

Commons Public Bill Committee: Health and Social Care (Re-committed) Bill 2011

From Hansard, 28th June 2011

Examination of Witnesses

Paul Jenkins, Jeremy Taylor, Ciarán Devane , Neil Churchill, Baroness Barbara Young and Joe Korner ga ve evidence.

5.15 pm

The Chair: Welcome, lady and gentlemen. Can I have a bid for questions? Emily Thornberry?

Q 139 Emily Thornberry: I want to begin with a general question to put your evidence in context. Do you feel that you have had sufficient time to look at the 180 Government amendments, the Future Forum report and the Government's response, and to consult your

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members before coming before us to give evidence? I know that not many of you have been able to do written evidence for us, and I wondered whether you were hoping that you may be able to in future.

Paul Jenkins: We have not had the greatest time to consider things. It is clearly part of a process, so we have been checking to see whether the commitments made in the response to the Future Forum report are addressed in the amendments. It is very important that, whatever we think and say about the amendments today, there is the opportunity to continue to influence the process as it goes through, so that we get the best legislation. If the deal is that what we have today is what we have today, that is probably not very helpful. If there is the opportunity to refine things as we go through, that is more positive.

Jeremy Taylor: We would not want this to be our last word, that's for sure.

Q 140 Emily Thornberry: Do any of you have any particular anxieties about the process?

Joe Korner: I have not really had a chance to study the amendments in detail at all, but I have just come from a meeting of 200 stroke survivors at the UK stroke assembly in Birmingham. I was giving a talk about the potential reforms to the NHS, and there is an enormous amount of anxiety and confusion. That is compounded because there is already change and some disintegration going on locally in existing health structures, but there is not a lot of clarity about what is going to replace them in the future. There

are great concerns, and I was not able to give them much clarity, because we have not had enough time. However, we welcome the chance to give evidence and give our view, such as it is. Our view is maybe more general, rather than about specific parts of the amendments.

Baroness Young: A particular anxiety is that it was a very complicated set of changes in the first place, and they have now been added to in order to meet the call that the Future Forum gave and also many of the issues that we had raised as a group and individually. It feels slightly churlish to complain that more complexity has been added. On the other hand, however, that means two things. Apart from the point that was made by the Stroke Association about the disintegration of services that we are seeing at the moment, there is an issue of complexity for the future and it being difficult to understand how all these bits fit together.

For me, the biggest challenge is not particularly what we get in the legislation but what comes in secondary legislation—in guidance—and in the various pieces of implementation, because they will be coming thick and furious over the next two years. Are we going to have enough time, as a set of organisations representing patients, really to scrutinise those carefully? There will be tens, if not hundreds, of individual changes that will be subject to consultation; that will have guidance put out; and that will have secondary legislation. The devil will be in the detail of those, and my concern is that we will be on a bit of a treadmill for the next two to three years of trying to keep up with a very broad programme of changes, and a very complex set of issues. There are plenty of slogans around but not yet any clear understanding of how they all fit together.

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Neil Churchill: It would also be fair to say that the quality of the engagement in the latter part of the discussion has been much better than it was in the earlier part. We are very much hoping that that engagement will continue as we get into the phases of implementation and dealing with secondary legislation and guidance. We see the patient voice as being a real strength in coming up with the right answers about how those things can be done.

Emily Thornberry: A fair summary: for those who have not spoken, you have been spoken for. Thank you.

Q 141 Mr Barron: I have a question for all of you. There has been much talk in the past seven days about how the changes will open up decision making, commissioning and such things to patients. Given the organisations that you represent, do you feel that the concerns of the different charities will get more of a hearing in what happens now than in what was going to happen three weeks ago?

Ciarán Devane: We welcome, for example, lay representation on the commissioning groups; that is very important. We welcome some of the strengthening of scrutiny of

health and well-being boards. We are still concerned about the engagement of the patient voice at a national, collective level. The national commissioning board can set the example of genuinely putting the patient at the centre of things so that when we look at the national commissioning board, in the same way as we look at the medical director of the board and say, “Yes, we can believe that he represents the medical view,” we can look at the individuals on the board and say that they genuinely get the collective national patient view.

Similarly, as the secondary processes and secondary legislation get through, it is important that it is not just a debate between the professionals of the health service and the clinical professionals, but that the patient view is genuinely involved in designing those processes as well. We absolutely welcome a number of the changes that have been made, and we commend them, but we have that reservation as well.

Baroness Young: Our concern is much the same. It is always very churlish of charities that have pressed for changes in legislation to look, when they ostensibly get them, as though they are being a bit dog in the manger-ish about it. That is something I would very much want to guard against. We have to recognise that many changes have been made to the Bill that are in the interests of patients.

For me, the biggest issue in terms of the patient voice is the dichotomy that Ciarán referred to between what individual patients will be saying about patient choice, and collective views about, for example, commissioning integrated pathways of care. I find it quite difficult to understand how those two fit together at the moment. This collective voice for patients about the commissioning processes nationally and locally, and about integration of pathways of care, has got to be predominant. On choice, which is very strongly driven through the Bill—the whole mandate for choice is quite a strong set of amendments—I need somebody to explain how it works with collective views from patients about integrated care.

Neil Churchill: The proposals are undoubtedly strengthened from what we saw before. We came in on the end of a discussion about population need, as

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opposed to the patient in front of you. A lot of the patients whom we are worried about are not well engaged, if at all, with the health service. We feel that engaging them effectively and involving them in the design of services will be important in meeting the challenges that we face in improving outcomes and productivity. There are a few outstanding questions in relation to what the networks and the senates will do and the patient voice in some of those settings, all of which we would like some clarity on as we move forward. There is definitely a strengthening in the service, but we would like to see it reaching out to patients who are quite hard to get to and involving them in the process.

Paul Jenkins: This issue, like others, is undoubtedly a lot more prominent and a lot more recognised in the revised legislation, which is really important because that

harnessing of the collective patient view will be essential if we are to design services that are high quality and sustainable for the future. Like others, I would like more scrutiny of the definition of collective involvement as the Bill goes through Committee. There may be two angles to that: either to put patients and carers on the same footing as specialist clinicians in terms of the requirement to seek advice, so the advice of expert patients is as important in some aspects of long-term conditions as that of clinicians; or to change the public involvement stuff, so that there is much greater emphasis on the proactive engagement of the public and patients before decisions are made, rather than follow what has been the typical model of involvement whereby you make a decision and then you test it and consult people to see whether they object too much to what you propose.

Jeremy Taylor: The NHS Future Forum, on which I sat as one of the voluntary sector members, said:

“The declaration of ‘no decision about me, without me’ must be hard-wired into every part of the system—from the legislation through to each and every encounter between”

doctor and patient. That is a really strong and radical vision. The amendments that the Government have put forward takes us further in that direction, and to that extent they are welcome with the greater emphasis on the duty to involve patients and public, greater transparency and lay people on consortia. We probably have still further to go. This is one of the areas in which we need more time to make sense of the amendments and understand what difference they will make. It seems to us that more could be done in defining what patient involvement means, because it is so central not only to improving quality but to meeting the so-called Nicholson challenge, so there is a case for being more explicit about what we mean about engaging people in their care.

The duty of public involvement still reads very much along the lines of the old section 242 template of informing and consulting. That is still the model of public involvement that is expressed in the Bill as amended. Many of us here think that that is a rather old-fashioned way of engaging and involving people, and we would like to see something a bit stronger.

Joe Korner: I agree with my colleagues from the charities. There is a dichotomy in the Bill and that is the involvement of patients in decision making, which has been strengthened, but there is also this idea of patient choice, or patients as consumers. The stroke survivors I have just been talking to are not interested in a choice of

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providers. They are interested in engaging to make sure that an integrated complete pathway of care is available for them, that there are no gaps in the care and that it is integrated. To that extent, the collective voice, or the voice of representative organisations such as ourselves, is very useful because we can express a collective view of people who have experienced stroke services and help to ensure that those services are commissioned properly across the country.

Dr Poulter: There is obviously an issue here about how we have and how we put into legislation effective discussion and engagement with patients. Often, the people with whom we want to engage do not engage. Patients are incredibly accepting, but unfortunately there are sometimes things that are unacceptable: for example, being treated with chemotherapy in a hospital corridor or on mixed sex wards, which, thankfully, are almost a thing of the past now, but they have been going on, and still go on in some cases, and are not very good practice. Nevertheless, the point is that we often see in local LINK organisations, for example, the agenda is hijacked by one or two articulate individuals who have their own agenda, which is not necessarily representative of a wider body of patient opinion and does not necessarily capture the key challenges for patient care either at the local hospital or in local community services and community care. How do you see the Bill improving engagement with patients to make it more effective, as that is a key challenge?

Paul Jenkins: There are plenty of mechanisms in the Bill that could help; it is very much a question of they are enabled to do their jobs. Let me start with an example: we are a group of charities representing a very diverse groups of patients and we could have gone into the exercise around this Bill just concerned, in my case, with people with mental illness, or stroke survivors, or people with asthma, but we have recognised the importance of working together and providing a generic response to the issues in the Bill. We hope that that style of working together among patient groups locally will be one of the things that we can take forward after the Bill is enacted.

There are other key things—the role of healthwatch is very important. We are pleased that the Government recognise the importance of healthwatch having a duty to engage all parts of the community. It is very important that healthwatch is properly funded and resourced to carry out that function. We were disappointed that there was not a commitment to ring-fence the funding and we hope that that is something that can be reconsidered. We also welcome the role of the lay representatives on clinical commissioning groups and one of them having a specific remit on patient involvement. They need to be real leaders in their local community, along with health and well-being boards, to get the right kind of involvement of patients and carers in decision making.

Ciarán Devane: May I elaborate on that? I think the processes that one puts in place to sample the voice of the patient should not rely on one individual. It is why when we look at a commissioning consortium, we need to look at the lay representations and their quality and the skills they bring. We need to look at the processes by which they do the public engagement and the transparency with which what they do is available for scrutiny by ourselves, among others. It is that collective process that

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drives genuine public and patient engagement, not a tokenistic individual, who may or may not be of the calibre who will represent the broad patient voice.

Baroness Young: There are some interesting methodologies arising to make sure that the patient voice is heard, including hard-to-reach sections of patients and the public.

We have just completed a pilot study in three PCTs of new ways of involving users in decision making about care, and if you go to our website you can see a toolkit that we have developed for commissioners and providers to enable them to learn from the experience of these three pilot districts. For me it is going to need, first, time; secondly, investment; and thirdly, skills. We are going to need people involved with commissioners, providers, the health and well-being boards, the NHS commissioning board, Monitor and the CQC who are experts in how to develop that patient and public engagement. Otherwise it will be the tokenism of having an individual.

Q 142 Liz Kendall: Thank you all for coming today. I want to ask you about your views on HealthWatch and whether you think it is strong enough. Do you think that it will be as powerful a voice for driving change in the system as the Care Quality Commission, Monitor and the national NHS commissioning board, when we now know from the Government's response to the Future Forum that it remains a sub-committee of the CQC?

Jeremy Taylor: I am not sure that it matters where HealthWatch England sits. What matters is whether it has clout, credibility, independence and sufficient resources. One could have a big debate about whether it should sit as a separate body or as part of the CQC. Colleagues may have different views. My view and the view expressed in the forum is that HealthWatch England will be an important part of the architecture for the patient voice, so we should welcome it.

We would like to see it set up quickly—I hope that you are listening to this, Paul Burstow, because according to current plans the NHS commissioning board will be up and running in shadow form from this October, but HealthWatch England will not be in action until October 2012. Why the delay? Why not get on with it? Even within the CQC, that body has the potential to set the tone and leadership for the emerging local healthwatch bodies. Timing is important, and there is something about everybody's duty to deal with and involve HealthWatch England. The Bill, as amended, gives me greater assurance that people will have to treat HealthWatch England as an important player.

Overall, there are still some concerns about whether the healthwatch system will be powerful enough when compared to the local involvement networks. LINKs have suffered from scarce resources, not many staff and not a great deal of clout; as a result, they have been patchy. Some have been very good and have started to get off the ground and do some fantastic stuff, others have not. It would be a tragedy if healthwatch ended up being incredibly patchy. We have an opportunity to get something that works well everywhere.

Q 143 John Pugh: I wonder whether the Government can keep all you guys and girls happy. Clearly, some of you want to provide services for the NHS, and some want to monitor what services the NHS provides.

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I was struck by the report “Choice and Competition: Delivering Real Choice” by the Future Forum group, whose members included people from Mind, Marie Curie, Turning Point and so on. As part of the framework on choice and competition, it recommended that

“Consortia would apply the policy on choice and the competition model to their local commissioning decisions to ensure they are delivering real choice”—

although I am not sure how real choice differs from ordinary choice. There seems to be a paradox here, in that some of you are unhappy with too much choice because it prevents integration, and others want a piece of the action. I am not clear whether the Government can write legislation that would satisfy you all, other than by including a clause saying, “Give only so much choice as would please the charitable sector.” How can they do that?

Joe Korner: As a charity that is a service provider, I do not think that it means that one cannot have a view about the complete pathway of care that the charities that we represent need to deliver. The services that we provide are parts of the pathway that hitherto have not been provided by anyone else. Traditionally, the voluntary sector is good at identifying those needs of our constituents that are not being met. That is why the type of services that we provide do not normally carry a tariff, and in many cases, they are probably not worth enough to go for tender, so we have great concerns about how they are to be commissioned at all in the future. There is no problem with people choosing between providers; the real problem is that in many areas people have no choice at all because those services do not exist—they are not commissioned.

Q 144 John Pugh: If you offer choice, to use the BMA’s words, you are not going at any stage to undermine existing NHS facilities?

Joe Korner: We do not try to replicate existing services; that is not our function. Our function is to meet the needs of people that have had a stroke whose needs are not being met in other ways. Certainly, there are some things that we do—for example, providing information—that we believe the NHS should be doing, and rather than provide it free, we decided to start charging for it, because we do not believe we should use voluntary donations to do that. We are clear about what needs should be paid for by health and social care, but that we are in a better position to provide.

Q 145 John Pugh: Bearing in mind that the choice and competition section was chaired by the Association of Chief Executives of Voluntary Organisations. He may be off on one and not representative of you as a whole—

Baroness Young: May I say categorically that he was not representing views as a whole? ACEVO is an umbrella body; it is not a body that votes and takes a position. Although many of us are members of ACEVO, he is not mandated by our organisation. That has to be clear.

Ciarán Devane: For me, ultimately it has to be a choice between quality providers. Ultimate ownership is a second-order issue. Where NICE has produced evidence-based outcomes guidance that says, for example, that clinical nurse specialists drive good patient experience and that if you want good outcomes for sarcoma you

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have to do 100 cases a year, otherwise more people die, we have to get that definition of quality in. Whoever is the provider, whether it is one NHS hospital or another, they should meet those standards.

Q 146 John Pugh: Do you not think that commissioners will be properly mindful of that, given their knowledge of their patients?

Ciarán Devane: History would suggest that some are and some are not. In the world we are going into, we need to find a way to ensure, encourage, incentivise and mandate that you do not get to do low-volume operations just because you want to have a go. That mechanism should be in place so that the provider, whatever their ownership and shareholding, meets the minimum quality standards, which are evidence-based, but beyond that, they can be innovative and everything else.

Paul Jenkins: It is a matter of the order in which you do things. If you start with the collective patient experience of services, you rapidly identify, as you would in the area of mental health, a number of issues where it really matters to patients whether they get a service or what service they get. That ought to be defining the choice agenda. In mental health, it is about the choice of medication and the choice of whether you have access to psychological therapies, and it defines choices patients might want in terms of realising personal goals, such as getting a job or other things. That is not unfettered choice; it is a defined agenda of choice. I am not uncomfortable with what the Bill in its amended form says about choice, but that is the order of the argument. We use patient and care input to define where the current system is failing, which then defines a choice agenda, and where the existing system cannot provide that choice, it is important to have diversity of supply.

Jeremy Taylor: That is a very sensible way of looking at choice. There is no single voluntary sector view on choice, and I am not sure there needs to be. Choice is a contentious and politicised issue and there are different views on it. The Future Forum has said that it is meaningful choices that matter to patients and individuals—I paraphrase—rather than the choices that politicians may think that people want. You have to start with the patients and understand their needs, which is Paul's point.

Sometimes people resist the notion of choice because they think too much fuss is being made about it. The evidence is that people care about a number of things: access to services, the quality of services, meaningful choices—an example might be that I choose to die at home rather than in a hospital, which is the example that Stephen Budd used, and it is a good example of a choice that is meaningful to individuals, but that is

often denied to them by the services—and a voice in the system. All of those things are important, and choice plays a part in that.

The Chair: Our witnesses are inspiring or inciting Members to think of questions, and Members are indicating to me that they want to come in to ask questions. I have my own waiting list, and I can only call people in order. If Members are able to come in later, they may refer back to the point that inspired or incited them.

Q 147 Emily Thornberry: I want briefly to go back to the CQC and HealthWatch, and then I want to ask about choice. If HealthWatch had been up and running

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during the scandal at Winterbourne View, one of the things we would expect it to do would be to investigate the CQC's failure properly to watch what was going on. HealthWatch might have decided that we should be looking not only at Winterbourne View but at large locked institutions for people with learning disabilities and that it is important that the CQC does a study of many organisations. That is a real-life situation happening at the moment. Let us think about the impact of that. With HealthWatch being a sub-department or committee of the CQC, would it not be subject to, for example, pressures from the CQC saying, "We're 300 people short; we simply can't do that."? Do we not need the two organisations to be a little more separate, so that the CQC at the very least can be watched by HealthWatch?

Jeremy Taylor: That is a very good challenge. If HealthWatch England is in the CQC, there has to be a satisfactory answer to how you have sufficient separation and independence that HealthWatch England can operate without fear or favour in relation to the CQC. However, it seems to me that the whole regulatory system has to work, and there is a number of critical ingredients in that. We will probably hear more about this when the Francis inquiry reports, but you must have a system whereby people can blow the whistle at local level and are heard and there is a quick response, so that it does not end up being a national regulatory issue.

We have learned about the failings of Winterbourne View. One of the failings is that nobody picked up on that at an earlier stage, when there were plenty of opportunities to do so. Having mechanisms for understanding and measuring people's response to the services and allowing them to voice that is critical and may, in fact, be more important than the machinery you have at national level, because the national regulators will never be able to cover everything. They need good intelligence and the willingness to respond quickly when they get it.

Q 148 Emily Thornberry: May I move on to choice? In a way, perhaps that has been investigated sufficiently, but I want to take this opportunity to underline it. For most patients, choice is not, "I'm going to this hospital instead of that hospital." As you explained, it is about sitting down with your doctor and saying, "My daughter comes to me three days a week. I have diabetes. I also have this condition and that condition.

What are the different ways in which we can work together to give me the support that I need to keep me out of hospital?" That is choice in the modern context, isn't it?

Baroness Young: The problem is that we have the wrong word. I do not think that it is choice that patients want. They do not want to go shopping, particularly when they are ill, or old, or perhaps have a touch of dementia, or are very depressed about their condition, or have other really horrible pressures in their lives. They want to sit down with their professional and understand what the options are for them and how they can put together a pathway of care that will last for the duration of their condition, which for some can be 30, 40 or 50 years. They want to be confident that they will play a role in selecting those options and that the options will have some way of being met—that the services will be there.

One of the problems at the moment with many long-term conditions is that it is not about choice. If you are a patient with diabetes, it is not a matter of

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which podiatrist you want to choose to go to; it is whether you will be one of the 80% who do not get a service or one of the 20% who do get a service. The point was made that the first step must be getting integrated pathways of care commissioned, because that is what people with diabetes and people with long-term conditions are telling our organisations that they want. They want options, not shopping.

Q 149 Margot James (Stourbridge) (Con): I would like to keep the focus on clinical pathways, because there are various roles for the patient voice in the health service, but one of the most important is in the devising of the clinical pathway. Do you not feel that under the amended legislation, there is even more scope for patient organisations to have an input into commissioning plans, not from the general LINKs-type approach, but more from the specialist patient organisations such as yours, whereby you have input into the commissioning of diabetes or asthma services at local level. We heard this morning that the push to more community involvement and greater input into commissioning plans would be extended. Do you not see that as an opportunity?

Paul Jenkins: Very much so. There is a lot more in the amended legislation that provides a lot more levers to push not only the best performers. We always believe that motivated GPs and other clinicians will involve patients. Our concern was with the bottom quartile, with the people who do not get that and do not get the value of it and who have more paternalistic attitudes towards patients. Undoubtedly there is opportunity and it is better.

Going back to the point we raised earlier, I think that as you consider the detail, there is a little more strengthening around the collective patient voice, particularly to direct it in exactly the area that you have just highlighted in terms of involvement in the proactive design of clinical pathways and getting patients and carers in right at the beginning, rather than when decisions are already being taken by clinicians or managers.

Joe Korner: There is an opportunity, but commissioning a complete pathway for stroke involves a lot of different levels, so you might need to reconfigure your acute hospitals, and you might need to do that across your commissioning boundaries. London is a perfect example, and the Prime Minister was at University college hospital praising London's stroke care two or three weeks ago. What delivered that was bringing together the 30 PCTs in London and the four stroke networks under the direction of the strategic health authority, with patient involvement through the networks and through the Stroke Association being involved. It was a top-down, strategically planned reconfiguration of a part of the pathway. That is going to need to happen in the areas of the country where stroke services have not reached the standard they should meet and patients still are not getting access to emergency care and stroke unit care. At that level you can have involvement, but it is not clear from the legislation how that strategic input will take place.

There might be other parts of the pathway that can be done locally, but we want to see integrated commissioning across the whole pathway, so there will need to be a way in which patients can be involved with different levels and some way of integrating—bundling up—commissioning groups, with the stroke networks involved.

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I would have also thought that the national commissioning board would need to impose some of those things strategically, because the strategic health authorities will not be there to do those things in the future.

Baroness Young: Diabetes UK represents professionals as well as patients, and the most powerful thing in designing an integrated pathway is a grouping of doctors, nurses and other professionals in clinical networks with patients, designing that network. That, I hope, is something that will be taken account of in the way in which the Bill is implemented. Those clinical networks operating not just at national level but at local level will be incredibly important, but they must include the patient voice, because that is the most powerful thing for getting the options that patients are looking for built into the process of commissioning and indeed delivering those integrated networks. They are not just about commissioners; they are about deliverers—providers.

Ciarán Devane: May I add one small comment? When that happens, the reinvention of pathways is more radical, produces higher quality and is more cost-effective. Accessing the money that we all recognise needs to be accessed to have a sustainable health service is more achievable when that patient voice is embedded in the pathway redesign, because you get something that is less conservative and more prone to bringing choice and to bringing care closer to the home, into the community and out of the expensive hospital bed.

Q 150 Margot James: Can I add a rider to that? The challenge to you is to operate at the local level, which the Bill gives you the opportunity to do, but also to operate at the national level on the evidence base through your channels into NICE, so that the

evidence on which clinical pathways should be based has your input at that level as well, and that that is also facilitated. Do you agree?

Ciarán Devane: From a legislative point of point, I absolutely accept that there could be mechanisms. There is the institutional issue as well: without being unkind to NICE, it is not always known to have the most patient-centred view of life, and we need to apply the same principles to the substructures of the health system as we apply to commissioning consortia and so on.

Neil Churchill: I echo that. This is where we are not aligned in the system, and there is plenty of good evidence that is well accepted by clinicians but is not accepted by NICE. We see that, for example, with the quality standard on chronic obstructive pulmonary disease, which did not take into account the considerable evidence that exists on smoking cessation and prevention of COPD, and we are getting the same thing at the moment with a reluctance to accept the evidence supplied by organisations such as the British Thoracic Society. For us, it is an area where further integration is needed to align incentives to make things that we want to happen, happen. That is not currently there.

Q 151 Owen Smith: My question is specifically for Mr Korner and Mr Devane. It is about the level at which services might be commissioned. I am asking you specifically because of the interest groups that you represent. There has obviously been a concern that, with the national commissioning board commissioning some things nationally, specialist services, and with

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consortia commissioning things locally, will consortia at the local level have the requisite expertise, and will the national commissioning board have the insight into local conditions to be able adequately to commission across the country? Do you think those concerns have been addressed by the changes in the Bill, notably the creation of senates and networks?

Joe Korner: At the moment we have the stroke improvement programme and stroke and cardiac networks across the country. Those bodies are extremely good at promoting good practice and collaboration, but they have no teeth. I do not think we are suggesting that there should be national commissioning of stroke services, but certainly in acute care you do need a critical mass of patients if you want to commission really good acute care. As with Ciarán's example in cancer, you need doctors to see enough patients to get good enough to provide clot-busting treatments safely. The evidence is clear that the more experienced they are, the better they are at making decisions about thrombolysis.

We feel that there are reconfiguration issues, which are commissioning issues, that need to be considered at a regional level, but there is nothing in the Bill that says that there will be any structures to do that. We have heard that the national commissioning board may have sub-national structures, but until they are in existence and we know they are and what powers they have, and whether they will be able to do more than

encourage and advise commissioning groups to get together, we are going to be very concerned. There are areas of the country where services will fall behind the best. If you look at London again as an example, we probably now have there the best acute stroke services in the world. I want to see that for everybody throughout the country. I worry that we have not got the mechanisms in the Bill to guarantee that we can enforce the type of change that is needed.

Many aspects of stroke services should be done locally, such as the ones we provide of community rehab. However, there is a danger that in trying to save money, people are going to start commissioning generic physiotherapy or generic services, when actually we know that it is the specialist services—specialist stroke physiotherapists, for example—who are going to make the difference. It may be that we do need to get those consortia to work together, so that there is a critical mass of patients to make it economically viable to do so.

Ciarán Devane: I absolutely welcome what is in the legislation to ensure that networks exist, and the message that they will be hosted by the commissioning board. When it gets to their application, there are a number of things that we have to get right. Let us say that one GP consortium does not want to play when the network says it wants to put in a linac in a radiotherapy unit. One consortium, for whatever reason, might say it is not interested, does not want to and does not like it. What authority will say that it will or will not happen? There are some things that we need to work through.

The preservation of the networks was one of the most important things from our point of view, because, with the best will in the world, a GP consortium will not see a childhood leukaemia more often than one in x number of years. They will not have the expertise. We have to bring that up to a collective view, but give them more teeth to ensure that they are unlike some of the existing networks, where people opt out, they do not

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play, they do not conform, they go around the back and do these operations. I hope that hosting them in the commissioning board will do that. That would be huge step forward.

Q 152 The Minister of State, Department of Health (Paul Burstow): I want to pick up on Mr Korner's comment. He posited the notion that the Bill does not provide the changes that will deliver the stroke care that he and every member of the Committee want to see. If we maintained the status quo, would the current system do that?

Joe Korner: The current system has succeeded in some areas, such as Manchester and London—

Paul Burstow: Manchester and London?

Joe Korner: Those are two examples off the top of my head. The current system has delivered across the country a dramatic improvement in stroke care since the stroke strategy was published in 2007. We have seen, for example, that the proportion of

people being treated for the majority of their stay on a stroke unit, which is the strongest evidence base for good care and better outcomes, has increased dramatically since 2007, when the strategy was brought in. It has been disappointing that some areas of the country, some stroke networks and some strategic health authorities have not taken the quality markers that were in the stroke strategy and used them to drive improvement in services, so the improvement that is going on is patchy.

The national sentinel audit for stroke, which audits all the hospitals in England and Wales, shows that there has been a dramatic improvement. The audits take place every two years, and the two most recent audits have shown that dramatic improvement. They have also shown where we are failing to make as much improvement as we should. I am not suggesting that the current system is delivering everything that we want, but I am concerned that the legislation as it sits does not provide for the type of strategic planning to improve services that, as we have seen, has made a dramatic change in certain areas of the country.

Q 153 Paul Burstow: I want to pursue something that was said earlier about choice, to make sure that I understand; it was the point made by Baroness Young regarding the use of the word and what it encapsulates. To be absolutely clear whether we are talking about the word and its application or what it means, I will refer to the Future Forum and the report on choice and competition. The report mentions some work that was done at the seminar co-ordinated by the Health Foundation, which suggested that choice includes:

“Choices to support healthy living; choice of provider and the way in which care is provided; and choice of treatment including self-management support.”

I thought that really echoed the point that you were making, Baroness Young.

Baroness Young: I absolutely support the first and the last of those two. Patients are very interested in those as options because they are about the mix of care that they receive as part of the care pathway. I think that they are not particularly interested in choosing between providers, because I do not think that they have that luxury in many cases. Most of them are anxious to get an integrated

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service that gives them, for example, the nine health checks every year that they need. We are just about to launch the national diabetes audit tomorrow, which will demonstrate that very many patients do not get those checks.

Most patients are not interested in selecting their provider; they are interested in having someone bring together that pathway of care and discussing with them what that pathway might look like for them. That might include whether they want to go for healthy walks or would rather have a gym subscription, or whether they would rather have their foot care done in the community, in their own home or in some other way. It would not include the idea that somehow they will select a provider on the basis of information

about quality of services, because in many cases people who are in that position will find that their condition makes it very difficult for them to expend that amount of time, effort and energy. Indeed, they may not be in a place where they can easily tackle the assimilation of a huge amount of information about the quality of competing services, for example if they are older; if their first language is not English; if they are very sick; if they are in some sort of emergency situation; if they have dementia; or if they are struggling with other aspects of their life.

Q 154 Paul Burstow: But you would agree that choice is a far richer thing than just choice of provider.

Baroness Young: I think that is why I prefer the word “options” rather than choice.

Q 155 Margot James: I take your point, Baroness Young, about options in cases where care is inadequate. I understand your point. Surely, however, a lot of patients with diabetes would like to have the choice between going to hospital for various ongoing needs, or having a facility that perhaps GP practices have negotiated that provides the necessary care within the community, where they do not have to wait so long and they do not have to worry about parking their car. Surely, that is an element of choice; are we not rather playing with words in talking about options? Having option A or option B is a choice, really, is it not?

Baroness Young: Absolutely. But the point at which that needs to be expressed is collectively when the pathway is designed, with groups of patients being involved with the clinical networks. To be honest, I do not think there is enough resource in the health service to have the luxury of having a service both in the hospital and in the community, without there being a considerable amount of waste involved. We are very, very thin on specialist staff with diabetes skills. To have them duplicated both in a community and a hospital setting for the same service is very wasteful.

Ciarán Devane: May I bring the word “transparency” into this? Publishing the 30-day mortality rate of a cancer surgical team is a good thing because of the peer pressure it puts on one team to say, “Well actually we think we’re better than Fred and his pals down the road, but maybe not quite as good as Mary. How come we’re here in the data?” That mechanism of transparency and of showing performance will drive some people to make different choices. It will have a salutary effect that will improve standards, even when some people do not make choices.

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One of things that the national bit of the national health service needs to ensure it does is to publish data that are measured in a consistent way and that are available for all of us to scrutinise. That can be used as a way of driving up standards. Yes, some people will exercise choice. If I know that the mortality in one place is higher than another, I will do what I can to make sure I do not go there. I completely accept what Barbara is saying that there are no options and no choices and you have to go in and do

something, but publishing performance data that will drive some people to make different choices will have an absolutely salutary effect. We welcome that hugely.

Q 156 Fiona O'Donnell: People really trust the voluntary sector. Part of the reason is because often the service that people such as you provide is not to say to the patient, "This is what we offer," but to say, "What do you need?" There is more flexibility. You would never compromise on quality so, in this new market, do you have concerns about the tendering process and whether or not your services will be commissioned, given some of the issues regarding price and tariffs?

Jeremy Taylor: May I offer an overview because National Voices is an umbrella organisation for health charities—big and small? Not all voluntary sector organisations are providers of services. Even those that are, which are a minority, do a lot of other things, too. They are about championing people with particular conditions or needs and influencing the commissioning process. They may be about providing a service, but there are a rich mix of things that the voluntary sector does that are not just about being another service provider. It is about really caring about your beneficiaries. That is a really important part of the mix and I wanted to get that out in the open. There are some more detailed questions about tendering and procurement that colleagues can answer.

Joe Korner: We are not concerned about the tendering process. We go through tenders and we believe that it is very good that we are tested on the quality of our services to make sure that they are cost-effective. We welcome the idea in the outcomes framework of patient reported outcomes because our services are really about the well-being of people, rather than about health outcomes. So, patient reported outcomes are extremely important.

Where we have a concern is, first of all, in the transition because, at the moment, we are finding that, locally, health economies are disintegrating in some places. Primary care trusts only want to commission services for a six-month period or a year, which is very difficult for us. We have staff who we may have to put on notice. In terms of continuity of care for our service users, that is terribly destabilising and upsetting. There is a real worry about what is happening locally. Perhaps less for us, but certainly for smaller organisations, there is a real concern about whether they have the resources to do all the work that is involved in tendering all the other things.

I was speaking to someone who runs a smallish stroke charity in the north-west called Speakeasy, which has just been denied its £35,000 annual grant from the PCT. It has 20 years of experience and does brilliant work around user involvement. It is doing work with the Department of Health and with the stroke improvement programme. All that expertise will be lost for the want

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of £35,000. It ticked all the boxes and spent a lot of time doing this, but in a climate of needing to make efficiency gains, one "efficiency gain" is actually losing Speakeasy and all of that work. For me, it is not necessarily about what is happening in the future; it is

about what is happening now. What is happening now is that we have a real blight in many areas of the country in terms of committing to the types of services that we provide, and that is a real worry.

On the commissioning process, again, it is rather unclear how it might work for us, because, as I said earlier, our services do not carry a tariff at the moment, and it would perhaps be good if there was a tariff for them. Many of them are not worth enough to be part of a tendering process. From the pilot work that we have done, we know that if it is actually about patients' own health budgets, people do not find their way to the types of services we provide. We are very concerned about where we fit in. That may shake out in the future, but the uncertainty is terrible for our service users, and it may be that we will have to issue redundancy notices to our staff, even though we may be getting contracts in the future, because we just cannot guarantee that. We are responsible for letting them know as far in advance as possible. At the moment, we are holding it all together, but we just do not know what the future holds.

Paul Jenkins: We all know that we are living in hard times, and those of us who provide services know that we have to engage with the debate about how we meet patients' needs and deliver better value. Our experience has been that there are two very marked ways of doing it. Where commissioners have engaged with us as an organisation, shared their problem and involved us and the service users and carers we represent in redesigning services, we have sometimes come out with services that may be better in some ways than what we were doing before. In other places, we have just been told, "We're taking 10% or 15% off your budget." That is not the way to do it. Again, this proactive engagement with our sort of organisations, to understand how you can address issues of quality and how you get better value for money, is crucial.

Going back to the word "choice", choice is not always about what you want; it may also be about things you do not want. Patients see some of the needless waste of resources in assessment by service x, assessment by service b, assessment by service c, none of which actually meets their needs or necessarily offers them anything as a result. Patients prefer sometimes to get a low-level intervention in the community while they are still well, rather than have the sirens blaring, taking them to an acute hospital when they are very ill. Patients actually have insights into how resources can be saved, as well how resources can be spent.

Q 157 Fiona O'Donnell: Another important role that the voluntary sector plays is in research, but we cannot rely upon you alone to do it. Do you think the Bill is strong enough in ensuring a duty on the commissioning board to commission research?

Ciarán Devane: Yes. That, again, is one of the things we welcome in the introduction of that clause. Of course, as patient organisations, we would say that there should be no compulsion on the patient to take part in that research; we just need to ensure that. It goes back to the choice thing. Patients tell us that it is about

genuinely informed consent, such as knowing what the side-effects or the real implications are, and the ability to make the right decisions. So, absolutely, but let us make sure that there is genuinely informed consent around it.

Baroness Young: Could we extend it from research to clinical audit? If we are going to have a more diverse market of providers, it is absolutely vital that they all take part in clinical audit. That is how we will get the information about the quality of services that patients want to see and to understand and that commissioners will absolutely need to see. We would like to see clinical audit being made mandatory across the board for providers, whichever sector they come from.

Neil Churchill: We may need to see more information about how this is going to work, because there is a huge opportunity here, and I am not sure that as much support as is needed has gone into the knowledge transfer that might be needed. There are some questions. Where are the quality observatories going to go? How will what they have started to do, in helping to equip patient organisations to use some of this data, interpret it and communicate it to patients, be continued and ramped up over the next period? We have not yet discussed how that will work, but it is actually quite exciting.

The Chair: That brings us to the end of our evidence session. I thank our witnesses for being with us.