

## Uncorrected evidence

### HSC HEARING ON SPECIALISED COMMISSIONING – 11.15HRS ON THURSDAY 14<sup>TH</sup> JANUARY 2010

Witnesses: **Professor Rod Griffiths**, Chair, National Specialised Commissioning Group, **Mr John Murray**, Director, Specialised Healthcare Alliance, **Ms Deborah Evans**, Chief Executive, NHS Bristol and Chair of South West Specialised Commissioning Group, and **Ms Teresa Moss**, Director, National Specialised Commissioning Team, gave evidence.

**Q228 Chairman:** Welcome to the second evidence session in our inquiry into commissioning. For the record, perhaps you would give us your names and current positions.

Ms Moss: I am Teresa Moss, director of Nationalised Specialised Commissioning.

Ms Evans: I am Deborah Evans and I chair the South West Specialised Commissioning Group and I am chief executive of NHS Bristol.

Mr Murray: I am John Murray, director of the Specialised Healthcare Alliance.

Professor Griffiths: I am Rod Griffiths, chair of the National Specialised Commissioning Group.

**Q229 Chairman:** Ms Moss, can you explain the structure of commissioning for specialised services and the rationale behind it?

Ms Moss: Thank you for giving me this opportunity. I will give a brief overview of specialised commissioning. It is important to begin by stressing that the NHS is here for everyone, not just those with conditions we can diagnose and treat rapidly. The NHS is there even for patients with very rare conditions which sometimes require expensive and specialist treatment. We refer to very rare treatments and therapies as specialised services. They are commissioned either regionally by specialised commissioning groups, of which there are 10 in England based in the 10 strategic health authorities or nationally by the National Specialised Commissioning Group. The distinction between those two tiers is really based on the rarity of the disease. For national commissioning one really expects only 400 or 500 patients with those conditions needing that treatment a year. We are talking of a wide range of specialised services. To give examples, at national level we commission heart and lung transplants and liver transplants; at regional level we commission bone marrow transplants, children's heart surgery and brain surgery. They really are very specialised services. By commissioning these services centrally either on a regional or national basis we can achieve very important benefits on behalf of patients. The first of those is equity. If this was left to every PCT they would have different arrangements. By doing it on a collaborative basis across a region we can ensure more equitable access to these services no matter where patients live. The second good reason for doing it is that we can start to establish common standards that patients can expect across the country which means better outcomes. There is another issue about what we call risk sharing or cost sharing. The 152 primary care trusts around the country can share the costs of these treatments so that no single PCT is overwhelmed by the cost if they have a cluster of patients perhaps with a rare inherited genetic disorder or a number of expensive treatments they need to resource for their patients in a single year. That is another important reason. Most importantly, by co-ordinating this

commissioning we can set up specialist centres and concentrate the services for these rare conditions in specialist services. Clinicians become very knowledgeable about those services and patients get a much higher quality service. That is really important for patients with a rare condition who have been from pillar to post trying to find somebody who understands their condition.

**Q230 Chairman:** The Carter Review of specialised commissioning took place in 2006. We have had evidence submitted to us that some of the reforms recommended by that inquiry have not been fully introduced. Do you have a view about that?

Ms Moss: We have made a lot of progress so far and there is still work to do on that. Sir David Carter said we needed to review the processes that he recommended about now. Where have we got to? He proposed that we set up the arrangement that I have described in part. All of the regional specialised commissioning groups in each SHA are fully in place and are stronger than they have been in the past. We have the national commissioning group in place and the National Specialised Commissioning Group oversees national commissioning and also supports those specialised commissioning groups to make pan-SCG decisions. The groups are there and we need to keep developing the expertise we have been building in those committees and get the further benefits of those structures. He recommended that we completely revise the specialised services national definitions set that describes rare conditions and services in much greater detail. We have completed that revision in the past few days. It was an enormous task with enormous consultation around it. There were contributions from a huge number of patient and clinical groups. I believe that will be a valuable tool as we go into the next phase of specialised commissioning. He also asked that we focus on service mapping and costing to identify costs and quality indicators so we could do effective benchmarking across the country for specialised services. All of the SCGs have agreed a top 10 list of priority areas and each leads on one of those to identify those costs and quality indicators they can take forward and benchmark. That project is well under way but it will need to be resourced if we are to pick up the pace of it. From my perspective it is important we do that so the specialised commissioning groups have that information available to them; otherwise, we rely on patient groups to give feedback on variations across the country and the services we are commissioning and that cannot be right. There are lots of examples of where we have made progress since.

**Q231 Chairman:** Who is responsible for pushing through the reforms of the Carter Review?

Ms Moss: It is done at different levels. For national commissioning I lead that particular team and NHS London does that on behalf of the other SHAs. For the 10 SCGs PCT chief executives are given the responsibility to chair those local services. Sir David Carter laid strong emphasis on SHAs providing a championship role to oversee the strength of SHAs in specialised commissioning in their areas. It is important to make sure that all the PCTs are fully engaged around the specialised commissioning agenda.

**Q232 Dr Stoaite:** Ms Evans, who holds the purse strings?

Ms Evans: The arrangement is that PCTs and their regional specialised commissioning groups make an agreement about what will be commissioned by the specialised commissioning group regionally. That amount of money is drawn from the PCT baseline, so they agree on a sum of money and their list of services and those are the things that the specialised commissioning group commissions on behalf of PCTs.

**Q233 Dr Stoate:** Are the SCGs free to make any spending decisions on their own or do they have to listen to the PCTs?

Ms Evans: It has a very strong and clear government arrangement which is that the specialised commissioning group is formally set up as a sub-committee of every primary care trust in a region. In my region there are 14 primary care trusts. Each chief executive is a voting member of the specialised commissioning group and collectively takes those decisions. Those decisions are reported back to every primary care trust board.

**Q234 Dr Stoate:** Is it fair to say that the national commissioning group has no influence in this at all; it has to be done locally?

Ms Evans: The PCT level of governance is very clear. We have to make sure that when we are formally taking decisions about service change they are rooted at the appropriate level. A lot of the decision-making is formally to do with the primary care trust, but I do not think it is right to say that the NSCG does not have a role. Each of the chairs of the specialised commissioning group - I am chair for the south west - is a voting member of the National Specialised Commissioning Group. We sit collectively in that group and take decisions about the priorities for work that is to be done and so on. The national specialised group is also the place where NCG agenda and budgets are discussed. Ms Moss may want to talk a little more about the role of NSCG in that respect.

**Q235 Dr Stoate:** Surely, the NSCG does not have any financial power. My understanding is that the rules insist that it is all done locally. Does that not lead to the risk of a postcode lottery among the different groups, or is all of that being ironed out?

Ms Evans: My colleague was right to put equity as one of the key things we are trying to achieve. We try to do that in a number of ways. For example, when we look at designation of services we consider the whole pathway and concentrate on the specialised element of the pathway. We go through a process of setting service standards which we expect to be met. Those are set jointly with clinical, managerial and patient involvement. We get a set of standards and then a process by which we designate centres. What each SCG also has to do - we are able to draw it together by looking across the country - is look at some of the difficult issues about access. To use an example close to home, in the south west when we were first established in 2006 we looked in a basic way across our region and asked whether we had deficits in terms of specialised services. One that leapt out was services for neuromuscular diseases where in outline we appeared to be doing poorly in terms of outcomes. That suggested we did not have good enough access and since then we have had a programme to develop and invest in those services which is partly under way now. We are at an early stage with some of these services in being able to understand access and compare how well we are doing across the country. That is work that increasingly we need to strengthen. My colleague has already mentioned the service mapping and costing groups which mean that each SCG will take a lead. For example, one will look at both the costing and quality issues in renal services; one will look at neurosurgery; another will look at HIV, and so on.

**Q236 Dr Stoate:** But what if you looked at your neuromuscular services and found them wanting but decided you did not care much about them? What would happen then? Obviously, I am caricaturing it. Let us say you decided that you were pretty poor at it but it was not a priority.

Ms Evans: One of the reasons why the role of specialised commissioning groups is very hard is that it is our responsibility to make those decisions and be accountable for them.

**Q237 Dr Stoate:** To whom are you accountable if there is no national standard?

Ms Evans: All of us have to work with the evidence we have and strengthen it as we go along; we have to look at what we know about health needs. We have already heard a lot about assessing health needs this morning.

**Q238 Dr Stoate:** You are telling us about the process that you undergo, but if you decided that it simply was not an issue because it was not a priority for you and you would not do it what would happen?

Ms Evans: Clearly, we have made those decisions and are accountable to our primary care trust board, so each board carries that responsibility and would have to account for it. It is also right to acknowledge that strategic health authorities have a responsibility to performance manage specialised commissioning groups. Their role is to make sure we are doing our job properly. Obviously, they have decided to ask the chief executive of NHS London to be responsible for having a specialist in specialised commissioning and chairing the national group. Therefore, we have performance management at that level and accountability at the PCT board level.

**Q239 Chairman:** On average specialised commissioning groups have about 15 PCTs sitting on them. What happens if you do not reach agreement? How do you get a consensus?

Ms Evans: We have very long meetings if we do not get agreement. We have a clear national establishment agreement which sets out how decisions will be taken. We have a quorum. In our case there is a requirement that 10 of the chief executives out of the 14 will be present at any one time, so it is a demanding quorum. We have a formal route by which we take decisions by majority if we have to. We prefer not to do it that way and wherever we can we will sit down and hammer out the debate until we have agreement round the table.

**Q240 Chairman:** Ms Moss, does that happen with other specialised commissioning groups? Is it the norm?

Ms Moss: Inevitably, there are specialised commissioning groups that are stronger, visionary and strategic in their thinking and others that perhaps are not as strong in those ways. That is why regional oversight is really important. As we go into tighter financial circumstances it is inevitable that different PCTs have different financial difficulties within that cluster. I think the art is to make sure that each of those SCGs does not move at the pace of the slowest.

**Q241 Chairman:** Are you convinced that if there is a gap between them it does not happen in such a way that there is a lesser service?

Ms Moss: It is about getting better information and benchmarking. Dr Brambleby talked of the importance of information being available to commissioners. The information available to PCTs around the majority of their services is much stronger than it is about specialised services. Perhaps I may suggest that in your report you make that recommendation to help us get better information, and the support and infrastructure for that is really important. You will also know that through the World-Class Commissioning process we have developed a toolkit

for an assurance process around collaborative decision-making between the PCTs. I believe that will become more and more important. With formalised processes each of the SCGs can see how well it is doing relative to other areas of the country. Tools and mechanisms are being developed. There is a developmental process this year and probably it will need to be formalised over the years to come.

**Q242 Chairman:** Ms Evans, you have been involved in the burns review in the south west. Can you explain to us what this involved and why it has taken so long?

Ms Evans: I would be happy to do that. Designating burn services is an interesting example to consider. It was the first of its kind that the NHS tried to do. I believe its antecedents were in 2004, so you are right that it has taken a long time and we hope we are coming towards the end of the process. It is complex because we looked at different severity of burns. The area that has been most difficult is to address the very complex and most severe burns which are very small in number. For the south west, south central and South Wales there might be 30 to 40 adult patients a year, so they are small numbers of very complex cases. We expected to designate a centre which would serve a number of regions, so it would be supra-regional and go beyond one region. In our case we had the south west, Wales and south central all working together, which in itself is complex. The purpose of designation is to ensure that we can achieve the highest quality, concentration of workforce, expertise and so on. That was highly contested by clinicians. In these designation processes often they are contested by somebody; it might be by clinicians, hospital trusts that do not want to lose a service; it might be contested by service users sometimes, although there is a lot of evidence that they are prepared to go far to get what they see as the best quality. In all of that it was important to have a cast iron process. When our specialised commissioning group was formed in 2006 we reviewed where we had got to and decided whether or not we were ready to go out to public consultation. We came to the view that it just was not strong enough and we wanted to redo various part of the work. One was to get to the bottom of understanding clinical outcomes, which I do not believe has ever been done before with very complex burns. We wanted to redo all the work about travel and access and have much better patient involvement. We did not feel that our service user involvement had been robust enough. Therefore, we took the time to redo all of that. We paused for a general election and NHS reorganisation on the way. I am pleased to say that we have now reached the point where we are working through the very complex arrangements we need to make to establish whether public consultation is necessary. I should like to outline those to you because they will make your mind boggle. We have eight or nine overview and scrutiny committees in south central. They came together and said they would form one committee to consider whether or not it wanted public consultation, and they did so. Wales does not have overview and scrutiny committees; it still has community health councils. Therefore, Wales used that mechanism to decide whether or not it wanted public consultation. The 15 overview and scrutiny committees in the south west decided not to form a joint committee and asked whether we could work round them individually. We have done the Isles of Scilly, Cornwall, Bournemouth, Poole, Dorset, Devon and Bristol and have a number more to work through before we can come to a view about whether or not public consultation is necessary. That is why it has taken a long time, but I am confident we now have a set of proposals formed in the right way and are cast iron and if we do need public consultation, even if we have to pause for another general election, we will come out with the right answer in the end. What I have described is a designation process in which we were learning that took a lot longer than any of us would have wanted. It is also the most complex type you can get. While we have been doing burns over the past 18 months we have done two other designations, sarcoma and bariatric surgery, in the south west from start

to finish. Not all of them have to take this long but each is a process that requires a high degree of resource and skill.

**Q243 Chairman:** Is there a level of disinvestment in that as you suggest hospitals do not want to lose the provision of a service? Is that level of disinvestment higher in this particular instance?

Ms Evans: It is significant but it is not at a level which will damage the surrounding services, for example plastic surgery or critical care services, but one of the complexities is that we need to understand these services in their context and the impact they can have on other hospital services. That is one reason why local authorities become very anxious.

**Q244 Dr Naysmith:** Mr Murray, what are your views on some of the things we have been talking about? Do you believe that specialised commissioning groups are free to make spending decisions on their own; if so, do they exercise that ability? What about the slowness of decisions in some cases?

Mr Murray: First, I emphasise that the Specialised Healthcare Alliance is strongly supportive of the Carter reforms. We agree with Ms Moss that the structures are in place. Where we might disagree is in relation to the extent of underlying reform. We believe that a huge amount of progress remains to be made. We question whether the current approach is capable of delivering that progress. To revert to the underlying principles which are mentioned in the submissions to the Committee of both the Department of Health and the National Specialised Commissioning Group, above all the intention here is to deliver equity of access and to share risk. I would argue that the Department of Health has a strong overarching responsibility to ensure that the Carter reforms are effectively delivered in their entirety. In the operating frameworks immediately following publication of the Carter Review it sought to do so. Most recently in the document for 2008/09 it urged SCGs to cover progressively more of the national definitions set. The definition set in its entirety would pool budgets by 2009/10. If we look at what has actually happened, there are notable examples of progress. Indeed, from a standing start the south west has made significant progress, but we suggest that in no case is there an SCG that is anywhere near commissioning the whole of the national definitions set. For example, as far as we can see from its response the south east coast commissions six of the chapters in their entirety, but it is complicated by the fact that sometimes there are a number of services within a definition. With rarer cancers there are about half a dozen services encompassed within it. South central is commissioning 19 out of 73 services covered within the definition set. There are some disparities here. The northwest covers 22 out of 81. That gives an indication that there is still a long way to go.

**Q245 Dr Taylor:** Just when I thought we had all the acronyms sorted out we had further mind-boggling from Ms Evans. I want to ask about strategic health authorities to make sure I have their role clear. Although the regional SCGs are coterminous with the strategic health authorities the latter do not have much to do with it. You said they had a championship role. What does that mean? How do they do that? You said that SCGs are made up of chief executives of the local PCTs. Who else is there?

Ms Evans: The health authority has a director who sits on the specialised commissioning group. The role of the health authority is to performance manage the specialised commissioning group. I recognise that it will vary across the country, but perhaps I can give you a flavour of the level of our health authority's involvement.

**Q246 Dr Taylor:** Do all your PCT chief executives come to the meetings or do they have deputies?

Ms Evans: They can send deputies if they need to. There are 14 of us and the quorum is 10. We always have 10 present; sometimes all of us attend. Last week we did it by telephone because all 14 were snowed in at home. We have a high level of chief executive attendance. The health authority is very involved because it scrutinises our communications and our patient and public involvement work. It also scrutinises the reviews we carry out, so for the designation of bariatric surgery, burns or any of those things it will be involved in reviewing all of that. It has a slot on the directors of finance and performance at every monthly meeting which discusses specialised commissioning issues. We then directly brief the chief executive of the health authority as necessary. Our health authority is thoroughly involved in the work of the specialised commissioning group.

**Q247 Dr Taylor:** You have also said that you send certain disease groups to other SCGs. Is that not just going back to the supra-SCGs that one had before Carter?

Ms Evans: We keep to ourselves within the SCG the responsibility for commissioning the services, but we have 10 directors of specialised services who work together to use their resources in the best way. For instance, one region will say it will develop the quality standards of neurosurgery for designation for the whole country and we can have a look to see if they are all right. Otherwise, we would be reinventing things 10 times over. One region will do a lot of work on behalf of the others. For example, what standards do we need for the renal pathway? One will take the lead in developing that and it will then be consulted on more widely.

**Q248 Dr Taylor:** Each SCG has a director?

Ms Evans: Yes.

**Q249 Dr Taylor:** Do those directors meet regularly?

Ms Evans: Yes. One very important message is that we need to regard specialised commissioning as something that is still strongly developing in its competencies and ability. In order to get better we need to keep developing the skills of our people, information systems and so on. Building up our ability to be successful is really important if we are to deliver the Carter Review and I am sure that the Specialised Healthcare Alliance would support that view.

**Q250 Dr Taylor:** Did Mr Murray imply that there were some disease groups that were not covered by all the SCGs?

Ms Evans: I think that is true.

**Q251 Dr Taylor:** They ought to be covered but they are not in some areas?

Mr Murray: Furthermore, there are areas that are ostensibly covered. I take deep brain stimulation as an example where in practice because the budgets are not pooled the decisions go back to PCTs and patients encounter delay - sometimes more than that - in getting treatment.

**Q252 Dr Naysmith:** Mr Murray, we have returned to where we were a few minutes ago and started to explain why it is that so many specialised commissioning groups have not yet begun to commission all the services in the national definitions set. You suggested that it was partly to do with the pooled budgets.

Mr Murray: Yes. A stronger part of the rationale is to share risk. The evidence suggests that PCTs within the SCGs are reluctant to do so and the engagement of PCTs is highly variable. I believe that the south west is the most developed in that regard. There is another SCG which has over 20 PCTs in membership and the only chief executive representative is the PCT chief executive who chairs it. Similarly, there is an SCG where there is no SHA representation, so it is hugely variable. We asked SCGs in the past few weeks to let us know the proportion of their budgets which were pooled bearing in mind that this was a primary objective of Carter. In a couple of cases it was between 1% and 2%. In most cases it was in single figures and the very best performance adduced was around 20%. All the SCGs for the most part have to work with resources attributable to individual PCTs and it is therefore understandable that the latter feel they retain ownership of the money and where particular treatment decisions are concerned they may well ask the SCG to refer back to them. That was certainly not intended under the Carter reforms.

**Q253 Dr Naysmith:** How far does the need for a critical mass mean that one or two PCTs can potentially frustrate the commissioning plans of several others? Does that ever happen? Perhaps you would also pick up some of the points made by Mr Murray.

Ms Evans: I pick up a number of points. One is about the definition set and which specialised commissioning services are picked up and which are not. One of the issues we think about in the south west is that because the definition set was originally on the basis that anything that needed to serve a population of over one million must be designated as specialised there are lots of things that have come under the definition set we now regard as matters that PCTs can and would expect to commission within their normal pathways. An example would be a lot of local cardiology and cardiac surgery. In our case we have decided that that will stay with the PCTs and the SCG will handle the more complex end of that, so new cardiology interventions will be done by the SCGs. Similarly, there is a whole issue about child and adolescent mental health where what we have decided is that it is only the very complex end that will be done by the specialised commissioning group. The rest of it has so many links with local education, children's services and families that we think it is better commissioned by PCTs. There is not an absolute rule here. We would expect some things to move into designated specialised services. Over time new things will come in and others will move out and go back to PCTs.

Ms Moss: I support what my colleague has said. My interpretation of the Carter Report - Mr Murray and I have had conversations about this - is that he set SCGs up to oversee the commissioning arrangements of all the specialised services on the list. That is a really important role. Now that we have redefined them it is important to set up the notion of SCG guardianship of those services or, if appropriate, national services. We have that conversation and have finished defining and refining that list so it can happen now. The guardianship of those services is definitely in Carter. I do not think it means one has to commission or procure all of those services for the reasons Ms Evans said. Some PCTs have a population of one million and they can perfectly well lead the commissioning of those services, but I believe that the SCGs have a role in the way Ms Evans indicated. Are the commissioning arm

arrangements appropriate for this service or is it a mess and do we need to focus on it? I believe the term "guardianship" is important.

**Q254 Dr Naysmith:** Is not a logical extension of it that you should move to a system whereby the money goes to the specialised commissioning group directly and leaves out the PCTs? Obviously, you have got the definition bit right and not have other bits that really should not be there, but if that was the case that is what should happen?

Ms Moss: If you are trying to be responsive to the different sizes of PCTs in your area and the like it is difficult to identify a particular sum of money that you are to pull out for these services. I think we would spend the next 15 years trying to work out exactly what the right budget would be to take out for these services, a lot of which do not have tariffs so there are different costs in different places even within the same SCG. That would be quite a tough process.

Ms Evans: I do not believe it is in the interests of patients to take all the money to do with specialised commissioning away from PCTs and put it with another body, whether or not that specialised commissioning group is a part of the health authority. We have heard this morning that the challenge but also the strength of PCTs is that they look after a whole population and look across a whole pathway. I do not think it makes sense to take the very specialised end of, say, renal services and give it to another body and then say that all the other aspects of renal services, like looking after people in primary care, early detection of disease and end-of-life care, should be put elsewhere. We should not leave part of it with PCTs and take the rest of it and put it somewhere else. That is not in the best interests of patients. The best interests of patients are for us to make the dynamic between PCT commissioning and SCG commissioning work. Rather than give up on it we should make it work better and that is in the interests of patients. Turning to Dr Naysmith's question, do we find in effect that two or three PCTs veto something which will be good for everybody? We have not found that yet. We have some big debates about whether to invest in things. Neuromuscular services is a good example where, looking across the whole pathway, some PCTs do not feel that their local general hospital neurology services are very strong, so they ask whether it is right to invest all this in the very specialist end. We resolved that in a positive light by looking at the evidence and health needs and having that discussion. We have not found that to be a problem yet.

**Q255 Dr Naysmith:** You said you had a quorum of 10. Does that mean you can have a majority vote with 10 people present and outvote somebody who is not present?

Ms Evans: I know that politicians like voting arrangements. In our national establishment agreement there are very clear voting arrangements, but we try not to resort to that because the next time you sit round the table it creates bad feelings if you have outvoted your colleague from Devon.

Mr Murray: It is ironic that the reference to services which can be commissioned at PCT level encompasses renal services. When the national definitions set was recently revised the question whether renal services should be in or out was the subject of heated debate. There was a substantial body of opinion among PCTs that they should be taken out because the number of patients in receipt of those services has grown, but supported by the renal tsar the decision taken ultimately was that they should remain in. As I understand it, the renal tsar felt that the services would be more effectively integrated right along the patient pathway if they

continued to retain specialised status. It is interesting to note that if it were seen as a service that was primarily the responsibility of PCTs it is also one of those 10 services which have been taken on by the SCGs for the purposes of designation. By comparison, a lot of the more specialised stuff easily gets overlooked. I think the evidence from the Children's Trust Tadworth is particularly compelling in that respect. It clearly feels that these services are not engaging PCTs because the latter do not see the number of children involved as significant in their terms and so they are not priorities, and the costs involved can be extremely high. The budgets and risk are not shared and therefore young people are suffering according to the Children's Trust Tadworth. You might say that to go from PCT to SCG level would be the right thing to do, but reading between the lines there seems to be a certain lack of confidence because the proposal they make is that they should go from the current situation where these services are apparently in the gift of the PCTs to national commissioning. There must be something wrong with a system if one goes from one extreme to the other. I think that a healthy regional commissioning system would be exactly one where services move between different tiers depending on the needs at the time. I do not believe that we have that healthy system at the moment.

Professor Griffiths: I was a member of the Carter Committee. The crucial point to which we must keep returning is that the intention was that these service should be just as good everywhere in the country. Whilst I agree it is very complicated - I endorse all the discussions that have been described - what the NSCG has not spent much time on is trying to challenge itself to assure everybody that it has made the effort to try to find out if services in place x are as good as in place y. I do not mind if the money is moved around in different ways but we have not yet done that bit of what Carter intended and we need to do so. Now that the definitions set is in place maybe that is a greater possibility, but I believe that is the real challenge.

**Q256 Sandra Gidley:** I have a question to Ms Evans and Mr Murray. What is your opinion on how World-Class Commissioning fits with specialised commissioning?

Ms Evans: As a PCT chief executive, the World-Class Commissioning programme which has run through its first year has been a really useful development tool and helped us focus on key health outcomes that we want to achieve and the range of competencies we need. It has been a very useful spur to our development. I should like to see the same discipline, appraisal and, importantly, development programme applied to specialised commissioning. Ms Moss and I have talked about how much we need further development. Professor Griffiths has just made the point that different specialised commissioning groups need to compare themselves one to the other; they must benchmark themselves. We need to know what the best is and work out how we can move more quickly towards it. I believe that the World-Class Commissioning programme can be a good vehicle for doing that but not the only one.

Mr Murray: We were very keen for World-Class Commissioning to apply to specialised services and we were pleased when eventually it emerged from the bowels of the department but we were disappointed when we discovered that it would not be part of the overall assurance process. I am indebted to Gary Belfield's reply to your question at the end of the previous session in which he rather said it all in exemplifying the difficult position where specialised commissioning sits. He said: "One thing I would like to say though is that every PCT has the responsibility within their portfolio for commissioning specialist services. They do not discharge that responsibility; they involve a specialised care commissioning group to do it on their behalf, but they still have to take responsibility and accountability at a local

level." That perhaps explains why there is presently a difficulty in addressing specialised commissioning in the context of something like World-Class Commissioning in the wider regulatory sense where the Care Quality Commission and its predecessor bodies have also struggled to reconcile the fact that their focus of attention is on primary care trusts, or potentially strategic health authorities, and the SCGs sit in a kind of limbo in between. I think that is a weakness to be addressed one way or the other.

**Q257 Sandra Gidley:** You mentioned that World-Class Specialised Commissioning had been introduced but it seemed to be half-hearted. Can you explain that?

Mr Murray: My understanding, to which Ms Moss may wish to add more detail, is that after a pilot in the north west last year the materials were developed further with all SCGs but they were allowed to assure the process rather as they saw fit. Some have employed independent auditors to help them to do so; some have decided to do something by way of internal assessment; and some are probably not doing very much at all. It is a very mixed bag.

**Q258 Sandra Gidley:** Do you think World-Class Commissioning should be mandatory?

Mr Murray: For specialised services, absolutely so. How can you leave 10% of NHS activity outside and have a worthwhile scheme?

**Q259 Dr Taylor:** Ms Evans, some of the groups that have submitted evidence to us argue for a more integrated approach to commissioning for rarer conditions which they think could save the NHS money and improve care. For example, CLIC Sargent says: "Specialist commissioning must better connect with the whole range of community services including health, social care, information and education in order to provide a holistic community-based service that sick children and young people need." Should PCTs be doing something about that, or are you trying to do it in any case?

Ms Evans: I think we are. I read that submission to the Committee. I am aware that a number of other submissions to you say the same thing and I agree with it. It illustrates my point that we need the PCT and specialised commissioning perspectives to work side by side. To go back to my neuromuscular example for a moment, there are some elements of service for children with neuromuscular diseases which are highly specialised. We know we need to address that. But there are also some very important elements of those services that are not specialised; they are to do with children's equipment, like wheelchairs and so on. That is firmly in PCT territory. In my PCT we have done a lot of work on sorting out those services which frankly have been very poor. We have spent the past 18 months improving children's equipment services and getting them into a much better position. That is the dynamic we need between the PCT and specialised levels so we get the whole pathway right for these families who are dealing with very difficult, enduring and long-term conditions.

**Q260 Dr Taylor:** Is it right that one of our recommendations should be that the presence of PCT executives in these groups is absolutely vital?

Ms Evans: I think so.

**Q261 Dr Taylor:** Mr Murray, in your evidence you have picked out some SCGs where there are very few PCT chief executives.

Mr Murray: At the extreme it is one out of 24. Most of them are somewhere in the middle ground. For some the previous structures are reflected in current chief executive attendance, so there may be some subsidiary collaborative arrangements. Let us say there are 15 PCTs represented in the SCG but there will be five chief executives who go along to represent in each case two of their colleagues. It is that kind of approach.

**Q262 Dr Taylor:** I believe the Carter Review called for commissioners to seek the views of patients, carers and the public.

Ms Evans: Yes.

**Q263 Dr Taylor:** How do you do it?

Ms Evans: We do it in lots of ways. We have built into our process for service review and development some approaches which include having stakeholder days that include clinicians, service users and the local authority overview and scrutiny representatives. We often get them to work together so the clinicians directly hear the views of patients as do the local authorities. We have service user representatives and interest group representatives on some of our steering groups to implement services, of which neuromuscular is another example. As to the burns review, when we designate services we have visits to the centres which include representatives of LINKs; they include service user representatives and they can also include representatives from the relevant interest groups. We have a lot of standard mechanisms by which in all our routine work we incorporate the service user view and the great expertise of the sorts of organisations that are represented by the Specialised Healthcare Alliance.

**Q264 Dr Taylor:** Do you find that overview and scrutiny committee members and LINKs members are helpful and interested in these very specific and rare conditions?

Ms Evans: I think they are interested. Local authority representatives quite understandably are always interested in the impact of a service proposal on their local area. They start with the local area as one would expect, but they have made a good effort to understand what happens when you have to serve a very wide geographical area where you have small numbers of patient and the different challenges involved in that.

**Q265 Dr Stoaite:** Listening to this session one matter that comes through without question is the horrendous complexity of it all. I am genuinely more confused by the level of complexity than I was when we started the session. There are so many different tiers and so much bureaucracy. We have heard from people like the Specialised Healthcare Alliance. Some of the SCGs commission only six out of a possible 36 services. The possibilities for postcode lotteries and confusion are endless. When patients move from one part of the country to another I despair at how they can access what services they might need. Rare Disease UK argues that with payment by results, practice-based commissioning, foundation trust commissioning and regional and national commissioning the system is altogether more complex than it was before. The top prize goes to the witnesses who can come up with a way of simplifying the system in a few words. Who wants to pick up the challenge?

Mr Murray: I am surprised to hear you say that. The system is not as complicated as it was prior to Carter. If you go back to the arrangements prior to Carter not only were they very complicated but there was even more of a laissez faire approach and enormous scope for services to fall between the paving stones at many different levels. The levels of

commissioning that we have are probably right. The problems relate to the way in which services are picked up by those levels and there is simply not sufficient consistency across the country in the way those services are funded. Ultimately, I think experience shows that unless you have responsibility for services along with the funds to procure them you will not be in a position to do a good job.

**Q266 Dr Stoate:** If PCTs can withhold or keep back the funding it makes it practically impossible for an individual SCG, let alone across the country. It is a dog's breakfast.

Mr Murray: That is why in our submission we propose that the funding issue should be revisited. I do not pretend that this is an easy issue because obviously one does not want to enter into a fixed funding arrangement when one does not understand the costs properly. For example, the Spinal Injuries Association has drawn our attention to the fact that no one knows how many patients there are with such injuries across the country, let alone in different regions of it. Carter proposed that as a priority costs should be properly mapped in relation to the different parts of the national definitions set. It has scarcely got under way.

**Q267 Dr Stoate:** We have had the purchaser/provider split now for 20 years and you are telling me that it has scarcely got under way. In inquiry after inquiry we hear about the purchaser/provider split; we have had the internal market. It has been going for 20 years. Guess what? Most of it has not started yet. What will it take to get anything moving?

Mr Murray: I tell you one thing that might get it moving, although it will appal Ms Evans. Let us suppose that the money went to the specialised commissioning groups and that it was, as it is presently, top-sliced from the primary care trusts but only on the basis of proper costing analysis by the SCGs. That would concentrate minds very rapidly in terms of introducing a far more robust approach. I also think that in a situation of greater economic stringency there is a huge amount to recommend the greater use of commissioning at regional level. Notably, a couple of the specialised commissioning groups observe that their management costs are in one case .4% and in another case .5%. That seems to me to be a strikingly low figure. I might say that it is not necessarily adequate to do the job properly which may be one of the reasons things are not progressing as fast as they should, but it suggests there is tremendous potential to do a good job and do it efficiently in relation to these services at that level.

**Q268 Dr Stoate:** We always hear there is a lot of potential. Professor Griffiths, there is a lot of potential to do better but no one has actually achieved it. What can we do to simplify this?

Professor Griffiths: The crucial point is that the system should be patient rather than system-facing. I accept that the country is a complicated case and what you do in Birmingham is likely to be different from what you do in Cornwall or whatever just because of life. Why does not the system deal with it rather than make the patient have to grapple with it? If we gave SCGs the responsibility for facing the patient with all the regional services and somebody had a problem because he or she moved to another region and wanted to know what to do the patient could phone them and they would sort it out. You might well have an arrangement whereby some PCT commissioned this or that in your particular patch, but that is not to bother the patient. At the moment it is a system-facing arrangement and it is left to the patient somehow to grapple with it. That can be tricky and you need determination above and beyond the call of duty sometimes to be able to do it, but it is being paid for by the patient.

**Q269 Dr Stoate:** All I ask for is a system I can understand. I have been a GP for a long time. Frankly, I am really now more confused than I was a while ago. I thought I knew this stuff but now I find I do not. I just want a system I can understand and I hope I can help my patients understand and I do not see it happening.

Professor Griffiths: In that case we ought not to reorganise every five years. Yes, we started in 1990 but we have messed it about. Any time anybody got any good at it we kicked the horse from under them, but somehow or other you must change the way performance management thinks to make the system face towards the patient.

Mr Murray: Having policy is one thing; implementing it is another. The Carter policy is absolutely right in establishing SCGs as a one-stop shop for people who need information about services which they or their families require, whether those services are commissioned, as they probably would be for the most part, in a fully implemented system by the SCG or for whatever reasons commissioned by the PCT, but that is not happening because it has not been properly implemented. It requires consistency of purpose which sadly is sometimes lacking in the NHS.

**Q270 Dr Stoate:** We heard from Ms Evans earlier. We even have to decide whether to go to public consultation which will take two or three years. By that time I will probably have forgotten the question. It is completely insane. There must be a simpler way of doing it. There is silence.

Ms Moss: If we could simplify the public consultation systems that would be enormously helpful. They are truly very complex and we need to do something about that. This is a complex arena and I am not sure we will ever make it very simple. Dr Brambleby talked about programme budgeting. For that you have to get all the people in the room, focus on the patient pathway and plan their care along that pathway: the key interventions and the right places to prioritise. You need to get these different systems into the room to do that planning, decide your priorities and then leave them to commission appropriately to high standards the part of the care pathway for which they are responsible.

Dr Stoate: I know the theory; it is just that I do not see it happening.

**Q271 Dr Naysmith:** Mr Murray, what do you think about public consultation? Is it too onerous or could it be done in a much simpler way?

Mr Murray: You are not talking about patient engagement but public engagement?

**Q272 Dr Naysmith:** We heard about how long it was taking.

Mr Murray: It is hugely complex and sometimes it militates against very necessary change.

**Q273 Sandra Gidley:** Our earlier session was mainly about payment by results. How does that work in the area of specialised commissioning?

Ms Evans: In specialised services as in PCT commissioning we have a mix. Some of it is under payment by results and some of it is not. Most of it is not under payment by results. In particular, there are whole sectors like mental health where payment by results is said to be coming but we do not have it yet. Probably for the south west 20% to 30% of our whole

portfolio is payments by results. Next year our portfolio will be £520 million, so we will have moved to one of the SCGs who is commissioning a huge amount of the potential portfolio, but only 20% to 30% is payments by results. Examples of the parts that fall under that are cardiac and bariatric surgery and paediatric intensive care, but renal and neonatal intensive care does not. Therefore, the large and some of the more commonly used parts of specialised services are not subject to payment by results. That means one has local pricing. The price for something might be different in Plymouth from what it is in Bristol. That means PCTs and specialised commissioners have to work together because if when wearing my Bristol PCT hat I am commissioning ordinary general hospital services for Bristol from the main teaching hospital and specialised services are being commissioned from the same hospital and there are parts which are not payment by results, if we are not careful we shall pay for things twice. That is another complexity in specialised commissioning. Increasingly, we need to be able to make cost comparisons and know what we are getting for what we are paying and its quality, so it is difficult.

**Q274 Sandra Gidley:** Perhaps I am being a bit slow here. Why are some areas of specialised commissioning part payment by results and others not? How was that decision arrived at?

Ms Evans: Because the payment by results national financial regime has been rolled out over a number of years. It started with things that were relatively easy which would be common hospital procedures that are approximately the same up and down the country where one can set a normative tariff. Obviously, specialised commissioning is much more complex and quirky than that. By and large, specialised commissioning has not been able to be boxed up and put into payment by results. We are working on some areas. For instance, I have a responsibility for spinal injuries commissioning in the south of England. Currently, we are leading some national work on standard commissioning. We are working very hard to get to the point where we have standard pricing for spinal services across the whole country. We are one of the areas of specialised commissioning that has been working hard on that. We have had good support from the Department of Health, but each service must be worked through individually.

Professor Griffiths: For a lot of the national services there is not the level of detail in the standard data systems to be able to recognise them. You might be commissioning a particular procedure or just the delivery of a particular drugs and that is not coded in a way that you can pick it up nationally to work out a cost for it, so in a sense you are stuck; you have to do a local deal with the person who does that process. Maybe we will get it one day but we have not got it so far.

Ms Moss: I fear that we are coming again to the term "granularity". What it means is that sometimes we need bespoke databases to be able to capture this information from the services we commission regionally and at national level. We need stronger support to be able to put those in place and have co-ordination if we are to progress in the way we need to do.

Mr Murray: It is crucially important if payment by results is extended to specialised services that it captures the costs involved in delivering high-quality care effectively. That is always a concern for us. If it cannot do so we prefer payment by results not to be applied to specialised services. Equally, we have always been acutely aware of the fact that because it is difficult to control expenditure under payment by results everything outside potentially could come under a squeeze and that includes those specialised services. We see the process of designation as potentially a very important tool in identifying the providers who deliver

requisite quality services in these areas and consequently giving an opportunity to capture the costs involved. That is another reason why we are very concerned, notwithstanding the more recent evidence of progress, about the very slow rate of progress in terms of designation. Service specification and standards of care were according to Carter meant to feature within the revision of the national definitions set. That was taken out of the national definitions set and put into designation. It is therefore very concerning that designation has progressed so slowly. That slow rate of progress, which is due partly to lack of resource, has potential knock-on effects in relation to things like payment by results.

**Q275 Chairman:** We received a submission from the Cystic Fibrosis Trust. Getting a tariff for somebody who suffers from cystic fibrosis is no mean task, is it? It affects so many different parts of the body. These are not simple things that can be dealt with rather quickly; they are complex areas.

Mr Murray: The Cystic Fibrosis Trust is strongly committed to the development of the tariff on a banded basis.

**Q276 Chairman:** It is still no easy task, committed or not.

Mr Murray: It is not.

**Q277 Dr Naysmith:** That is a relatively common condition.

Professor Griffiths: As relatively rare conditions go it is one of the more frequent ones.

**Q278 Dr Naysmith:** Ms Evans, how effective is the present system in sharing risks and costs? Some patients require expensive treatment but in relatively small numbers. Does it achieve equity in terms of sharing costs, or not?

Ms Evans: I was interested to listen to the concerns of the Specialised Healthcare Alliance which clearly see the fact that SCGs tend not to do risk sharing as a negative factor or perhaps prevents patients from getting treatment. I do not see it in that way. We might be at a turning point and as more financial pressure comes upon the system PCTs as they sit round the specialised commissioning group table may find risk sharing more appealing than they have in the past. There are two or three reasons they have not felt the need to do it so much since the Carter Review in 2006, some of them simple. One is that in the 2006 reorganisation many PCTs were put together to create bigger ones. The bigger ones felt that they had more critical mass to withstand financial risk and did not necessarily feel the need to risk share. In addition, at that point the health service took the view that there was a need for health authorities to hold contingency funds on behalf of PCTs and for PCTs themselves also to hold bigger reserves than they had previously. The question then is: how many reserves and contingencies do you need? Those were the probable reasons why the risk sharing and pooling arrangements were not immediately taken up; they were not felt to be quite so pressing, but we may see signs of that beginning to come back as the NHS financial settlement is less generous than the very generous amounts it has had in the past two or three years. The other point I pick up is about PCTs taking a decision to withdraw certain treatments from the SCG portfolio and take decisions in their exceptional funding panels. In my experience that tends to happen where the evidence base is not absolutely clear and that is why the PCTs say they will look at it on a one-by-one basis and consider the evidence and be

held accountable for it. I cannot give a view for the whole country; it may be there are different positions in different parts of the country.

**Q279 Dr Naysmith:** But you suggest that risk sharing is not taking place all that much?

Ms Evans: It probably is not. Ms Moss may have a bigger national picture than I do; mine is not substantial.

Ms Moss: Different PCTs and SCGs come up with different views. There is an element about: how do you retain the engagement of a PCT in treating their patients with diabetes well? That may move on renal failure and the need for a specialist service. You need to keep all PCTs engaged in that good proactive treatment of diabetes. That is one area where it is said we need PCTs to take responsibility for their specialist treatments. There is a different area where people may have groupings of inherited disorders in their PCT. Frankly, the allocation formulas do not take account of that. I believe that cost and risk-sharing arrangements are appropriate for PCTs that happen to face those problems. There are different tensions in play and again there is complexity.

Mr Murray: It is not the policy of the Specialised Healthcare Alliance; it is the policy of the Department of Health which is set out clearly in its submissions that risk sharing of this kind is a primary function of specialised commissioning. On the basis of the numbers that I quoted earlier with SCGs pooling as little as 1% of their funds by weighted capitation it is self-evidently not happening. Why is it not happening? It arises possibly because they look at an individual service and with that specialised service, which may be a high-cost one, they do not have many or any patients within their patch and so have no incentive to risk share. Maybe their neighbours do but that is a neighbouring PCT, not them. It is only when you look at a broad spectrum of services where what you gain on swings you lose on roundabouts and vice versa that the incentive for sharing grows. I think this is part of the problem with the pick-and-mix approach to the national definitions set that we have at present. I find it deeply worrying that in Dr Howell's submission he calls into question the very purpose of the national definitions set and says he really does not believe it will have much relevance to the West Midlands in future. That is a pretty worrying attitude when so much time and effort has been invested in the revision of the national definitions set.

**Q280 Dr Naysmith:** Do you believe patients are suffering because of it?

Mr Murray: I refer to the Tadworth example, the Spinal Injuries Association and the question of deep brain stimulation. I am aware of other anecdotal examples. There is clear evidence that in some cases there is a problem.

**Q281 Dr Naysmith:** Ms Evans, you referred to the developing financial climate. Do you think it may have a deleterious effect on the services for rare conditions? We really do not know what will happen to the National Health Service apart from the fact it will be protected.

Ms Evans: We know that we will not continue to have the very generous levels of funding. We have always known that because the intention was to achieve a standard equivalent to European levels. We know that it is at least plateauing. There will be tremendous pressure on the NHS to look at ways to make patient pathways more effective. There is a good deal of scope for us to do that and that probably applies as much to specialised services as to PCT commissioning as a whole. There are a number of way in which we run and deliver

healthcare at the moment that need more work, of which outpatient services is a good example. People have talked about length of stay. Reference has been made to trim points and long lengths of stay and whether they are good for people or we can organise care more effectively. There will be tremendous pressure on the system and a lot of that will be good and will stimulate innovation and change. It is our responsibility as specialised commissioning groups and PCTs to look hard at issues of equity and ensure that the people who have the specialised conditions are not being unfairly penalised because of all the difficulties we have talked about today: they are less able to be counted, managed and all the rest of it.

**Q282 Dr Taylor:** I turn to Ms Moss and Professor Griffiths and deal with the very rare diseases. For my information, do the definitions roughly fit with orphan and ultra-orphan drugs?

Professor Griffiths: Yes. We work on fewer than 400 cases. I could take you through some of the arithmetic which suggests that that is about the right number. It could be even less but certainly not more than that.

**Q283 Dr Taylor:** When you say it includes heart and lung transplantation is that just the combined transplantations or both?

Professor Griffiths: Both together or whatever.

**Q284 Dr Taylor:** What are the real challenges for commissioning healthcare for this group of people?

Professor Griffiths: Essentially, there are two or three issues. One is that some things are very expensive. That comes down to the cost of developing new drugs. If it costs £1 billion to develop a new drug the UK's population is probably 5% or less of the total world population that might be able to afford it. The patent life is probably five to 10 years. You can divide it up and work out how much money the company must recover to pay back that £1 billion. Then you divide by the number of patients. Once you get past 400 patients you are down to a figure under £20,000, so that is in the same ballpark as everybody else. But up in the very rare region the thing is bound to cost more than NICE would normally say was cost effective. You must either say to those patients to forget it and they might as well go hang or you need a special mechanism to deal with things that are that rare. In a sense that is what the NCG does. The second thing is about expertise. Almost anybody can stand up and say he can treat some condition that nobody has ever heard of, but you need a way to make sure that is believable. We have some quite skilled medical advisers, plus we have the royal colleges and various other stakeholders on the committee. When we say that we will designate that person the idea is that everybody else can believe that person really does know what to do. By designating it in effect you create managerial pressure that only those hospitals will do it because the rest will not be paid. You have clinical and managerial pressures lined up in the same direction to say that is where you go for this condition. That means you can publicise it and you hope to get the referrals so patients get to it quickly. Those two things work reasonably well together. The last issue one is left with is gaming. Will the trust load overheads into that one and not the other, charge for something twice or whatever? Although people criticise the current arrangements I think that having the NSCG able to crawl all over what the SCG does allows us to say that, yes, they drive just as hard a bargain at that level as we do at local level and that at least gives everybody confidence. If we go back to when

NSCG was inside the Department of Health - I chaired it then - there was a definite feeling in the health service that somehow those really rare things got a free ride and loads of money were chucked at them. I do not believe it was true but because nobody could scrutinise and challenge it that was what they thought. We have gone some way to being able to break that. There is a risk in the new proposals that that notion will re-emerge unless we believe that the people on the new committee are able to challenge and drive just as hard a bargain on behalf of everybody else. I will not be chairman by then; I shall be out of it, but it has to be as good as it is now.

**Q285 Dr Taylor:** We have NSCT as well as NSCG.

Professor Griffiths: The "T" stands for "Team".

Ms Moss: It is the team of clinicians and managers who commission the 50-plus services at national level.

Ms Evans: It is Ms Moss's team.

**Q286 Dr Taylor:** I have gathered that. They do the work for the NSCG?

Ms Moss: We do; we are the legs on the ground going round visiting the services and working with the hospitals to set them up and monitor those services and driving a bargain.

**Q287 Dr Taylor:** We are told that you have the presence of the larger royal colleges. Are they pretty good at turning up at these meetings?

Ms Evans: They are.

Professor Griffiths: The surgeons and physicians usually have a job and so they send deputies; the other three normally send their presidents. They are very good. In the past I was president of a faculty in an academy and I have a bit of leverage in persuading them to come. If we really want them to be there for particular things I write to them individually or ring them and most of them turn up.

**Q288 Dr Naysmith:** How are therapies assessed for clinical and cost-effectiveness? What role does NICE play in this?

Professor Griffiths: NICE does not. There are some things that we have asked NICE to look at but it just puts it back to us, saying that it is too rare for it to bother with it. We collaborate and things are discussed, but it is not easy. Obviously, where you have something that is very rare it is difficult to organise a controlled trial because the numbers are too small. It must be international and so forth. You have to look at a range of evidence. I believe that is where the colleges are very useful. It means that you can put it in front of the colleges. Sometimes they will pass it through into their committee structure. You get the best opinion you can. We would press for trials wherever possible. In some cases we have funded services in order that a trial can be conducted. Referring to ECMO which was in the news during the height of the 'flu scare, we funded the service for a while in order that a trial could be completed because we did not feel confident in saying that it definitely worked until we had a trial. We try to get the best evidence we can. Take the service in the south west where a chap glues an acrylic lens onto a piece of tooth and then transplants it into the eye. He has done only about 10. It

will take a while before you get a trial going, but the fact is that patients who were blind can now see in 90% of cases, so you believe it. You do the best you can.

**Q289 Dr Naysmith:** Does cost-effectiveness come into it at all?

Professor Griffiths: Some but not all of these things will be expensive. If you average the whole lot they would probably come in under the threshold, but some things are very expensive. I think you can do some modelling to estimate where drug companies are really over-charging, and some are. The trouble is that the way the drug costs are done in this country is through the PPRS which caps profit rather than price, so sometimes we do not challenge one or two companies that I think are overdoing it. You could put in place that sort of mechanism. There would be a case for working with the rest of the EU perhaps to try to get tighter prices on some of these things, but the total amount you gain from it will not be a hill of beans compared with the total NHS drug budget. Some people may say that it will save only £30 million or £40 million, so why bother? If money gets really tight I imagine that that issue would re-emerge.

**Q290 Dr Naysmith:** How is the final decision on whether to buy or not buy a very expensive orphan drug taken?

Professor Griffiths: At the moment we thrash it out in the NCG and come to a conclusion on whether or not it is a good idea. We then propose that to the NSCG - the folk like Ms Evans - and they argue about it and gets their finance directors to crawl all over it. Some of it is chucked out and we end up with a bunch of things which people say look like a good idea. Those are then commissioned.

**Q291 Dr Naysmith:** How long can that take?

Professor Griffiths: We have an annual cycle and we get them done in the year.

Ms Moss: It has worked very well for the new proposals around services that have come up. We have worked very well with the finance and public health directors and SCGs to agree whether it should be commissioned nationally or should remain regionally commissioned. Usually they are not co-ordinated at all. In quite a number of cases this year we knew that the NHS was wasting more money treating patients badly than getting a proper service set up where they could be diagnosed, assessed, given the right treatment and sorted. That is very often the storyline behind our services. Infrequently new technologies will emerge which have usually gone to PCT exception committees and different views have been taken. They are the ones that involve high-cost services. Those are much more difficult areas. We have had more difficulty with the system in coming to a consistent view on patients, and that applies also to ministers.

**Q292 Dr Naysmith:** When a new and sometimes very expensive therapy is being developed for a rare condition how is the patient and the community best served in the interim?

Professor Griffiths, you probably have an example that is apposite: Eculizumab.

Professor Griffiths: It depends a little on how the thing has developed. There are two standard patterns. One is where a particular clinician or a team over a period of time, perhaps because they have done research on it, has developed a new service. They gradually get to the point where their trust says that they keep bringing in these terribly expensive patients and they

cannot get the money back, or it looks like they are about to retire and perhaps they should recruit somebody else with that skillset. They then say that if they can get it nationally commissioned they can stabilise the position. There is an argument as to whether it does or does not require it and whether or not they are doing something clever and that goes through all the process. Those are reasonably straightforward because they develop over quite a period of time. The other example is something like Eculizumab where somebody invents a new drug and discovers almost out of the blue that it works on some condition he has not expected. Eculizumab was thought originally to be good for asthma and it turns out to be terrific for an extremely rare condition of which very few have heard. Surprisingly, they did a trial and our people were in touch with the clinicians who conducted it. Everybody thought it would cost about £30,000 a year, which is expensive but not exorbitant. At the end of the trial they said that it would be £300,000 per patient per year and the patient would need to take it for quite a while, possibly for ever. Some may get better but because it has never existed before we do not know. Suddenly you have problem because that looks like it is off the clock. We spent a long time discussing that. It was then discussed by the NSCG. Between the end of the trial and our making a decision individual patients were thrown at individual PCTs or SCGs and there was debate within the individual regions, so there was a period of uncertainty. Some regions said no, some yes and so forth. Eventually we arrived at a common position and it went up to the minister. The minister decided to pay for it but we thought it was a bit on the dear side. We hoped that perhaps a different bargain would be struck. However, the decision was made. It took about six months to chunter through that process. That was the extreme end of things; it was a lot more than anybody expected. On modelling grounds one could argue that they are charging more than is reasonable. I have sent my arithmetic to your clerk. There are grounds for challenging it, but you have to make a decision as to whether or not you say to these patients that you are sorry but you will not pay for this in the UK. I think you can insist on the numbers in terms of treatment being as close as possible to one in one; in other words, it works every time you use it. If something works only one out of five times or gives only a small gain we would probably say it is not worth it at those prices. But the issue is: how do you defend that decision? That is where the difficult process is at the moment. That was discussed when Carter came along. We need to make sure that those processes are robust, can withstand challenge and so forth. I have said in my paper that I am not completely happy with some of the things in the new consultation proposed, but we have to be able to say that occasionally there are very small numbers of patients where to pay over the odds is justified, but we need a mechanism to be able to argue about price and properly assess effectiveness. We have most of it in place but there are a few bits left to deal with.

**Q293 Dr Taylor:** Moving on to consultation, the title is Strengthening National Commissioning. Ms Moss, can you tell us how it is going to do it before we get Professor Griffiths' objections to it?

Ms Moss: It is a Department of Health consultation as a team decision with the NHS but we have worked with the department on it. National commissioning is pretty strong and as a country we have some very specialist services that do a fantastic job. The nature of the NHS means that we can focus on getting these services into very few places in the country, get that expertise to flourish and control the entry of new services and not let them go everywhere and increase cost everywhere. It is a good story. The bit on which we have had a problem is where new technologies come in that may be pretty expensive and there is a need for consistent decisions for patients, not a postcode lottery for them. There are difficult and complex decisions to be made. Carter set up a set of arrangements; he also said we needed to

review them. With the benefit of hindsight if you were trying to get a consistent set of decisions you would not set up a group comprising largely clinicians, then put the proposals to a group almost entirely composed of chief executives of PCTs and then put the proposals to SHAs and hope to get something clear and concise out of it. Essentially, the proposals are to bring the different stakeholders into a room together and thrash out those proposals, taking into account all of the different issues that we need to take into account: the costs, the clinical effectiveness, the benefits that that gives to patients who often have very painful and awful conditions, societal benefits and a whole range of other issues. One looks at those in the round rather than different aspects in different rooms and then makes recommendations and puts them to ministers on behalf of patients. That is our aim and that is the proposal within the consultation. The oversight of NSCG about whether you get good value for money in the way you commission is there and I will carry on accounting to them; we assure them that we will do that. But it is really about the new services that will come into national commissioning, in particular new technologies. Let us have a good, effective way to get a quick decision on whether or not we fund these as a country. It will always be difficult and painful, but at the moment we do not even have a robust system. If we felt we needed to say no we probably do not have a sufficient robust system to withstand scrutiny.

**Q294 Dr Taylor:** To say no to the drug for PNH would have been incredibly difficult. The aims sound pretty good. What are the criticisms?

Professor Griffiths: I do not have objections; they are slight anxieties if you like. First, I am not convinced that you need to change the system, but this is partly because I have sat through so many reorganisations I have lost count. I think the knee-jerk reaction every time a problem comes up that we should redesign the committees is total rubbish. It has not made any difference each time we have done it. Why not just say to these two committees that they have to come up with a clear answer and it must be judicial review-proof? They all understand rules, so they should do it properly. My second point may be modified by the way the circular eventually comes out and is implemented. I do not believe it is sensible to have the minister appoint everybody rather than having them as representatives as they are at the moment. I think all the stakeholders should be there. I agree with Ms Moss that it is quite useful if you have everybody in the same room. I am glad that I shall not be chairing the meetings. Get all of them there but ensure that their stakeholders know why they are there and believe that these people will not go native when they turn up at the NSCG meeting and take the soft option by saying yes to something they should not agree to. By all means let the minister appoint the chair but have the committee clearly representative of the stakeholders who need to be there with a process that guarantees that when they turn up they know to whom they are accountable. I think that will give it a lot more power and will maintain the basis of trust between national commissioning and the other levels which we have spent the past two years trying to create. Having chaired NSCG and been part of the public health community since I was president of a faculty I know what people thought about in NSCG. We have done a lot of work to try to put that right and build that kind of trust. There is a risk that it would be thrown away by these processes. I already sense some of that distrust turning up in opinions that I tap outside. It is not insoluble; you can get it right by the implementation even if you go ahead with this, but you need to get that right.

Ms Moss: We are out to consultation at the moment and we hope everybody writes in to say they think it is a very good idea that the presidents of the royal colleges continue to be part of that committee and that the PCTs that chair the SCGs are part of that committee. Some of the most expert PCT chief executives in the country chair the SCG committees. I believe that

would be perfectly appropriate and that we have an appointments panel to get the lay representatives and the like. One hopes that will come out of the consultation.

**Q295 Dr Taylor:** So, the presidents of the royal colleges and the best chief executives should remain there?

Ms Moss: I think that will be one of the results of consultation.

Professor Griffiths: We need lay members to be appointed; we also need patients. They are not the same. Clearly, patients have a vested interest in having the service. Somebody else has to represent the opportunity cost. If you decide to pay for some of these expensive treatments you are taking money away from other services. They may be happy enough with you because we all feel that nobody should be left out, but we need all those balances. I am sure it is better to have a clear process of appointment that does not just disappear somewhere inside Whitehall.

Mr Murray: Ultimately, there is a political dimension to that which is why ministerial involvement remains important. What kind of society do we want? Do we want to help these people in dire need at the extreme or do we want to follow a rigorous purely bureaucratic approach? We feel very strongly that there should be an involvement for that reason. We welcome the proposals. We have not yet finalised our thinking but we believe that greater robustness in the arrangements will be no bad thing.

**Q296 Sandra Gidley:** Ms Evans, senior officials from the department told us that commissioning had not really started to work until two years ago. Do you agree with that statement?

Ms Evans: I read that evidence with interest. Whilst I do not think it is fair to say that commissioning did not start until two or three years ago today we have talked a lot about ways in which the health service has been developing, for example payment by results, programme budgeting approaches, developing sophisticated approaches to health needs analysis, developing and understanding social marketing and how to target particular groups within the population with health messages. A lot of these disciplines and approaches have been developing over time. Over the past, say, three years we have seen a real acceleration of what commissioning can achieve because we have PCTs with capability, skills and an appetite for innovation. We have seen PCTs that are increasingly close to their local authorities and communities, so they get a really rich source of partnership and ways to bring about change. It is that combination of things that has allowed us to see a lot of improvements. In some of the evidence the Committee has received I was encouraged to see PCTs giving you very clear examples of their achievements for their populations. It has really taken off as a result of being able to use lots of different tools and approaches.

**Q297 Sandra Gidley:** Has commissioning started to work properly now or do you still have quite a way to go?

Ms Evans: It is still work in progress. The first year of World-Class Commissioning results has showed a real spread against those competency and outcome measures. The important thing is about distance travelled. As long as the next time round we can show we are travelling a good distance and improving on what we can achieve for communities, populations and people then we are delivering what we need to deliver. As we go into the

next period, which we know will be subject to considerable financial pressure, there will be management cost restraints. It will be all about PCTs working together to make their money go further in producing capability and levers for change.

**Q298 Dr Naysmith:** Wearing your PCT chief executive hat - it is nothing to do with specialised commissioning - obviously from what you have said already you believe that World-Class Commissioning is a good thing. Is there any real evidence that it has improved patient care? Can you give any examples of its impact on the work of NHS Bristol?

Ms Evans: The issue as to whether it has improved patient care is a big one. In NHS Bristol our governance committee reviews what we are doing on health improvement; it reviews what we are doing on commissioning health services, and it looks at how our organisation is working. In that committee we look at all the national standards and service frameworks, so we look at the national service framework for mental health which sets out all the quality standards in mental health and looks at how we are doing. We look at the stroke care pathway to see how we are doing against that. Dementia services are in the news today. We look at the recent review conducted by our health authority to see whether we are making improvements. I believe we can demonstrate that we are making improvements in health service delivery and the parts in the pathway that go back to prevention, early intervention and preventing people becoming ill in the first place. For World-Class Commissioning we chose 10 outcomes of which eight were oriented towards the health improvement end. As to alcohol misuse, in our PCT and in the core cities we are campaigning for a minimum unit price because we believe that will have a big impact. We were delighted with this Committee's work on it. Therefore, we are concerned with alcohol, smoking, teenage pregnancy and all the things you would expect in a city. It is difficult to measure progress on that. We believe we are making progress on those matters. We also believe we are making broad progress on the commissioning of health services.

**Q299 Dr Naysmith:** Has it helped with the commissioning of mental health services in Bristol? You and I both know that there have been a few problems there in the past.

Ms Evans: I can say a number of things about that. We have an annual assessment against a whole range of indicators about how we are doing on mental health services. I am pleased to say that we have improved our performance. We have a green rating for 20 indicators whereas a year ago we had only seven. There has been a broad improvement. This is an interesting example of the use of the different tools available to us. The PCT recently went out to tender; it invited people to bid to provide a city-wide primary mental health service. This is the first time we have had a city-wide primary mental health service. It is part of a government initiative about improving access to psychological therapy. The organisation that won that competitive process was a respected national voluntary organisation called Turning Point. This is an example of being quite strategic about where you want to open up the market to bring in new blood and run a different model of service from that we have run in the health service before to be very responsive to local communities, particularly those with different needs. It is a good example of the use of a whole range of commissioning skills in order to make an improvement for people.

Chairman: I thank all four witnesses very much for coming along to help us with our inquiry.