Extract from the palantypist transcript from the 18 July 2013 Board meeting

Professor Sir Malcolm Grant (Chair):

"Let's move on then if we may to item 13, which is the new review of congenital heart disease, and I would like to invite Bill, please, to introduce the paper."

Bill McCarthy (National Director: Policy):

"Thank you, Malcolm. I just want to start by making what may sound like a very, very obvious point, but one that at times I think can become obscured, that this is all about people with congenital heart disease, some very young babies born with heart problems, and our collective responsibility to secure the services for them, not just now but for when they grow as adults, and indeed for children to come. There are times when you see some of the debate over the past that you might think this is simply a kind of competition between different locations, and I think if we allowed ourselves to slip into that sort of thinking we'd be doing a serious disservice to people who depend upon these services in this country. This is about those people, their needs, and their continuing needs now and into the future.

The context for how this has come to the Board is set out in the paper. It's a fairly long story and it is a story of the Safe and Sustainable process which was run under the previous health system, through a Joint National Committee of Primary Care Trusts with the intention of securing better services for, at that time, children and babies with congenital heart problems. The process took four years; it was a very intensive process, but it was challenged in two ways: one through the courts in judicial review, and also through a Scrutiny Committee referral to the Secretary of State, who asked for the independent review panel (IRP) advice. Now both of these challenges, when they played out, did identify flaws in that process, and last month Secretary of State accepted that the proposals could not go ahead as planned, asked NHS England – we are now the successor to that Joint Committee of PCTs – to take the process forward and to take it forward in the light of the IRP recommendations, so that is why we are discussing it here today.

I just wanted to make a few observations about the context, before we talk a little bit about the process. I think the first really important point is neither the judicial review process nor indeed the independent review panel at all questioned the need for change in these services. So, they supported the aspiration to improve outcomes, improve the sustainability of safe services into the future, and recognised that there was some important work that had been done with that aim. Second point, I say, is many of the clinicians and patient groups that we have managed to speak to since we took on the responsibility have been involved in this for many years. And they're living this, and

they're, you know, eating and drinking this all the time, and I think understandably they are now questioning the passion with which we would want to take this process forward. So there are some questions that we'll need to address about our determination to improve outcomes, create absolutely excellent services in future, given a lot of the difficulties that were had with the previous process.

I've heard suggestions, again from those meetings over the past weeks, that one of the consequences of the review findings has been weaker relationships between some of the units currently providing services. And again, I may ask Bruce to comment on this when I've finished the introduction, but it feels to me that that's quite a dangerous thing. This a service which, I think, depends upon the leading clinicians working together, communicating and co-operating really well, and we need to make sure that in taking this forward we're trying to strengthen that collaboration in the interests of patients and certainly not doing anything which would weaken or exacerbate problems that I think are there now, following the current process.

The most hopeful thing that I can share with you is whoever I have spoken to, whether they have felt harshly done by, either through the process or through the findings of the reviews, without exception I have met people with an absolute passion to improve care and improve the quality of care for patients, not just now but what's really remarkable is that these are people who've lived with these services for a long time and feel almost a generational responsibility to be part of securing even better, even more excellent services in years to come. So, there is that passion there as well as, if you like, a question mark over our ability to really drive ahead. So that's the context and, I think, the environment that I have picked up from the discussions I have had so far. As I said, the Safe and Sustainable process took four years, and I don't believe we've got that time. The paper here talks about the governance arrangements that we've proposed including the Committee that, Chairman, you're chairing and we've met once, and at that meeting it was very clear there is a determination to come back within twelve months with a plan that we can implement for improvement and change, and that's what is reflected in this paper.

I am quite sure in the discussions I've had so far that we need to talk much more about a national service, so: this is not a service with very many clinicians; it's not a huge service in terms of the demand; it should be a service that we see as one serving the whole population; and I think that should be the case in the standards we would expect everywhere; and the collaboration and the co-operation we expect everywhere. And again that message about a national service in the public interest is one that has had a strong response from clinicians.

In the paper itself, we set out at paragraph 21 a set of principles which we propose to underpin the approach we want to take forward, as well as setting out in paragraph 23 the governance arrangements which would enable us to make decisions. I spoke to a number of the patient groups just the day before yesterday, and one of the points that they were making is try not, if you can avoid to it, to keep all the decisions to the end. And I think that is a very good point for us. If we find spaces of agreement, whether it's over standards, whether it's over how networks and collaborations should work, we should take the opportunity to capture those, because I think that will help improve services as we go along. So that's another principle that I would perhaps suggest we supplement the paper with.

And my final message of introduction, I think, is to have a degree of confidence. I do know people are worried about this; I do know that they feel hard done by, but I think we need to display the confidence and the determination to bring about the right thing for patients, and in that discussion we were having yesterday about specialised commissioning and how becoming a national organisation and national commissioner is perhaps enabling us to break through some of the difficulties that previously have been experienced, I'd say this might be a first opportunity to put that into practice, in albeit a controversial area, nevertheless one that is extremely important for patients and families. I don't know if Bruce wanted to add to that?"

Professor Sir Bruce Keogh (National Medical Director):

"Thank you, Chair. I would quite like to come at it from a slightly different perspective, because some people have asked why do we spend quite so much time focusing on something which is really a very small specialty. It's only about 10% of heart surgery in general, which itself is only a tiny proportion of NHS work. But I think it's a small and really important specialty because, firstly, there is nothing more precious than your child, and, secondly, there are no more vulnerable people in our society than these children, who if they get good surgery can live a successful and fulfilling life.

And one of the problems is that nowhere do we see such a complex mix of science, technology, surgical skill, ethics and human emotion come together than in this specialty. And against that background, the nature of the surgery is changing. So it's quite clear now that the sooner you do many of these operations, which used to be done when children were of a reasonable size, the sooner you can do them, the better the results you get. So, these operations are being conducted on babies now who are much smaller; their hearts are really tiny; it requires huge technical skill to be able to do it, with great emotional demands on those doing the operations and those looking after the children afterwards. I'm a heart surgeon, as you know – my background: I could not do this technically; it is really complicated and the emotional side is really demanding. And furthermore, there is very complex intensive care management involved in the recovery of children after these complicated operations.

And there is, for such a small specialty, there is quite a vast array of operations done in different combinations, something of the order of 150, and, quite frankly, not all surgeons are equally skilled at doing each and every one of those operations. But all the surgeons in the country need to do enough of some sort of operation to keep their hands in. And as though that's not enough, both professional and parental expectations of a good result are growing. And that poses quite a significant demand on the services. So what we have to focus on, and I am quite clear about this, is we have to focus on getting the best outcomes for these babies, because if you don't get the best outcome, it doesn't just ruin things for the baby; it ruins things for the whole family and that is really, in my view, really, really important. So if we want to get the best outcomes, then we have to have an unequivocal ambition to develop what I think could be the best children's heart surgery service in the world. I think that is within our grasp. And the trouble is, that because of the complex mix in all of this, that the closer we get to some of the changes, personal and professional interests, and people have heard me say this before, and occasionally political interests, conspire to perpetuate the status quo and inhibit the pursuit of excellence for these really small and vulnerable kids.

So I don't want to lose the ambition, and I am sure none of us want to lose the ambition, for this service. Not just because I think it will be really good for our health service and really good for the specialty, but most importantly because it will be really good for the kids that are treated. But the trouble is, as Bill said, for many people this has ground on for so long that they're feeling utterly dispirited and disheartened and the atmosphere at times has become quite toxic, and we have to start, we have to try and get back to an even playing field without losing much of the good stuff that's been done, and also being sure that our evidence base for change is absolute appropriate. So I think there are people out there who are still up for this ambition, but we owe it to them to come to a solution much quicker than we have tried to in the past, as Bill alluded to. So we need further debate with colleagues and we really need that debate on how, how we get there, because much of the disheartenment, if you like, that people feel has come from: they just haven't felt the process has been right; they haven't felt that it's been tackled in the right way; so we need to get agreement on that, I think, fairly soon. I think that's all I'd like to say, Chair."

Professor Sir Malcolm Grant (Chair):

"Thank you very much, Bruce, and you remind us why we're here. It's the patient. It's doing the very best for the patient. And I think the suggestion that came through in Bill's introduction about a national service, which is able to ensure the highest quality of treatment, and your points about the multiplicity of operations and the inability of any surgeon to be at the top of the world on more than a limited number is absolutely critical. So may I invite any further comments as to the paper and the objectives of the next phase of the review and the process that we propose to undertake? No. I think generally people are warmly behind this. Bill, thank you, thank you very much."