurologists. The numbers have been going up by about 4% to 5% a year. Of course, like every specialty, people would like to have more, but we are hunting within a fixed pool of extra medical graduates and consultant trainees, so the realistic answer for this Committee is that we are unlikely to see an acceleration in the growth rate for neurologists over the next four or five years. That is an unfortunate fact, given the numbers in training and the funding available over the next five-year period.



**Q74 Mrs Trevelyan:** Am I right in thinking that there's about to be a cliff edge drop-off of those nearing retirement in the sector?

**Simon Stevens:** I'm not sure about a cliff edge, but there was a big increase in the numbers at the time that stroke services were improved some years ago. Some of those folks are now coming up to retirement.

In my opinion—I obviously defer to Bruce and David on this—neurology is a specialty in transition, and there are pushes and pulls in terms of localisation versus centralisation. The push towards localisation is the obvious benefit of having more readily accessible out-patient services. The pull towards concentration is the benefit of co-locating acute neurology with stroke care and full seven-day services to deal with the quality effects that we can see showing up in in-patient services. What that means is that it is too simplistic to say that this is all just about distributing more neurologists and out-patients in every footprint where the health service operates. There is also a requirement for some of the extra neurologists we are producing to beef up the multidisciplinary teams in some of the acute in-patient settings.

There is no straightforward answer or one size that fits all. Interesting new models of experimentation are under way—I mentioned the work that the Walton centre for neurology in the north-west is doing in Merseyside and Cheshire. It is one of our acute care vanguard programmes and is looking at trying to square that circle. I would say that the Association of British Neurologists and others have been innovative in thinking about some of this, including telemedicine outreach in some situations. Those are the kinds of contours of the debate we are having.

**Q75 Mrs Trevelyan:** That is very helpful. I would be interested to know whether Dr David Bateman has the same view on the numbers, because different messages have come through to me.

**Dr David Bateman:** In England, there are only 25 neuroscience centres. Clearly, they are not sufficient to provide an acute neurology and an acute stroke service for England as a whole, so there have got to be a number of other places that are designated as acute neuro centres, if you like, and have services for acute neurology conditions and acute stroke conditions. I have been trying to propose aligning neurology and stroke more closely, because 50% of people who are admitted with a suspected stroke have some other acute neurology condition. We need to get them to work together, but it is not sufficient for it to be done in centres. We need to increase the provision of acute neurology care in DGHs. That is fundamental.

At the moment, we have a long-standing manpower problem. I have not had the time or the resources to solve it. The ABN has very kindly tried to achieve that, but, as it said, we need a significant increase in the number of neurologists. Recruitment in stroke is difficult now, but it is not into neurology, so I think that is a way of dealing with it. If we want seven-day services, which I fully support, and seven-day acute neurology services, we have got to go down to a provision model that is in between what Simon Stevens is saying and what we have currently got. We have got to try to reorganise things.

We have got to work smartly and try to get other people to do some of the things that neurologists do. That is the whole point of the NHS England collaborative commissioning framework for long-term conditions. If we can get that work well done, then it can be done by other people in a much more effective way.

**Q76 Mr Bacon:** On this point about numbers, Dr Bateman, you said that you would ideally like 50%, which would give you roughly another 325 over the next five years, taking you up to 975. Mr Stevens says that you are going to get 5% growth, which would give you half of that: 162. Do you get the sense that this is being placed as a high priority by the NHS, or is it just part of the generality of growth in NHS spending?

**Dr David Bateman:** At the moment, the neurology numbers are determined by the numbers of training posts. They have not been increased. The ABN kindly went to Health Education England and tried to persuade them to increase the numbers by illustrating the additional work and problems that we have got coping with the workload as it currently is, and with the desire to improve services that, by comparison with Europe and a lot of the rest of the world, are relatively poor. We have not been successful in that regard.

**Q77 Mr Bacon:** What I do not understand, Mr Stevens, is that the answer you gave made it sound like, “Yes, well, there’ll be a few more neurologists,” but it doesn’t sound like there is any push for this, and Dr Paul Morrish said it was not even on the radar.

**Simon Stevens:** You say you don’t understand, but I am sure you actually do. This is a zero sum set of choices that Health Education England has to make when—

**Q78 Mr Bacon:** I don’t understand that at all. That was going to be my point. It makes it sound like there is fixed number—

**Simon Stevens:** There is. There is a fixed number of medical graduates coming out of British medical schools together with some international—

**Q79 Mr Bacon:** Therein lies the rub. It is not a fixed number. We were going to give you £8 billion extra in the comprehensive spending review, although I blinked and now it is £10 billion. So a lot more money is going into the NHS, and I know you have got lots of things that you could spend it on, but this is a relatively small amount of money compared with the totality of the extra you are getting, never mind the extra you could get through greater efficiency.

**Simon Stevens:** I would be delighted to run through the numbers with you either in this Committee or outside it and show you that that figure does not include provision for a huge increase in medical school education and specialist training in this country. If we were to be spending at the level of, say, France or Germany, then we would be able to afford the kinds of medical staffing ratios that those countries have.

To underline this point, the reason this is a zero sum choice is, sitting in this Committee on prior occasions—no doubt we will do so in the future—we have talked about cancer services and the need to expand the number of radiotherapists and medical oncologists. We have talked about GP services, the relative underinvestment in GPs, with the growth rate in consultants having been three times faster than GPs.

**Chair:** We get the point—

**Simon Stevens:** This is actually a set of choices. We do want more neurology services and we do want more consultant neurologists, but to pretend that that is not a choice that has offsetting consequences for other areas that we also want to improve in the NHS would be an unfair proposition.

**Q80 Chair:** Following on from that, Simon Stevens and Dr David Bateman, both of you have talked about staffing issues. Dr Bateman, you talked about other professions coming into the teams. If not neurologists—we recognise that in the short term you cannot conjure them from nowhere, and even with a major overseas recruitment it would be quite challenging—what other professions could make a difference to the outcomes for people with long-term neurological conditions? Whereabouts should that be in the system—at primary care level or in acute hospitals?

**Simon Stevens:** Dr Bateman made a very important point earlier, which is that quite a large part of what a number of our neurologists are doing is looking after stroke conditions, but there are other specialities that are also involved in stroke care, so there is a discussion about what is the disciplinary mix there. He also made the point that quite a lot of the conditions that neurologists are dealing with in their out-patient clinics could potentially be managed by other medical disciplines.

That is the conversation that the various parts of the country who are redesigning their neurology services are focusing on hard. And there is also the opportunity, frankly, to put more effort into new onset conditions when they arise so as to improve people's outcomes subsequently and potentially reduce the burden on the neurology services downstream. A good example would be the variation in epilepsy rates and the proportion of people who are admitted for epilepsy care on an unplanned basis. One recommendation for dealing with that is that, for example, parts of the country might look at rapid-access first-seizure clinics, so that people get that care early on and are unlikely to need the same degree of ongoing follow-up support.

**Q81 Chair:** So it is the pathways as well as staff.

**Simon Stevens:** There are pathways and there is staffing. By the way, I would also make the point about the important role that specialist nurses play in the care of people with neurological conditions. It is not all doom and gloom.

**Q82 Chair:** Dr Bateman, do you have anything to add to that? Who did you have in mind?

**Dr David Bateman:** I agree. We need to make sure that neurologists don't do the things that they don't need to do, but that means that other people have to be available to do them. Specialist nurses have clearly made a fantastic difference to the management of many long-term neurology conditions. They do an enormous amount of work and save a lot of consultant neurology time. Provided that there are enough specialist nurses and they are tied to and integrated with a team that is working effectively and well in the community—NHS England is trying to scope a commissioning model to try to develop that service, of which I am fully supportive—I think that that will make a difference.

To return to the point about neurologists, at the moment, according to data from the ABN, something like between 30% and 50% of new consultant neurology posts that are advertised are not being appointed because we just don't have the neurology specialist trainees to fill them. We have a

need, and trusts have determined that there is a need for this work to be done, but we cannot provide it.

**Q83 Chair:** I suppose this should be addressed to Simon Stevens: has there been any attempt to use overseas recruitment to fill these positions that Dr Bateman says cannot be filled?

**Simon Stevens:** Individual trusts have done that from time to time, but I do not have a figure to hand.

**Q84 Chair:** So there is no plan in NHS England to do that. For the record, I see Sir Bruce shaking his head. If there are vacancies that cannot be filled, for all that you have just explained to us the challenges and other options, those are still vacant posts.

**Simon Stevens:** It is something that potentially should be looked at. I don't know whether this specialty is particularly amenable to that, but certainly in psychiatry, a number of European psychiatrists are providing fantastic care.

**Q85 Chair:** Just to be really clear: there has been no attempt.

**Simon Stevens:** Well, NHS England is not charged with and does not run an international recruitment programme. That is obviously for employers and for trusts.

**Q86 Chair:** But given that there is a gap, and given what we have just heard from Dr Bateman about posts that are not filled—

**Simon Stevens:** In principle, I am all in favour of international recruitment of high-quality candidates.

**Q87 Chair:** So there is no bar by NHS England to stop that happening.

**Simon Stevens:** No, far from it. In fact, as you know, we sought to ensure that there were not arbitrary restrictions on the NHS's ability to recruit from outside the EU.

**Q88 Chair:** It is helpful to have that on record, given that we have heard quite a bit about key staff shortages.

Dame Una, when we were discussing data earlier you said you could not give dates and wanted a "once and for all solution". I suspect that that sent a bit of a chill down the spine of most Committee members, because once and for all big solutions do not have a great record in the NHS. You talked about getting a proper data solution before 2020. Why is it always going to be in the future? These problems and issues around data protection have been around for a long time. We have had a number of hearings recently—I think you are our most frequent visitor this term—and we keep hearing about data issues. Why is it still not solved? What is the sticking point that is

preventing GPs from sharing data with other clinicians and generally getting this right? It is constantly a problem.

**Dame Una O'Brien:** Let me be clear that there is no bar to the sharing of data around the care of an individual patient. Nobody should have any worry that individual clinicians cannot see the data, because the person's care is at stake. That is really important.

**Q89 Chair:** We get that; it is just the issue of the aggregated data.

**Dame Una O'Brien:** My view is that one of the reasons why it has been hard to solve this problem is that the pace at which the technology is moving, and what the technology enables us to do, open up new possibilities about what could be done with the data that precede when even the legislation was put together. You are now potentially able to put together vast amounts of healthcare data to, for example, drive a diagnostic model. That was never understood or known about when the original legislation was compiled around data protection. This is why it is complicated, because we have duties to protect the individual information, and we have a mounting number of possibilities of what could be done with that data.

**Q90 Chair:** I am not trying to cut you short, but I think we have got that point. What is the barrier? We are going to make recommendations, which we will make partly to you, but we can also make to other people. Is there a magic thing that could happen that would make this possible, or is it inertia in the system? That is the impression we get sometimes.

**Dame Una O'Brien:** It is certainly not inertia.

**Chair:** So what is the magic thing? What is the solution?

**Dame Una O'Brien:** It is understanding precisely how far we could amalgamate data for, let us say, commissioning purposes without changing the law as it stands, or whether significant major legislation will be required to do it. That is the question that we are working on currently in the Department of Health. The precise task that Dame Fiona Caldicott is now looking at is whether, within the existing legislative framework, we could have a simpler choice for patients, so beyond the sharing of data for their personal care, what is the level of permission they are prepared to give, and should that be an opt in or an opt out? The question really lies in how far we can do that within the existing legislation and to what extent the Government would need to bring forward something much more fundamental.

**Q91 Chair:** May I push you on that? You say you cannot give dates, but you have people—

**Dame Una O'Brien:** Dame Fiona's report will be completed by the end of January. We will consider that report in the light of other analysis that is being undertaken. From my understanding, no group of Ministers is more determined to sort this out than the group that we have at the moment.

**Q92 Chair:** That is helpful, because it gives us at least the end of January as a starting point to think about. I just wanted to touch on the tariffs issue, and I think that is you, Simon Stevens. We heard from Dr Morrish about the “bizarre tariffs”, to use his phrase. He came up with this having just done an FOI inquiry, so it is out there that some hospitals are being paid £600 for a patient and some £200. Does that accord with your experience and, if so, what are you doing about it? It seems a bit crazy, frankly.

**Simon Stevens:** The split between specialised commissioning of neurology services and CCG commissioning of neurology services might have had a logic at its inception, but it has also created a fragmentation, particularly when it comes to out-patient services. That is the reason why we are making a change from next year such that all neurology out-patient services that arise from a referral from a GP are locally commissioned by CCGs, so that we have more holistic planning and commissioning back into the system for those neurology services.

In terms of the particular pricing of individual tariff components, obviously there is a consultation that takes place annually on that. Monitor then takes account of the responses and will promulgate a set of prices for consultation under section 118 of the 2012 Act in due course, to go live for April. Those are continually improved upon—

**Q93 Chair:** So is the simple answer to my question is that the changes that you talk about will stop this variation?

**Simon Stevens:** No, the changes that I have talked about in terms of the holistic commissioning will make it easier to have a total view as to what out-patient services should look like for the people living in a given constituency or CCG. In terms of how individual parts of neurology services are priced, that is a responsibility for Monitor under the tariff and is subject to consultation, and they will set out what the plan is for 2016.

**Q94 Chair:** So why is it so out of kilter now? Why is it so different now?

**Simon Stevens:** Could you say a little more about how it is out of kilter?

**Chair:** Unless you disagree with what Dr Morrish said, in which case make it clear—

**Simon Stevens:** I think I would need to see a little more detail to give you a proper response, but I would be happy to have a look.

**Q95 Chair:** It seems that there is a variation—a very wide variation—in the amount a hospital gets for treating somebody with a neurological condition, which presumably, as you have hinted at, wraps in other things in some cases, but not in others. Was that news to you when Dr Morrish said it, or were you aware of this anyway? *[Interruption.]* Oh, forgive me; you were not in the room when Dr Morrish gave his evidence. I think I have explained what his evidence was, so is that news to you?

**Simon Stevens:** If it is a consequence of the fact that the status quo ante is that if you are referred to a neurology out-patient appointment at one of the 25 specialist centres by your GP, at the moment that is captured in the specialised commissioning programme. If you are referred by

your GP to a neurology out-patient appointment in one of the non-specialised centres, that is funded by your local CCG. That is a kind of dichotomy that I don't think makes a lot of sense. I don't know whether dealing with it will create the opportunity also to look at how elements of neurology services are priced per the tariff, but I will be happy to have a look at Dr Morrish's proposition in more detail.

**Q96 Chair:** Dr Bateman, you look like you have something to say on this.

**Dr David Bateman:** The tariffs vary quite considerably. I work in Sunderland and my neighbours are Newcastle and South Tees, and for exactly the same work, they charge 25% more. For the same volume of work, we could appoint two more neurologists, so it makes a big difference.

**Simon Stevens:** But Dr Bateman, doesn't that exemplify the point I'm making, which is that South Tees and Newcastle are two of the 25 designated neurology specialist centres—

**Dr David Bateman:** Yes, exactly. But I'm talking about—

**Chair:** Sorry, one at a time, or we will get completely lost as to what is going on.

**Simon Stevens:** At the moment, an out-patient appointment in Sunderland is classified differently from an out-patient appointment at the RVI, the Freeman or James Cook, simply by virtue of the other things that are going on in their neurosciences service and not by virtue of the clinical content of the out-patient consultation. We will change that from April.

**Q97 Chair:** Does that accord with your experience, Dr Bateman?

**Dr David Bateman:** The majority of activity that is going on in South Tees and in Newcastle is common, general neurology conditions. There has been a major problem with the designation of specialised commissioning. I think people tend to see "specialised" and "specialist" as meaning the same thing. In particular, CCGs have tended to interpret that all neurology is commissioned by a specialised route, via NHS England, whereas in fact the majority of neurology is common neurology conditions such as epilepsy, multiple sclerosis and Parkinson's disease.

What goes on in a neuroscience centre that is specialised is epilepsy surgery assessments, Parkinson's disease surgery assessments and specialised diagnosis of rare neuromuscular conditions. The majority of other work is common general neurology, but the commissioning framework has never caught up with the changes in how neurology services are developed.

**Simon Stevens:** Until April 2016—

**Q98 Chair:** Ah, it's always in the future, but at least it's in the future. We will grab hold of that.

**Dr David Bateman:** Can I just make another point about that? That will only catch up in regard to general practitioner referrals. A lot of out-patient neurology referrals are from other clinicians to whom people have been mistakenly referred, such as a rheumatologist, an orthopaedic surgeon or an ophthalmologist, and it will not deal with the very problems that my colleagues have



discussed and that I am trying to solve, which are how we improve the care pathways for people with acute seizures who are being admitted to hospital and how we improve the care pathways for those with acute headaches who are being admitted to hospital—those kinds of things. It will not resolve those sorts of issues.

**Q99 Chair:** I have one more before I shall pass over to Dr John Pugh, and then there will perhaps be a few more questions at the end.

One of the issues that came through quite a lot in the evidence—I guess, Dame Una and Simon Stevens, I refer this to you—is the lack of good join-up with social care for people with neurological conditions. A very high percentage of people with neurological conditions receive social care but, again, data is a problem, so we do not know the figures exactly. Dame Una, what is the Department of Health doing to try to improve that, because if it was done well, it could reduce the number of acute admissions?

**Dame Una O'Brien:** All I can do is to restate what I have talked to the Committee about before, which is that this problem has to be addressed generically and it has to be addressed in the following ways. First, we need—the Government are committed to this—greater integration of health and social care. That is absolutely fundamental. Secondly, we need more multispecialty teams working together in the community. Some of the examples of that we are now seeing through the vanguard projects are beginning to show that if you bring social care and healthcare people together early on, they can provide a better service.

The third thing—particularly, but not exclusively, in the case of people with certain severe long-term neurological conditions—is that we need an opportunity for more people to have a personal health budget that they can combine with their social care budget, putting them in charge of organising their care and support in the way that they want. The Government will set out a very clear expectation on personal health budgets in the new mandate for NHS England.

Those are three interventions that are important, because they apply across the board, and that is some of the centrality of what is important at the moment. We are embarking on a set of changes that should be of benefit to people with a range of different conditions, and we will make more progress if we do it at scale than if we try to do it specifically around each individual specialty.

**Q100 Chair:** This is all great, except that local authority social care budgets have been cut by at least 16% on average, depending on the local authority, over the past four or five years. There is less money available, and once again we are expecting social care to pick up these issues that could save the NHS money. Laura Brackwell wants to come in on this point to clarify a figure.

**Laura Brackwell:** You talked about personal health budgets and putting that in the mandate. At the moment, the mandate includes an objective for NHS England to ensure that everyone with a long-term condition is offered a personal care plan, yet we see that only 11% of people with neurological conditions have a personal care plan. I was interested to know why it would be different for personal health budgets when it did not seem to be working effectively for personal care plans.

**Dame Una O'Brien:** These are two completely different things. We can talk about the personal care plan—



**Q101 Chair:** But if we are talking about integrated care, they become the same thing, don't they?

**Dame Una O'Brien:** Most people who are in receipt of social care, particularly if they are adults under 65, are being offered, or should be offered—we have made big progress on this—a personal social care budget if they are eligible for help. When people are eligible for healthcare services, we want, within certain confines—this has been carefully piloted—to be able to give them that source of money as well, so that they can organise care in the way they want. We have seen far too many examples of people having different carers turn up at different times of the day, with care built not around their lives, but the convenience of the provider. A combined budget enables someone to have more control over that. They are different things.

**Laura Brackwell:** I was interested in the mandate as a mechanism for holding NHS England to account to achieve something. What is the Department doing, given that NHS England is not meeting that objective around personal care plans?

**Dame Una O'Brien:** If we move on from personal health budgets to personal care plans, part of the issue is how we are measuring things, because I do not think we are getting information that is telling us about the totality of a person's interaction with a general practitioner. We are asking the question in a very particular way with patients, and because they do not have a document called "personal care plan", they think they do not have one. I think there is an issue there that we need to explore further, and we are looking at what should be a better range of questions in the GP survey, but I do accept—I think this came up in the earlier evidence—that there is a sort of cultural problem around what is a plan and when someone knows that they have one that we have to address. That is not just in neurological conditions, but in long-term conditions more generally.

**Q102 Chair:** I can hear that there may be some truth in there, but it is in danger of sounding like patients do not know what they are getting. Most patients would know if they had a care plan.

**Dame Una O'Brien:** They do know what they are getting, but they may not necessarily know that it is called a care plan. It may not be designated as that. In the NAO Report and the evidence that you quote from the Neurological Alliance, when people are asked about their care, there is a very big gap between the much higher proportion of people saying, "Yes, I am getting care and I am satisfied with my care", and what people say about care plans. That leads me to think that there is a problem in how the question is structured in the survey.

**Chair:** I think we are possibly getting into surmise territory there. I will throw to Dr John Pugh, and then any other colleagues who want to can come in before we wrap up.

**Q103 John Pugh:** Is the NAO Report signed off with the agreement of the Department and NHS England? Do you both sign it off?

**Simon Stevens:** On the factual accuracy.

**John Pugh:** On accuracy, okay.

**Simon Stevens:** It also has some judgments that—

**Q104 John Pugh:** The general theme is that there is a problem with the fragmentary character of commissioning. It is regarded as “continued confusion” by the Neurological Alliance, and I do not think anything said here would dissuade us otherwise, but one of Dame Una’s remarks nearly made Mr Phillips and I fall off our seats. She suggested earlier that you are awash with data. I have read the Report fairly carefully. There may be confusion here, where you have perhaps confused patient data, which is mentioned in the care.data programme that Mr Stevens has spoken about—this gap that will be filled—with data about the commissioning process, which seem to be singularly lacking in some cases.

I just draw your attention to paragraph 1.3, which says that “NHS England does not know how many people have a neurological condition”. Paragraph 2.7 says: “NHS England does not hold information centrally on how much funding is available for strategic clinical network activity for neurological conditions specifically.” When you turn the page, paragraph 2.8 says: “NHS England does not hold information on how many staff support the different networks.” As you press on, paragraph 2.24 says: “The Department and NHS England do not hold data on the content of joint strategic needs assessments”.

Mr Stevens has put some emphasis on the holistic local commissioning, but you clearly are going to need data there. Paragraph 2.26 says: “NHS England does not hold information on the extent of joint commissioning of neurological services.” You are not exactly awash with data when it comes to the actual process of commissioning and delivering the service, which is what counts. We agree on that. Whose fault do you think that is? What can we do to rectify it?

**Simon Stevens:** That implies that you think it is wrong that we do not, and I am not sure that I would agree with that in each case.

**Q105 John Pugh:** You don’t think it is wrong?

**Simon Stevens:** No, I don’t. To say that we do not hold information locally on every joint strategic needs assessment when all that is out there on everybody’s website—what does it mean to say we do not hold it? It means we do not do a print-out of stuff that is on the internet and stick it in a filing cabinet somewhere. What does it mean to say that we do not have the share of time spent by people working on the strategic clinical network? It means we have not sent them an Excel spreadsheet and told them to do a time and motion study.

**Chair:** Mr Stevens, this is an agreed Report.

**Q106 John Pugh:** May I pursue that point? If you do have the data—if they are really not a problem for you and they are available—have you looked at them? It is illustrated in the document that what different areas do is very fragmentary. Have you looked at the data in a way that gives you assurance that the holistic local commissioning that you have identified as the way forward can be done and will be delivered effectively?

**Simon Stevens:** I think my predecessors did not agree with the recommendation that JSNA monitoring was, indeed, an appropriate route to bringing about integrated commissioning locally, so the fact that that is not being collated nationally would probably not be a surprise.

**Q107 John Pugh:** But if you are recommending that we do more of it, you have to have some view about how it is going at the moment, do you not?

**Simon Stevens:** Yes, but not through that mechanism. That mechanism was talked about at the time, three years ago, but it is not actually the principal route by which we are going to get person-centred care for people in this country. We are going to get that through stronger holistic primary care. We are going to get that through the kind of integrated care delivery that Dame Una was talking about. We are going to get that through the integrated personal commissioning of budgets coming together. We are going to get that through the sort of work that the vanguards are doing on the back of the “Five Year Forward View”. Frankly, we have moved on quite a long way from the idea that it is just about bulldog clips around local plans and the scrutiny thereof.

**Q108 John Pugh:** May I invite Sir Bruce to say something? You mentioned something called Right Care earlier on. Is that an attempt to get a grip on what is happening in the local commissioning picture?

**Sir Bruce Keogh:** Yes, it is—precisely. The whole aim of Right Care is to understand what commissioning for value is, which areas are doing it best and—

**Q109 John Pugh:** Is that separate from looking at the joint commissioning plans?

**Sir Bruce Keogh:** Yes. This is something that is run out of NHS England, with a view to improving the quality of commissioning at CCG level.

**Simon Stevens:** Basically, what we are trying to do is—we all know that there is huge practice pattern variation across the NHS, as there is across every healthcare system. We have had it in the Intelligence Network reports. We have had it in the Atlas of Variation and so on. We are trying to put together a single dashboard for each CCG that we can then use to support and hold them to account for driving change over the next five years.

What’s more, we have got some pretty big pound note signs off the back of it that we need as part of the contribution to efficiency over the next five years. This is not just about improving quality; it is also about how we are going to create value to give us the headroom to absorb the extra patients we are going to need to treat, and demand. So this is moving from an amateur minority sport into the mainstream, and it is central to the task of effective commissioning in the NHS.

**Q110 John Pugh:** So joint commissioning aside, do I take that as a general rebuttal of the point that I have made that there is not enough information available on commissioning? Point 2.26 says: “NHS England does not hold information on the extent of joint commissioning of neurological services.” Is that not a problem? You are saying it is not.

**Simon Stevens:** I do not think that in its own right it is necessarily a problem, no.

**John Pugh:** Oh.

**Dr David Bateman:** Let me just help out on one thing. As Bruce was saying, we have only just now got enough information to fill commissioning for value packs with neurological data. Next year will be the first opportunity that we have had to deliver these to CCGs, to try to get them interested in and thinking about how much money is being spent on care for their particular CCG and how it compares with how things are being done. I think it there is a fantastic opportunity to improve that, if they are supported by the clinical networks, and the CCGs realise that their commissioning can make a big difference.

**Q111 Chair:** One of the big gaps for me—you talked earlier, and again just now, about getting CCGs to do a better job. Two questions arise from that for me. Why is it so patchy, and do you as the clinical lead have the power and influence to push change? I am not saying that all lies at your door, but you are the lead. You seem positive that you can achieve that, but how? Why is it so patchy, and how can—

**Dr David Bateman:** This is one of the ways—by using the clinical networks to meet the CCGs with the commissioning for value packs, and organising that work to go on all together. I think that needs a bit more mandate than I—

**Q112 Chair:** But the variation is so wide. I won't repeat all the figures, but—

**Dr David Bateman:** Yes, it is huge. We have now got the data, and that can save an enormous amount of money, and at the same time improve care.

**Q113 Chair:** So basically, the argument to CCGs is, “If you do this, you will save money in the long term”?

**Dr David Bateman:** It is a win-win situation.

**Q114 Chair:** But actually, some of the problems with this are picked up by social care. Someone at the acute end, health-wise, is picked up, but if someone is living with a long-term condition and it is not going well, social services support will pick that up, so the cost can fall—part of it, anyway—elsewhere. Is that something that gets picked up?

**Dr David Bateman:** Of course, if your long-term condition is not being managed well, you are going to need more care and you will go into a home sooner. That is the whole point of why NHS England is scoping this new commissioning framework to provide better care in the community.

**Q115 Chair:** But isn't the danger there that CCGs will not see any of the benefit of that? If I had a long-term neurological condition that was not well managed and I ended up in a care home funded by the local authority, the NHS would not have to worry about the cost of that. Dame Una, you are shaking your head.

**Dame Una O'Brien:** Absolutely not. I would say that if a person is in a care home as a result of poor care, that is not a success for the NHS.

**Chair:** Clearly, it is not a success—

**Dame Una O'Brien:** Furthermore, if we are looking at it purely from the point of view of cost, of course that person continues to be completely eligible for health care. I refute the idea behind your question that a CCG somehow has an incentive not to care for people.

**Q116 Chair:** I don't mean it has a positive incentive. I do not mean for a moment that any clinician would willingly and knowingly not care for somebody, but the point is that the cost does not fall on the commissioners. We have talked often in this Committee about cost shunting. The cost of a problem is not always picked up by the organisation that could save the money to the system by investing up front. We have seen that there is a very wide variation in CCG commissioning of neurological services. Dr Bateman has talked about saving money and convincing CCGs partly because of the savings, but they do not actually reap the costs if they do not do it, so they will not see the savings quite as obviously as he suggests.

**Dame Una O'Brien:** This is precisely why we need the integration that I have described. It should be lose-lose for the CCG and social care if they do not come together. It needs to be win-win for the patient and the public that they work together.

**Q117 Chair:** Is that not one of the problems, though? We heard loud and clear from our first panel, in a lot of evidence and in the NAO Report that the Department and NHS England do not really know how many people have long-term neurological conditions in this country. There is no joining-up between those getting social care packages and those with neurological conditions, so it is very difficult to measure the impact of some of the things that you have been talking about, because you do not really know.

**Simon Stevens:** We know, obviously, how many cases of illness have been treated; we know how many unique patients are being treated on the back of that. We will have a much better picture of the pattern of care not just for neurological conditions, but for the totality of what we are doing when we have electronic health records embedded in hospitals that match the kind of data that are available from general practice and we can link the two. Until we have that, we can do the odd one-off survey, but we are not actually on a longitudinal basis going to have that kind of insight. That is why the investment in information and the analysis that goes off the back of it is not just a nice thing to have in its own right, but a foundational asset for improvement that we want to see.

**Q118 Chair:** So how can you plan intelligently in the meantime? We hear a lot about what is going to happen, but right here, right now, how can you convince us as a Committee and the people out there who have an interest in this that you are planning intelligently to make sure—

**Simon Stevens:** We are planning with the tools that we have. If we had a different set of tools available to us right now, we would be able to act differently, but—

**Q119 Chair:** You can be saving some of the £70 million—

**Simon Stevens:** If you talk to the CCGs in your areas and ask them the question: “Would you welcome another bespoke piece of information collection, a data survey, a form to fill in and the returns sent back to NHS England nationally to help you improve the quality of your commissioning of neurology services?” I think we can all predict the answer that they would give you.

**Q120 Chair:** Which means that we have got to make sure that data collection is easier—

**Simon Stevens:** Precisely, which therefore means that it has to be automatic, off the back of the—

**Q121 Chair:** I think you all know that it is likely, without pre-empting the Committee, that we will be making some recommendation around data in our report.

**Simon Stevens:** To will the end is to will the means, therefore by what mechanism and over what timescale? Otherwise it is just a—

**Q122 Chair:** Absolutely. All our recommendations, which you will be picking up, have timescales attached.

**Simon Stevens:** And price tags?

**Q123 Chair:** Well, we are thinking about that too. That is another idea for us—perhaps the NAO can take that. Seriously, we recognise that we need to make realistic recommendations, but, please, we keep hearing that things will get better on data, we keep hearing that it will happen, but it hasn’t yet.

I have two quick points, because I am aware that time is marching on. According to the Report, 58% of people with neurological conditions experience problems or delays in accessing treatment. Perhaps, Dr David Bateman, you could give us a brief summary of why you think the figure is that high. Earlier, you or some of your colleagues touched on GPs. Again, is there a couple of easy things to do, or is it a very complicated picture?

**Dr David Bateman:** Obviously there are delays in out-patient appointments and there is unavailability of urgent clinics. If we could transfer more out-patient work into urgent clinics, we could move those appropriate patients forward and—

**Q124 Chair:** So it is down to the number of neurologists, partly?

**Dr David Bateman:** Partly, obviously. But there are ways of improving things with the numbers we have got. We have already talked at length about in-patient acute care. I think we have to look at ways of deciding which DGHs should be acute neurology and acute stroke centres, if you see what I mean, and place a neurologist there so that they can run urgent clinics for people with acute seizures and people with acute headaches, and prevent them from being admitted. We have been able to show that, just by running an urgent clinic where the A&E people can get somebody

seen within a week in our hospital in Sunderland, we have reduced the number of admissions for acute headache by 60%<sup>7</sup>. Those sorts of things can make a big difference.

**Q125 Chair:** That is very helpful. Dame Una, when the Neurological Alliance did its survey, it showed that the services for commissioning neurological support or treating people with neurological conditions are often not very joined up. In our last report—we touched on this briefly earlier—we made a recommendation on joint commissioning to try and improve that position. You didn't accept that recommendation. I wonder whether you could explain why not, because we are very keen that our recommendations are realistic and taken up by the Department. It might help us in our next report.

**Dame Una O'Brien:** Just as a general reflection, it is very interesting to come back and recall the time when we were at the last hearing, when you made the recommendation, because actually the legislation had not yet been passed and an awful lot has happened in that time. The legislation has gone through Parliament, it was amended and then we had the whole period of implementation, and now we have had NHS England, including more than a year under Simon Stevens's leadership, driving forward the commissioning improvement agenda. So it is a challenge when crafting these recommendations that they find a fixed point that we can link back to in years to come, because actually, now I can see that some of the expectations—the way we were thinking about the JSNAs at the time—have been superseded by the commissioning development work of NHS England, and the role we now see for clinical commissioning groups.

**Q126 Chair:** In summary, that is quite a long answer to the question of why didn't you accept our previous recommendation.

**Dame Una O'Brien:** I honestly think that we never saw JSNAs as being that detailed, condition-specific, nor mandating that from the centre. The whole point of the JSNA was that it should be for the local commissioning organisation, involving all the different patient groups and other perspectives in a locality, to come together and set their local priorities; so the national priorities are set once through the mandate and local priorities are set through each JSNA. It would have been a sort of contradiction to then require things to go into what was effectively a local priority setting.

**Q127 Chair:** We have heard quite clearly from Dr Bateman and from the previous panel that there are some good things that we—or the profession, those expert in this area—know work. They know that they deliver patients improved quality of life. There is a tension, we know, between local commissioning; but when the Department knows something works, or NHS England does, how do you make sure that that really gets out there so that all local providers are doing a good job?

**Simon Stevens:** It is a combination of things, isn't it? First, we have NICE guidelines and other advice standards for the service. Secondly, we have a CQC process. Thirdly, we have the new Right Care scrutiny process that Bruce has described. Fourthly, as the Secretary of State has set out, we will be publishing a new CCG scorecard with a balanced assessment of how well they are doing, and ranking them on it.

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<sup>7</sup> Figure clarified by witness following session.



**Q128 Chair:** When they are not doing well, what do you do? That is the key thing.

**Simon Stevens:** We will have a special measures intervention regime, in the same way that applies to providers. That is being set out by Jeremy Hunt.

**Q129 Chair:** David Bateman, will that give strength to your hand or, if you aren't there in March, the hand of whatever body or individual succeeds you?

**Dr David Bateman:** I think those things are obviously going to be very helpful. The most helpful thing will be CCGs, which really hold the key—and if they have more information and more understanding of how their role and their commissioning for their particular population can make that difference—and I think that changes are taking place in the commissioning process to help support that and help improve it. So I think we have got to try to integrate all these things—commissioning for value, clinical networks, the neurologists on the ground. We have got to get them working with the CCGs to try to work out together how we can improve these pathways.

**Q130 Chair:** I think we have covered quite a lot of ground. There is probably more that we could cover on an issue that is as important to so many people as this. I think it is just worth going back to that figure that you gave us earlier, Dr David Bateman, about the £70 a million year it costs for emergency admissions for epilepsy alone, and reflecting on the point made in the Report that 10% of neurological patients are readmitted as an emergency within 30 days of discharge. There is a very big cost to the taxpayer of getting this wrong, let alone the cost to people's lives. I don't think I need to tell you that.

**Simon Stevens:** No. By way of context it is also worth pointing out, of course, that that emergency readmission rate for neurological conditions is lower than it is for other conditions, and, indeed, the rate of increase in emergency admissions for neurological conditions has been growing at a far slower pace in recent years than it did four, five or six years ago, and, indeed, at a slower rate than other conditions overall. So the neurologists and their colleagues the GPs are doing quite well on those measures.

**Q131 Chair:** That is very helpful, to have that on the record. Thank you, Simon Stevens.

**Dr David Bateman:** Individually that is not the case. If you look at epilepsy, for instance, the figures suggest that 30% of the patients are being readmitted more than five times. So we may be doing well overall, but I think there are these particular examples where we could do so much better. We know how to do better and we have got evidence that if a neurologist sees these patients more quickly we do a lot better and the patients do better.

**Q132 Chair:** Dr Bateman, I may be putting you in an awkward position by asking you this final question, but there has been talk—we have heard a lot—about the removal of the clinical leads. We heard Sir Bruce Keogh being quite up front about the fact that there is a review, and there is a definite question mark over not your personal position—I am not personalising it—but the role that you occupy. Do you think that you have been able to make a difference, and what do you think



the risks are of losing that very personal, accountable—I am assuming you feel personally accountable for some of this—clinical lead role that you occupy?

**Dr David Bateman:** I think the role is crucial and critical. I am in no doubt about that, because I have been able to facilitate and help support so many things in terms of both the clinical networks and the Neurology Intelligence Network and to try to resolve the commissioning difficulties. Unless you have somebody with broad general neurology experience who has been passionate about improving neurology services for their lifetime as a neurologist, with the connections and understanding, I don't think you are going to see the opportunities or be able to lead them.

**Q133 Chair:** Sir Bruce indicated that it might be replaced by—I don't want to over-paraphrase—some form of committee or alliance, rather than an individual.

**Sir Bruce Keogh:** We are still thinking that through.

**Chair:** Well it was worth getting that on the record so that Dr Bateman—

**Mr Bacon:** You possibly might get it right.

**Sir Bruce Keogh:** We will.

**Simon Stevens:** I think it is worth saying that the difficult task that Bruce has been set is that he is having to do this in the context of a substantial cut in the resourcing available—the running costs. He has been asked, as has everybody across NHS England, to slim down our operations yet further. That is part of the reason why he has to do what he has to do.

**Q134 Chair:** I think you are hearing what our concern is. I just want to ask Dr Bateman a final question. There is a difference in accountability if there is a group of people as opposed to just one named person. Do you feel personally accountable for the problems and improvements in dealing with neurological services because your name is at the top of the headed paper?

**Simon Stevens:** Think carefully about how you answer that question. *[Laughter.]*

**Dr David Bateman:** I am perfectly happy to be accountable and responsible within the resources that I have available and within the time available.

**Q135 Chair:** Three days a week.

**Dr David Bateman:** Two, but I have spent far more time than two days a week. It would be extremely difficult actually to get that kind of commitment from various other people, given that they are all very busy, and to know who would be the best person to get it from.

**Q136 Chair:** I said that that was going to be the final question, but given that you have just heard that, Sir Bruce, if you did go for a different structure, who would be the named accountable person? Would you plan that, or would it be you and Simon Stevens?

**Sir Bruce Keogh:** Ultimately, it would end up with me and Simon Stevens.

**Q137 Chair:** You are very eminent, Sir Bruce, but you are not a neurologist—although I don't whether you maybe did some neurology at some point—so who would be the eminent neurologist who would ultimately have their name at the top of the headed paper and be responsible?

**Sir Bruce Keogh:** I think we'd need to sort that out with the strategic bodies. You are pressing me for an answer that requires serious deliberation and cannot be given fast.

**Chair:** And we are glad that you are deliberating. It is just important to get these things out.

**Q138 Mr Bacon:** What is extraordinary is that if you were looking for new models where running costs were lower, you would go for a model where you had somebody who was doing one job and doing another job two days a week, which is what you've got. This is one of the areas where things appear to be working quite well. I mentioned the case of Sir Mike Richards earlier, only because he was the most outstandingly successful example we have seen so far in this Committee of a national clinical director. You preside over an organisation that even now, despite the fact that it is getting more money—can you remind us what the NHS budget in England is now?

**Simon Stevens:** NHS England is—the running costs—

**Mr Bacon:** I understand the running costs are separate—

**Simon Stevens:** That's what these costs are.

**Q139 Mr Bacon:** What is the total budget of the NHS in England?

**Simon Stevens:** For NHS England to deliver the mandate, call it £101 billion, but obviously the vast bulk of that is distributed to local health services to treat patients.

**Q140 Mr Bacon:** Yes. A great deal of it does get squandered, though. We know this because we see it routinely.

**Simon Stevens:** That will obviously be the subject of a further discussion. I think the National Health Service is probably the best value health system in the world.

**Chair:** That is what we are here for as a Committee—to make sure that there is value for money for the taxpayer and effective services for the patients. Hopefully we have teased some of that out, and we will be issuing our report at some point in the new year. Our transcript will be available, uncorrected, on the website in the next couple of days, so if you have any thoughts about anything you have said, do have a look at that. I thank our panel very much for coming and particularly Dr Bateman for travelling from Sunderland to be with us today. Thank you very much indeed for attending our hearing.

