Paediatric Congenital Cardiac Services Consultation

Public Meeting 5 December 2012

Stormont Hotel, Belfast

Panel members:

- William Crawley (Chair) (WC)
- Dr Frank Casey, Belfast Health and Social Care Trust (FC)
- Dr Miriam McCarthy, Public Health Agency (MMcC)
- Dean Sullivan, Health and Social Care Board (DS)
- Rosie Byrne, Belfast Health and Social Care Trust (RB)

WC: We will look at service specifications – what sort of service would we like? Secondly, the models – the options, how should we provide that service? And thirdly, how will we assess the service that is provided? Let's take the first one, the specification. What kind of service should be provided? Many of you have experience of the service already, and I would like to hear some of your stories as well.

P1: This is not a question really specific to the service, it is still a question that harks back to the consultation of Sir Ian Kennedy. And it is a question I asked Dean the other night in the focus group. There was a parent representative on Sir Ian Kennedy's team, and I would like to know who that was, and what was their experience of NI cases?

DS: I wouldn't be in a position to respond to that at the moment. I wasn't actually present. I don't know whether Rosie knows the details of the individual?

RB: I think her name was [redacted].

MMcC: We can find out – I cannot remember the name of the individual.

P1: Was the parent from NI? [No] So they wouldn't have any experience of NI cases or the problems that we would be facing?

MMcC: I think for all of the team, they were drawn together for their expertise rather than necessarily their familiarity with the local circumstances. So they were bringing their particular expertise from a wide range of areas and that would go for the parent representative in addition to others. I can certainly provide you with the names of the panel – I think it is probably included in the back of the report.

P1: I am sorry, but I have the report here. There is no parent representative listed as a parent representative and saying that they are an expert if they are coming from England just doesn't hold water at all.

P2: Miriam, not wanting to focus on you again, but I caught the end of your presentation and I noticed that you said about the safe and sustainable standards, about what ideal services, and they were endorsed by groups across the UK, and I would just like to call you on that point. When you say the UK, do you actually mean GB and what groups in NI endorsed these standards?

MMcC: My understanding is that they were endorsed by professional bodies and professional bodies tend to exist on a UK basis, for example the Royal College of Cardiologists, or Royal College of Paediatricians. So those bodies that are UK based that will have representatives in NI endorse them. Parent groups were involved and Irwyn McKibben who I hope will be joining us later was actually involved on behalf of his organisation in contributing to those, and supporting them. It was UK wide organisations.

P3: I would like to ask, it says a lot here about the UK, but it doesn't say anything about Scotland. What did Scotland do about this? It doesn't seem to be that Scotland has a review. Are our children less important? Obviously they stood up and said no. Or did they? Why do they not have a review in Scotland, yet we have it here?

DS: Miriam has sought as straightforwardly as possible to outline the context for the review in NI. There have been concerns for a number of years around the sustainability of the service in NI given the small number of patients that we see, and the difficulties that presents in terms of the sustainability and the resilience of the service. And it was within that context that the review was undertaken. It is right to reference the standards that are in place across the water, the safe and sustainable standards, but at the same time it is important that we remember why we are here tonight. We are here, among other things, to seek your views on the standards that are proposed for NI. Those are standards that appear in the consultation document as draft standards. They are standards that have been worked up with all members of the working group that Miriam described, and we would be very keen to hear your views on those. Those are the working group's efforts at coming up with an appropriate set of service standards for NI.

P3: I hear what you are saying, but you are not hearing what I am saying. Scotland is bigger than NI. It is part of the UK. If the government, or this review committee or whoever they were, deemed it necessary to go into the different parts and do it, why did Scotland and their assembly government say no, thank you very much, cheerio and shut the door behind you? And on another point, you are talking about Heartbeat NI, you mentioned another charity there, the Children's Heartbeat Trust. Where are they tonight? [Sarah is here tonight]. Well, why aren't they up there?

WC: Irwyn we hope will join us from Heartbeat NI.

P4: I am Sarah from Children's Heartbeat Trust. At the start of this process we were invited by the Minister to take part in the working group, which we did so we could

reflect parents' view. We had [redacted] who is a parent there, and we invited observers who were mainly parents, to come to the groups as well. At the Minister's request, we took part in that. However we don't think it is appropriate that we would deliver a consultation which is based on a review from the safe and sustainable team that we don't think stands up to scrutiny both in terms of its process and its recommendations. We felt as a charity that it would be disingenuous of us to sit up on the panel. We held public meetings, and over 1,000 people attended those public meetings, and the very clear mandate we had from our parents we represent is that the solution they favour would be an all island surgical unit with surgery based over two sites.

P5: I would just like to pick up on the issue that lady raised. Scotland rejected these proposals and didn't consider them. Because, unlike our Trust, they have a surgical team in place which suits their need and their caseload and it is sustainable. We cannot provide 24 hour cardiac surgery cover, and that is only because, it is no news to anybody, [redacted] was retiring for many years and the Trust never put a HR plan in place to provide surgical cover that meets our needs. Simple as. That is why we are in the situation that we are. That is why we are vulnerable to this review. There is no suggestion in this report at all about safety. It all comes down to – can we provide surgical cover? Which we can't. Do we have enough cases? Which apparently 140 cases plus isn't a big number, which it is, it is getting bigger every day. Surely it is going to get more sustainable. The reason we can't fight this review and the reason we have to now pair up with another provider, not get a provider, is because of a lack of inactivity from the Trust over a number of years. Now you sit in judgement in this decision which affects this country for generations.

MMcC: I think you have articulated the point very well. We do have a small volume of activity. We do only do about 90 procedures, but I need to say that I have been involved in this particular area now at various intervals over about a decade. There has been an enormous amount of planning. We knew when [redacted] was going to retire; he was a hugely well respected surgeon. But one surgeon cannot provide a service for a whole population. There was an enormous amount of planning for quite some time to try to identify what was the best way forward. But no matter what was done, and the Trust has been in successful in appointing and we have had discussions between Trust and Board on many occasions and with the Department. The difficulty is that in order to have a service that can run 24 hours a day, every day of the year you need to have the staff to run it. And in order to have the staff you need to have enough children going through who require the surgery to actually sustain the service. The standards developed in England, which are largely reflected in our consultation document, on which we are keen to hear your views. Those standards suggest that to run a service 24/7 you need a team of medical and nursing and support staff, a very expert team, you need to have at least 4 surgeons. Otherwise they are working far more hours than is legal and far more hours than would be healthy. You want a surgeon to be well slept and fresh doing what is

inevitably a very lengthy and complex operation. To have that in place you need typically four surgeons. Each one of those surgeons would be expected to do at least 100 procedures, and ideally 125 procedures. For our population in isolation, that is simply not possible. We have a small population and a very small number of surgeons. That means that at 2.00am on a Saturday morning or 4.00pm on a Sunday we can't necessarily guarantee that we will have the team standing by when they are needed. That creates an inherently vulnerable position that the Trust has been working towards trying to find a solution for quite some time. And we have been working towards finding a solution. But it is like squaring a circle. It has been incredibly difficult.

P5: I agree with everything you have said there. We cannot, but you missed my point. I am talking about a medical team that suits our standards of our case load. Not 400 cases. We will never provide 400 cases because we are not as big as the English centres. That is English standards that have been set out. You never put in place a surgical team that suits NI's caseload to provide 24 hour cover for our caseload. That was never ever put in place. Plus you are talking about standards for the UK and sustainability report. They are UK mainland standards. In the report, Mr Kennedy has outlined that children aren't allowed to fly – it is deemed unsafe and unreliable. Even he would like every child who requires immediate surgery to be within three hours travel by road. How do you propose that here? Also, it is not as much as a double standard as it is a blatant ignorance of what we need here.

MMcC: I do think it is an opportunity to hear from all of you as to what standards you think would be appropriate, because the working group has developed the set of standards that are in that document. We are very clear that safety and sustainability is the most important. We are absolutely clear, and there has been discussion at every single meeting of the working group, that urgent and emergency cases that need to be done, must be done in a timely manner. They must get children to a centre that can best meet their needs.

P5: He says flying is unreliable and unsafe. How do you get a child from here without having to fly them? [Parts inaudible, no microphone used]

DS: It is clear why we would wish to jump to what the answer might be, or might not be. There are a number of individuals in the room – Sarah is here, other panel members are here – a lot of these issues have been rehearsed at length within the work of the working group. It is important to remember that there has been no decision made. There is no option that is the definitive option. What we have sought to do is develop a service framework which Miriam has described and outlined, a set of options which might meet that framework, and a set of criteria against which to assess those options. It is clear that, in the same way you are agreeing with what Miriam is saying, I would agree with much of what you are saying. It has been said already to us within the working group. And I believe it is adequately reflected in the criteria and the weighting. That is why the particular criterion around emergency

access has such a high weighting. It is clearly more problematic to provide timely access in emergency urgent cases when service isn't provided locally. But we are seeking your views on those criteria, on the weightings, on the options, on the service specification.

P5: If we have a safe service, and a safe working service with Dublin, which is by road, you are talking about air ambulance. If it is an emergency, how can it be safe to travel by air ambulance if England has said that is not safe to travel by air? Also, we have good access to services; we have good arrangements for parents. It is not safety, it is sustainability that you keep going back to. As these parents here have brought their kids, is it small numbers? And can you tell these parents that it is small numbers?

P6: To follow up on what everyone else is saying, around the weightings. To me, the weightings seem ridiculous. The fact that you would 'ensuring emergency and urgent procedures are undertaken within clinical indicated timescales' give it 30 – it is life and death at that stage. To put safety and sustainability, which to me is a financial and economical thing as a 50 is totally disproportionate. Looking at the weightings, for me it is a no brainer for families that should be a 50.

WC: Do you want to explain how you came about those weightings?

DS: It might be helpful in the first instance just to rehearse again what the criteria are saying. The first safe and sustainability isn't to do with resources. It is an option that ensures that the services commissioned are safe and sustainable, of a high quality standard, and are compliant in terms of measures with best practice across the water. The criterion goes on to say that the overriding priority for us as a commissioner is to ensure that services are safe, sustainable and of a high quality. That does feel to me, it did feel to the working group, which included parents representatives including a number here tonight, that was the most important criterion. If children were going in to receive heart surgery that it would be undertaken in a safe, sustainable manner. That was the view of the working group. Clearly, it would be at your discretion to reach a different view to that. In terms of the weighting accorded to the criteria about emergency access, that was as I discussed with a number of people in the room and I think Miriam has as well in the focus groups, that particular criterion through the working group increased its weighting substantially through discussions because parents were of the same view that you are referring to tonight, that was a very important issue. That is now the second most important criterion within the list that we have, reflecting the need for timely access for the number of patients that are urgent or are emergencies. To go back to the numbers that Miriam talked about, 110 children or so, undertaken on kids that didn't have to go across the water to Birmingham, and of those about 20 that were urgent or emergencies. It is very important to remember, we want safe and sustainable services for all of the children. Not just for the 20, not just for the 90, but for all of them.

WC: So, can I just point out that we are consulting, so we want to hear your views. Not just questions, but your actual views. What kind of service should be provided? That is the specification question. What do you think should be provided?

P7: You keep mentioning safe and sustainability. That's what the title is and what keeps coming out, but you keep saying that they are one and the same thing. Safe and sustainable is not the same thing. Safe is the lives of our children, and there are a lot of people here. Sustainability is a management issue, and what you need to do is get your finger out and fix what is wrong with the management issue, and make safety the most important thing. Don't try and tie one to the other, because it is not fooling anybody. Safety is the major issue.

P8: My issue is on safety. My [redacted] would never ever have made it as far as the airport to go in the air ambulance. Safety should be the number one issue. Our children should not be made statistics because there is a small number. In Britain there is a population of 60 million. We have 1.8 million here and it should be reflected in the numbers. I would have never have seen [redacted] again alive, my husband would have brought [redacted] home in a coffin, [redacted]. I think it is ridiculous that what happens if [redacted] Where does [redacted] go then, because there would be no anaesthetist there in Belfast if they take the service away? What happens?

FC: I have waited to respond because I wanted to let people reflect their views on this, and I think the gentleman on the right made a very crucial point in that the dilemma here is safety and sustainability. The two things aren't necessarily the same thing. As someone who works in the service, our priority as a team is to provide the safest possible service to all of the patients and I think that in the past we have provided that, and we continue to provide it. In 2012 we have a huge challenge in terms of how that service can be provided in the future to ensure its safety and the numbers that have been outlined do present a challenge in providing the surgical aspect of the service in the future, and all of us in the service have thought long and hard about this. I can assure you that we have reflected the views and as the people who look after the children are most concerned about the potential difficulties in terms of safety of having children to travel outside of NI particularly by air in an emergency situation and I think that we have put that at the forefront of consideration. Our goal in terms of providing services as the team who work in congenital cardiology is to try and provide as much of the service for children as close to home as possible. We want to retain a surgical service if we can provide that in a safe manner, and what we are trying to put together without going into all of the details, we will make a detailed submission to this process, which I hope will help along the way in providing a solution to this. We are very conscious that the surgical

aspect of the service is crucial not just for the surgery, but for the future of the service in general and all of the other things that stem from that because we are talking not just about surgical, we are talking about interventional catheter procedures, we are also crucial to the care of the children. I think that in terms of giving some reassurance, certainly from the clinical team, there is no acceptance of any particular solution yet but we will work together with the HSCB, with the PHA to provide a way though this that will have a solution that is suitable for NI. And the points you make about a solution that is for the NI children is crucial here because the geographical position and the challenges that provides is very different from England where the safe and sustainable services review was initially designed for. We need a solution that works for the patients within NI. It won't be the same structure as we have had in the past. I think we have to accept that for Belfast to provide a service it does need to collaborate with at least one other centre to provide the surgical expertise and the volume of patients, but there are ways that I think we can work through that will sustain the same and an improving service for patients.

WC: Do you have any views Frank on whether that collaboration, that other centre, should be on this island?

FC: In terms of devising a service that can provide the best cardiology service to all of the children on the island of Ireland, I think that is the logical way forward. We have relationships with our cardiology and surgical colleagues. I do have to be honest in this process. There are challenges in making that work in terms of the pressures that the service in Dublin is already under in providing a surgical service to their own patients. It can't work with the existing resource so the departments of health north and south need to make that a feasible option, then there has to be a very major change in the way the services are run.

WC: And will the new hospital planned there be in the pipeline?

FC: The new hospital planned in the ROI realistically is a number of years away. But a solution for children's cardiac surgery and paediatric cardiology can't wait on a new hospital in ROI. It needs the resource put in now. It doesn't need a new hospital to deliver that.

WC: Do you think Frank that a collaboration relationship which will involve Belfast and somewhere in GB, perhaps Birmingham or somewhere else, do you believe that would be equally safe?

FC: If I can come back from that a little bit. When children are affected by heart disease, what you want to get is the best possible treatment for that child. There are some children at the very complex end of the spectrum where the expertise will only lie in 1 or 2 places within the UK, and for many years we have had a working relationship with Birmingham children's hospital to provide very good surgical service that they have for a specific group of patients and I think to get the best outcome for those patients we wouldn't plan to change that. But for the majority of patients,

particularly those who need surgery in an emergency situation as the lady described just now, it is crucial that we can access that in a short time frame. There are certainly concerns in terms of air travel for that particular group of patients. But is a much wider issue in terms of developing a future service outside of the political boundaries because there can be an exchange of patients, exchange of expertise and perhaps that is easier on an all island model where the expertise can be shared that way.

P9: If you bear with me a second, I have a very specific question, from page 16 of the consultation, and access to services. This is bullet point one and I will read it out and then if you could clarify something for me.

Emergency and urgent procedures should be available within clinically indicated timescales. For emergency cases, this should be consistent with the standards set out by the Paediatric Intensive Care Society that a retrieval team should be available at the referring centre within three hours.

The first question just to clarify for me, 'clinically indicated timescales' is that the same thing as a retrieval team being available?

MMcC: If I could answer it, and if Frank could provide more detail. The clinically indicated timescale just means whatever is required by that particular child, in that particular situation. Given that every child has their own individual needs. This was taken from the Paediatric Intensive Care Standards which say that a retrieval team should be able, within 3 hours to be at the referring hospital. So if for example, you are sitting in Belfast and you need to be transferred, within 3 hours to arrive to pick up the child, and there is further time beyond that.

P9: I understand that point. Something I would find helpful is that in a number of places throughout the report, you say things like clinically indicated timescales - could you tell me what that is? Can you tell me the minimum end of that? I understand that it is going to be very different, but are 10% of emergency cases needing treatment within two hours?

FC: Perhaps I can answer that. When a child is born with some particular conditions, the first procedure that needs to be performed within hours is not in fact a surgical procedure, but an interventional catheter procedure. For instance, a procedure called a balloon septostomy where we have to create an opening between the two chambers of the heart to allow the baby to survive. In that number of patients, which are probably six to eight patients a year, then that procedure has to be performed often within a few hours of birth, but very often within 24 hours of birth. Emergency surgery that has to be performed within 24 hours of birth is a small number of patients. It is less than five patients a year who need to have that done. That number seems small but five patients if they don't get that procedure is a very serious situation. So any arrangement that is agreed upon in the future has to be

able to provide that service for that small number of patients. Because it is a balance between safety and sustainability. You can have sustainability in a big centre, but that may not be safe for the population of NI. We know that in a small group of patients it will be hours, for a bigger number of patients a surgical procedure within days of birth, and for those patients then the transfer is more easily planned. It is still by any standard a complex procedure when a small baby with serious heart disease, but it can be done in a more planned way if the surgery doesn't have to be done as an emergency. I hope that answers, I am happy to address any more detail.

P9: Let's imagine a situation where surgical procedures were stopped in Belfast. Does that include interventional procedures such as a septostomy?

FC: One of the concerns that we as cardiologists have had is the impact on interventional cardiology procedures. In the absence of any surgical cover in Belfast or NI, that is a concern to us. We would in that situation be obliged to do what we could to help that child that would in some occasions involve doing a balloon septostomy in the absence of a surgeon there to deal with complications. That would be a worrying situation for us as doctors to be put in that situation and it is one that we have voiced our concerns on through all of this process. It is something that affects a small number of children, a small number of procedures but it is a lifesaving procedure.

P9: You have brought me round to the main point I was trying to get at. On this very point, [redacted]. If that surgical cover had of been across the city, never mind Birmingham, who knows. I didn't want to talk about it on a personal front. I would like to have numbers against things, if we are saying that we close down surgery in Belfast and we go to Birmingham, you are then saying that 3 hours for a retrieval team, that means how long until you are in a theatre in Birmingham? Three hours for a retrieval team, anther three hours back the other way, stick another three on until you are in the theatre. Say nine hours. How many emergency situations, and I am assuming there is data on this sort of thing, how many emergency procedures fall within nine hours say? So are you making a financial decision that say 2% fall within nine hours, that is ok? 50%, do you take notice?

DS: Maybe if I draw everyone's attention to this. This, as Frank has said, has been talked about at length in the working group. One patient would be too many to fall outside of the clinically indicated timescales – for the avoidance of any doubt on that. What the consultation document does seek to do, as we were asked to do by the department and the minister, we haven't just set out the options and criteria and left it like that. We sought as a working group at a high level to apply the criteria to the options, and if I look at the one you are referring to in the context of having no surgery undertaken in NI which would be option three, and what the consultation

document on page 24 says is in the provision of emergency of urgent response, the option of only having across the water, the working group said:

It is not clear that this option would ensure the provision of all emergency and urgent procedures within clinically indicated timescales and consistent with advice from the Safe and Sustainable team. Under this option, there will be the requirement for emergency cases to travel by air ambulance. There are a small number of children for which air transport may present particular risk. The evidence for air transport is that it is normally safe and effective but it is recognised that if there is a clinical emergency during the flight e.g. if resuscitation is required, this can be exceptionally challenging. The consistent availability of air transport may be impacted by severe weather and other factors.

I only read that out to try and highlight to everyone the extent to which you have just said we have sought to reflect within the document, any sense in which it would be straightforward to move to a position where surgery being undertaken within England and nothing undertaken in either Dublin or Belfast in the context of providing safe emergency urgent care. That is clearly problematic and we have sought to make that clear within the document.

P9: It is clear from that paragraph, but what is missing from that paragraph is the first sentence that you said, when you weren't reading it from the document and you said something like if one child is left outside the emergency then that line put into the criteria would be interesting. That line missing makes that whole paragraph a lot of words that are open for judgement, and I am aware that once you have something like this, we have criteria or requirements, we have words and no numbers or figures so people can move the bar later and say in my opinion that meets that. If you had numbers and percentages then I could look at it.

DS: That is fair enough. As Frank and Rosie will confirm, there are practical difficulties because the pattern for demand changes year in year out. It is the fact that routinely at least once every year there is at least one case that requires a very quick response, within a smaller number of hours. Yes, that is the case. That is fact. The fact is that as a working group and as a commissioning board, it would not be acceptable for us to be in a position like that where we were crossing our fingers and hoping everything would be ok. We would have to satisfy ourselves that there was a robust response arrangement in place for that one instance, in the same way that we would have to satisfy ourselves for the other 139 children that are cared for each year that robust safe sustainable services are in place for them. In terms of how these criteria will be applied, subject to the minister confirming the outcome of this consultation process as being an appropriate framework to apply, the criteria will be applied by the working group. There are four parents and parent representatives on the working group. As I am sure as Frank, Rosie and others within the room will testify, there is no sense in which this is somehow a push through process. This is a live, open, transparent process which anyone in the room, in terms of coming along to the working group meetings is very welcome to see that it is a live and transparent

process. I can assure you, without speaking for Frank, that Frank will help, as will Rosie and others, to ensure that it is. There will be no glossing over detail on these things.

P9: Just one final comment, I take your point and everything that you have said. I don't know who you are and I don't know what anyone's intentions are, and I don't know what the Health Minister's intentions will be, and so all of those things that you said – the first line that you said were that once a year there will be a case which needs very, very urgent surgical intervention and that needs met within this. But where is that in this document?

DS: It is set out in the context of the timely urgent response, the need for whatever option if chosen to ensure a timely urgent response to cases within clinically indicated timescales and in that one case it might be three, four hours or two hours.

P9: Can you say that – that there is a need for an urgent clinical response within two hours?

DS: I can't say that now within the document, the document is now out for consultation

WC: What you could do is, this is a consultation document, this is not the report declaring what is going to happen, and suggest that as you are doing right now in this meeting, and it is being noted. You can do it in writing as well, and you can say that I think you should put a safety requirement in terms of those timescales which, if I am reading your question correctly, would rule out option three. He doesn't think it is safe for those emergency interventions to take place in Birmingham because you are going to lose lives. They should happen somewhere within that timescale which would mean on the road in Belfast or somewhere close to Belfast – that's what you are saying?

P9: I am not qualified to say that, but that's what you just said!

P10: I have been one of the parents who has observed at the working group meetings and I have heard it said by the panel a number of times that the working group has been in agreement and that the service specification and the consultation document has been in agreement. Am I right in saying, with regards to the weighting, the safe and sustainable criteria was always going to be weighted at 50, therefore there was nothing that was to be weighted higher than that? So nothing could ever go higher than that criteria. I agree with the point that the gentleman at the front has made that safe and sustainable are two completely different things. Yes, safe should be weighted higher than the others, but sustainability doesn't necessarily have to be in there, unless we subscribe to these standards which we don't agree with.

MMcC: I think that it is really important to hear you views on the standards. They are important. Tell us, and we record all of this, we will be taking stock of this. There

was a lot of discussion in the group around every aspect in the report. I think probably more discussion around the emergency issues than any other, but a lot of discussion around the other criteria and the weighting. In the group, everybody will have different understandings of what the words mean in the group. We took safety to mean that children undergoing surgery will have a good outcome. And that the outcomes from surgery will be acceptable, doing well, good quality of life with adverse incidents including mortality rates in acceptable levels. It is complex surgery, but we want it to be safe. We want every child to do well. Sustainability is, from my perspective, to do that day after day, week after week. And our difficulty in Belfast is no matter how committed and how wonderful the team are, and it is a super team, and we are very, very lucky. It is really hard, how do you have a surgeon there day after day when there are only two bodies and therefore the sustainability is can you do safe procedures this week and do safe procedures at two o'clock in the morning next week, and do safe procedures on a Saturday afternoon the following week?

WC: This man is asking why you don't just employ more surgeons.

MMcC: We could employ more surgeons. We could bring in and have the four surgeons. There isn't work for the surgeons. For all of us working in all areas of medicine, and Frank will be able to say more from the clinical aspects, there is a requirement that we do certain things in order to remain a doctor. Interestingly, brand new things were brought in on Monday of this week, where every single doctor working in the UK needs to be revalidated and that means they must provide evidence that they are doing what's expected within their field. So, Frank can speak for himself, but for surgeons, the typical requirement for a surgeon operating on children's hearts is that every year they will do a minimum of 100 procedures. Two a week, roughly. Ideally they would do 125 procedures a year. So we could bring in surgeons, we could bring in half a dozen surgeons if they would come and work here, but there just isn't really the work for them to do. So then, what would happen, this does address the safety issue, then they would lose the skills and expertise that are so important.

WC: And they would lose their validation?

MMcC: Absolutely, do you want the person operating on your child to be somebody who is skilled who can go in and do that procedure, knows how to do the procedure? We often draw parallels with flying. You don't want to get on a flight to discover that the pilot is flying their first plane ever. You want that pilot to be experienced. Surgeons, we expect to have that experience, and that is really, really vital.

WC: It is a bit of a catch 22. If you were to have four or six surgeons there, within a reasonably short space of time, they would lose their qualification to act as surgeons in those cases. There wouldn't be enough work to meet the criteria.

P10: With all due respect, this is the second question that has been asked and not answered. I have asked you did the working group agree on the weighting on the first criteria which was safe and sustainability? Did the entire working group agree with that?

MMcC: Yes

P10: As I recall, it wasn't up for debate. That it would be weighted at the highest, which was 50 and nothing would be able to go above that.

DS: I suppose William, as speaking as chair of the working group, some of the parents in the room were there, everyone was given the opportunity and was asked individually to sign the consultation document off, and every member of the working group did, including all of the weightings of the criteria. You can't sign off half of the document. The document was signed off by all of the members of the working group.

P11: I am glad that this whole idea that the safe and sustainability not being the same thing was brought up here tonight, because I was at a meeting last week and that didn't come up, and I don't know about the other meetings that were also not well attended. But they are two very separate things. All the people here, and all the people with children, and all the families and all the supporters and the 100,000 people who signed petitions are interested in the safety of our children. Sustainability is for politicians, civil servants, accountants and whatever. That is not what we are here for. Secondly, I have attended other meetings. This meeting is really well attended tonight, and just to listen to the people in this hall tonight, very articulate, they know what they are talking about, heart in the right place and all that, so it is very worthwhile. However, having said that, I personally do not trust this process. I do not trust this consultation process, because everything that I have heard suggests to me that there is a box ticking exercise going on here. I happen to believe, and this is a personal view, [redacted], and given the reason why we are here, and [redacted] – I happen to believe that the winning of this battle will take place at Stormont and they will be going on public opinion about where we stand regards maintaining surgery for children at the Royal. I believe that argument has already been won, and the Children's Heartbeat Trust have won that argument, and the 100,000 or so petition signers are proof of that and I would suggest to the Children's Heartbeat Trust and to all the families that the way forward from here on in is to ignore these meetings. It is to get out on Saturday, meet at the Royal Hospital, march and let the politicians know, keep the pressure on, because that is what is going to win this battle, not this sham.

P12: I just would like to say this, we are talking about surgeons and the numbers that we need, so everyone in the room is aware that Dublin has high capacity of numbers. We know Belfast is safe, is it not a reasonable idea to take the children

from the border counties and make our safe service sustainable? Does that not make more sense?

FC: William, if I could just respond to a couple of the things. The issue of the number of surgeons and building a team of surgeons is a very difficult one. The surgeons do have to perform an adequate number of procedures to sustain their expertise. We, as a group within the Royal of cardiologists and surgeons, have to look at ways or discuss ways as to how that could be achieved, and amongst one of those has been the option that the lady has suggested in terms of looking at the surgical expertise on the island of Ireland, and looking at ways of four to five surgeons who would operate across two sites, which is one of the options in the consultation. It is still there, and just to respond to the gentleman at the back. I want to assure him that I and my colleagues, Rosie and others are not involved in a box ticking exercise. We feel that this process is still live and that there is a very big decision to be made in the springtime and all of these options here that are on this consultation document need to be looked at. I have a very strong feeling about which is the best option, as do all of you. I think that we should in the coming months – you as advocates for your children have done a superb job in making your opinion heard. We will make our opinion heard within the working group, and Dean and Miriam have considerations they need to consider in terms of looking at planning for the future. There should be a way through this, and as I have said, the solution that we come to has to be one that deals with the particular situation we find ourselves in in NI. It has its opportunities as well as its risks. It is a time when I hope we can create collaboration with another centre, and I don't think that we should be. It is not a situation that we should despair, there are times when I have despaired, but I do believe that we have a constructive process going on.

P4: I just wanted to add – I feel we are being slightly misrepresented in the role in the working group. We agreed for this document to go to consultation so that people could say these comments, around safety and sustainability. It is not that we said safety and sustainability is the most important one. We have just agreed for it to go to consultation. Can I just add, and I know that it is a very emotive subject, the most important thing that parents can do and anybody who is affected or involved in this, is to respond to this consultation document. Because then it is written down, it is heard in these meetings, and that's how you can be heard within this. And also you can come to our march on Saturday.

P8: On the deskilling of the surgeons. What happens when / if surgery is taken away from Belfast, what happens to the like of Dr Casey, all the cardiologists? What happens with the anaesthetists? Will we have dedicated anaesthetists on site? It is like what I said [redacted]earlier, [redacted] Would there be an anaesthetist there that could cope with a complex heart condition?

DS: I suppose again the point had been made [redacted] was raising exactly the same point. In my challenge, as chair of the group, working with the colleagues up here, with Sarah, and other members that are here tonight, was to ensure as far as possible within the document that we reflected all of these points. Certainly the issue of making sure that the other bits within the jigsaw all work well together in any model – that is reflected within the document. There is a specific criteria there that:

'The option ensures, through partnership working, the continued provision of medical and diagnostic paediatric cardiology services and other paediatric and cardiac services in Belfast and takes account of the need for multi-disciplinary training.'

We have sought to get at that, but I think as we said at the [redacted] meeting, the issue where children have a particular set of complexities, our general view was perhaps there was some scope to better reflect that than we had done, so even with everyone that we had on the working group, there was a sense in which we hadn't got quite as well with that point. So, I think the point is well made as it was [redacted].

WC: I am going to come to people who haven't spoken yet first.

P13: I am here with three hats on. One is that [redacted] and I am quite concerned by the consultation as well. I would agree with the Heartbeat Trust and the comments made by the majority of people in here, all the people in here, because from the position, if I put one hat on at a time, the hat that I would wear [redacted], is that we are concerned that this is part of the Transforming Your Care agenda where we are going to see 5% cuts in health services across the board across NI. We are very concerned about that, where £90million is going to be taken out of acute services in Belfast Trust alone allegedly, and we have to see the workings of that, to be transferred into the community service. We are concerned about that. But in relation to the cardiac services, we are also concerned about the service provision. [redacted], and I would be concerned that if this consultation goes through, then what we have is a withering of that service, and that service will be allowed to wither on the vine. We will see specialist trained nurses and doctors – it comes back to the point about the cardiac surgeons, if you don't have a service that provides the whole service, then why would doctors want to come and work in Clark Clinic? Why would specialist trained nurses want to come and work in Clark Clinic? [redacted] and I am telling you, the terminology is a bit worrying in relation to 'it's a challenging situation'. [redacted]

[redacted]. I would be very concerned. [redacted]. It comes back to the points that are made about what happens [redacted] How does [redacted] get the surgery that [redacted] needs? Even if it goes to Dublin, if [redacted] is lucky, that is still over an hour. [redacted] blues and twos down the road, it still takes you an hour no matter how quick you are going. That is my concern. The other issue is in relation to this – the cost. The costs to families. The people that will have to be put up if they are lucky, if it is going to be paid for, which is unlikely. It will cost them to actually have to travel, to give up work, to find other family arrangements, to deal with all the financial and irrespective of all the stress and worry and concern that you would have. These are the issues that we have, and I think fundamentally it is not about sustainability, it is about money. You need to put the money into the service. That service has been available and has been working very well for years. [redacted] The service as the consultation says is not about clinical care. So what is the issue? If it is about sustainability then fix the sustainability. Put the money into it. Just one point – I am glad to hear there is a march because I think that is extremely important. This man here is absolutely right, this battle – and it is a battle, it is a battle for our service and our children – this battle will not be won through the consultation. Everybody should certainly respond to the consultation, but you are absolutely right, it needs to be taken to the Assembly. It needs to be taken out to the public.

WC: What would you do? Can I ask that – what would you do? Which model would you propose?

P13: The model of care promoted by the Heartbeat Trust – two sites collaborating with sustainable funding put into it so that there are surgical teams on both sides that will cover. I have no doubt that children will have to go to England for their specialist care but the system that we have now – it does work. It needs more investment and properly resourced, that's what needs to be done.

P14: I am actually pretty new to this. This is my first time at a meeting, and I am here on a personal reason [redacted] and I can't believe I am sitting here tonight practically pleading for care for our children. I just can't believe that this is the stage that we have gotten to. I think it would be naive of us [redacted] for a long time that there are economics involved in that as well, there is no doubt about it. But from my experience, [redacted], and how many people it has affected, and I don't know an awful lot about what is going on except for on a personal basis. It is logical that there is care on the island of Ireland, whether it is one, or in Belfast and Dublin but to go to Birmingham I dread to think what would have happened in our situation.

And your question, if you could answer, does the working group actually make recommendations on the consultation process?

WC: Dean?

DS: The process will be in two stages. The consultation is about the things that we have been talking about tonight, about the service specification, about the criteria and about the options. This is, Miriam says, the fourth of five public meetings. We have had two or three focus groups with parents with a third one planned very shortly and a fourth one with young adults and teenagers who have had treatment already. The consultation closes on the 21st December. After that consultation closes, we will seek through the working group, to pull together a document which in due course will be forwarded onto the Minister which effectively sets out the outcome of the consultation process in relation to the framework.

P14: But I think Dr Casey touched on a number that he had personal recommendations, personal feelings on it – does the working group as a whole make recommendations?

DS: If I could maybe just finish my answer, I was going to get to that. It is a little bit long winded and apologies for it. [Is that a no?] No, it is not a no. Stage one of this process is to make a recommendation to the Minister as to the framework to be used to make a decision. Once the Minister has confirmed or otherwise that he is satisfied with the framework as it stands, which is what we are talking about tonight, and he is content with that framework, then stage two of the process for the working group, is to seek to apply that framework to the six options that are there, and any new options that might be proposed, and then the second stage would be to make a recommendation to the Minister, as you are saying, through the working group.

WC: You see the options laid out. I am taking seriously what you have been saying about sustainability. You are making all kinds of serious concerns about that. There is also a mood in the room where people are saying we need to be careful that the economics don't drive this, rather than the care of children. It is not about number crunching, it is about saving lives. These are the options that have been laid out. We want to get some feedback directly on these options. A number of people have said that the best way to go with this is collaboration between Belfast and Dublin, on this island rather than a GB collaboration. It maybe that there are additional interventions that require air ambulance transportation to GB, but that is what has been said in the room. Anybody disagree with that? Anybody think that there are other options that might be better? Not a dual option within Ireland, and if you take the view that it should be two centres within Ireland, then look at some of those options. Are they commissioned primarily from Belfast, primarily from Dublin, jointly commissioned from Belfast and Dublin? What are your views on these specific options. These are important and we need to get some feedback on this as well.

P15: Just on the Belfast Dublin option, the Royal is supposed to be a teaching hospital so why do we not promote Belfast as the primary care centre for our children? I know that there are waiting lists in the Republic, so why can we not take the kids from there? Also, because there are unsafe centres in England, they are happy enough for us to fly our children across could they not fly their children across and give us their numbers? [Here, here].

FC: The option of expanding the Belfast service in terms of being a bigger player in collaboration with Dublin is one that certainly does need to be explored. I think your point of flying children from England to Northern Ireland, probably the parents in England would have the same argument about it being unsafe for their children so we have to be realistic as to what will work and what will not work. We do need to look at all of the implications of what happens if there is no surgery. The gentleman at the back made the point in terms of the loss of the attraction of having staff who want to work in a service. And for everybody who works in paediatric cardiology unit that has provided a high standard of care, one of the concerns over losing a surgical service is that that service would over time wane, and that is a real concern, and I can tell you that we have reflected that in our discussions and we will continue to do so. The dilemma is trying to provide a safe service for children within NI within a situation where we can't realistically provide four surgeons in Belfast. Can that service be provided with the addition of input of surgeons from elsewhere? That's what has to be debated, but what has to come out of the far end of this process is something that can be both safe and sustainable, not just sustainable and less safe, but it has to satisfy both criteria. At the moment we have what we consider to be a safe service, and we have to ensure that the service can be provided in the long term, but not in the cost of any safety.

WC: [redacted]

P16: My name is [redacted]. If it wasn't for the absolutely outstanding team at the Royal Hospital, [redacted]. I would also like to ask you now, do you realise how many children's lives this will put to risk, if this goes ahead in how it has been said, that only 140 operations are carried out on children in NI every year that is 140 children's lives? Do 140 children's lives not matter?

P17: If the working group has no recommendations, why are the working group going to GB to have a look at these hospitals? Would you not say that is a waste of resources? The hospitals, it was mentioned that they are under review so would that not be false reading of those hospitals.

WC: Dean – and also take [redacted] point seriously as well, the number of children's whose lives are being saved, Miriam?

MMcC: In response to [redacted] and thanks for your input. You spoke very eloquently. The point that you make is absolutely spot on. Whatever the outcome of this consultation, and there are no decisions yet, we must ensure that services are better after the consultation with whatever model. Not more risky, not less safe. That is absolutely crucial. How we get to that is really important for us to hear what your views are and these meetings are really important in shaping the final document, but you are spot on. Yes – you matter, your friends matter, and all 140 children matter, that is why we are here today to try and work out the best model. I appreciate you bringing that up, [redacted] thank you. Can I briefly answer are we visiting centres in England, which is a very legitimate question. When we started this work, whatever option the Minister chooses to accept or develop as a way forward early next year, the Minister will rightly ask, is that option achievable and is it deliverable? In that respect we feel that we need, during this consultation, simply to be gathering information about what's available elsewhere. If we look at our criteria, and let's set aside the emergency one for the moment, if we look at our criteria, whoever is providing the care for children with heart disease should be able to provide volume of activity.

[Inaudible response from floor]

We aren't visiting all centres, we are visiting a small number [you are visiting five centres, is that right?]. We have written to centres and we have asked 'are you interested in exploring a conversation, and would you (we have emphasised that there is no decision) be able to do procedures on any of our children?' Some of the centres have written back to say that we can't because we've got our own workload and we don't have enough staff or whatever; or no we can't because we would need to have more buildings and more space. Others have written back and said yes in theory they could, and all we want to do at this point is explore what that looks like. So it is an information gathering.

P18: Personally I think it is a wee bit premature until the minister makes his decision.

MMcC: Just to come back on that, the difficulty is the Minister will need that information in order to make a decision, because for example, Frank has mentioned that we have had on going conversations with colleagues in Dublin, and I have been part of that for several years, so I am very well aware of that. We know for example, that if we wanted tomorrow to say Dublin is the option and all of our children can just go down the road to Dublin, if that were one option, we know that Dublin would have difficulty accommodating all of our children because they have their own pressures. Therefore we need to be able to have the information – are those options actually achievable, and the only way we can get to that is to explore the conversation and gather the information. It is not about making a decision at this point, and it is not

about making a decision about any particular unit. It is only to understand what the position is.

P18: But it wouldn't really be the true figures that you would be going to see in a couple of weeks' time whenever you go if they are under review?

MMcK: Within the review that was looked at, and the decisions taken in July, they looked at a number of patterns of services that they could have had in England. We tend to be visiting hospitals that were in each of those patterns. Who knows what will happen, but they are the big centres that are likely, and I can't prejudge the outcome of the current review, but they are likely still to be providing services and we are looking at what we need for next year. All of the units will probably be open next year, because any change will take some time to implement. We are conscious of all of the changes but we still need to gather the information that will help the Minister make a decision, and what really is important when we are going on these visits is that Frank is joining us on a number, and Irwyn and colleagues are joining us because we want to know what the arrangements are like for parents as well.

WC: We have a few minutes left.

P19: Thank you for the opportunity to ask a question. I am only here tonight because [redacted], you really don't know how it feels as a manager. I am a manager in my job and I can empathise to some extent with the people that I work with, but until you have sat and walked in those shoes you cannot really identify as a professional. [redacted] I am reassured tonight to hear Dr Casey and to know that at least the staff that work Clark Clinic are standing up for the parents and the children. I am disappointed with some of the other panel members that they don't seem to have the same heart for the children within this province, and on this island. My final point is just that I find the A4 document very helpful and very detailed. I find the actual pro-forma for responding to the consultation a little bit unclear. We are looking at options on the screen in front of us here. If I do feel for example that option four is the preferred option, in what way can I respond to that? It seems like many consultations that I have responded to – they are worded in such a way to confuse people who want to respond, and therefore the outcomes are equally confused, so that the panel can end up doing whatever they feel is appropriate. So perhaps you can clarify how we might respond to the various options in the document.

WC: Dean, I am conscious Rosie is here, she is managing cardiology services across Belfast, and we should be directing questions to Rosie.

RB: If I could clarify that yes I sit as a member of the working group in my management role within the Trust, but I also sit on the working group with my nursing background which is what I was before I became a manager within the Trust, and it

is invaluable that Frank as a clinician and myself as a manager with my nursing hat and a cardiac surgeon all sit on the working group and have our voices heard.

WC: On this point on how you respond?

DS: We sought, and if it is not as clear as it needs to be then that is regrettable, we certainly sought to make the process as clear as we can. As Miriam said on the outset it is consulting on the framework which in due course will allow a decision to be made.

WC: It is not recommending at this stage any particular option?

DS: No, it is not but having said that though, as has been the case to be fair in all of the public meetings and it is entirely reasonable that is the case. A lot of what is talked about at the public meetings is in relation to views on the options, and therefore it is entirely reasonable that we wouldn't straight jacket these responses and ignore views on that regards. But what I would say, our working assumption is that there is an 'other comments' section within the response box that would be an opportunity to respond to your thoughts on the options, which is getting to the next stage in the process, and what I would assure everybody in the room tonight, is certainly whilst the formal consultation response is in relation to the model for assessing different service options, we will share with the Minister any views that are expressed here.

WC: You are hearing some strong views tonight, that is for sure.

P20: It is actually about the next stage. When you get all of these documents back and you are doing this report, does the working group have to agree on the report, and if they don't agree on the report what goes to the Minister?

DS: I guess we will cross that bridge when we come to it. It hasn't presented itself as an issue to date in terms of the consultation document going out. It may present itself as an issue at some stage in the future. As described, there are two more stages to this. The 1st is the response based on the outcome of this consultation process, the 2nd thing for working group beyond that will be 'the recommended option is this'. There may well be challenges in securing a unanimous view as to what the way forward is. If there are difficulties like that, we will seek to overcome them but it may be that it is not possible to reach a unanimous view and in that case we will simply need to reflect to the Minister that there are different views within the working group. As far as possible, my role as chair is firstly to make sure everyone has a chance to express their view and as far as possible to reconcile those different views into a single response to the Minister.

P21: I would like to ask Dr McCarthy about something she said earlier on, and it goes to back to what happens to the child at 2am when there is no cardiac cover, and you make a point to say that the service is not sustainable with so few surgeons because nobody would have the rota be on call and therefore it is not safe but I find

that rather an ironic statement because ultimately what is being proposed here is the removal of cardiac cover altogether, so what happens to the child at 2am? Who is going to look after it?

WC: I guess we have to emphasise that we are not proposing anything yet, it is a consultation?

MMcC: And I suppose the issue is contained within the document. What happens to a child at 2am is dealing with an emergency and that is key and I think we have already touched on that and I know in our future meetings we will come back to that and we will spend, I would suspect, quite a large amount of time talking about that. I am not sure what happens at 2am at the moment, I dare say Frank and his colleagues are out of their beds stabilising ill babies but we just know that with our small surgical team that it is not possible to guarantee that somebody will be there every hour, that's simply an impossibility.

P21: This is my point. If what comes to be the removal of complete and utter cover for cardiac interventions at that time, that's the same thing. [redacted] I just don't understand why that can't be looked into further. What is going to happen in the middle of the night when there is no cardiac cover available?

FC: The lady raises a very valid point, and it is one that we have discussed in recent weeks, the risk of having no surgical cover 365 days of the year is a very real issue that has to be considered in this process and how you deal with that if it is the ultimate outcome, and it needs to be balanced against a surgical regime that may not have 24/7 cover but provides cover to a level. But that is the dilemma in this situation and it is a very important point that the lady raises.

WC: We are in the last five minutes or so, so particularly if you have spoken before. If we could keep our comments kind of brief as we are getting near the end.

P22: Just a very quick point Miriam you made about visiting the other hospitals and some of them coming back and saying that they don't have enough cover themselves so they can't take any more capacity. Are you as a working group bringing that back to the Minister himself to say that these hospitals don't have the capacity but we do in Belfast so let's be proactive about this, enhance our service in Belfast and support our colleagues and our colleagues in the mainland and in England as well?

WC: What do you think enhancing Belfast means?

P22: It is about not having enough cover in Belfast itself, and then we are going to hospitals in England asking them to take our children there because we can't cover them here. These hospitals are then telling us 'we can't do that because we don't have enough cover for our own' so why can't we help them? Why do we have to go to England for help or Dublin, why can't we help them? If we have the wonderful

surgeons that we have here and the safe service? Why can't we be the leaders for this?

P23: Miriam, you mentioned whenever you were talking about other hospitals in the mainland, and setting aside emergency cases for the meantime, you can't really do that when you are considering all of this. You can't set aside one part of this while you consider what the options are. Another thing you had mentioned earlier was you would want your surgeon to be well trained, at the best of their ability. One of the things that I was shocked to learn whenever we travelled to Birmingham was that our pilot wasn't actually a pilot. He was as a hobby, but was an architect by trade. We had a fair travel over, we didn't have an emergency situation fortunately and it was fairly relaxed, but if I had of learned that when it was an emergency situation I don't know where that would have left me.

He had a pilot's licence; he was a hobbyist before he was a pilot. Assuming your ambulance drivers are trained paramedics, his training in emergency situation I would question. As far as I understand the other pilots are the same. Maybe someone could clarify that for me, that was what he told me and that's all that I can take of that.

WC: I will come back to the panel in a second, but there is someone over here who hasn't spoken yet.

[redacted]

[redacted]

WC: [redacted]

[redacted]

This is a consultation, you are representing yourselves really well, all by yourself.

P25: [redacted] I just want to say, if surgery stopped here, how is it safe and sustainable for a child who has to travel miles away from their own home in a completely alien environment.

WC: I am going to try and squeeze in as many as these final comments as possible. Please make a couple of notes so that I can come back to you all just as we pick them up.

P26: I would like to ask the panel, would they be happy with their child having to travel to England to receive surgery should they require it?

P27: A few questions not answered. Are they going online once this is being recorded?

DS: I am looking to William to invite us to answer a question and then I am sure me and my colleagues would be happy to answer.

WC: If anybody feels that a particular question hasn't been answered, I am conscious that some of the questions are repeating but if there is particular question that hasn't been answered we can ask it again.

P28: The problem is that a lot of people are finding a crisis in confidence with some of the people involved in this. It was noted by [redacted] who was involved in the review, and [redacted] is on record with the BBC saying that at the very outset of this process, that they needed bigger centres. And strangely enough, when they came to creating these standards, funnily enough, at the end of it, they found the standards meant that they needed bigger centres, which was not a surprise. All of a sudden, at the last minute, this review was asked to come to NI and as it was pointed out in one of the parent groups, Belfast only had 10 days, a very small amount of time. You yourself Dean said to the Belfast group that it wouldn't have mattered if we had a year, it would never have passed the criteria. That leads me to ask, why did someone ask a review to come into Belfast which they already knew, Belfast was going to fail and what the motivation behind it?

DS: I guess there are a few points, and Miriam and colleagues may wish to chip in. I suppose maybe working through some of these in reverse order. We did discuss at the Belfast focus group, we've talked a lot tonight and Miriam has sought to explain the rationale and it is set out within the service specification as to why, as a minimum, units need to be going 400 procedures per annum and why ideally they would be doing 500 procedures per annum. That reads directly into the 100 – 125 number that Miriam was talking about four surgeons with a minimum doing 400 but ideally 500. Four surgeons being the minimum required to provide 24 hour cover. Responding to the lady's issue that she raised in terms of the 2am emergency and how that might be responded to. Yes, that is the case. The reason why we asked for an independent review was to more generally assure ourselves as to where the issues were within the service in NI, and understand that better in the context of for a number of years concerns had been around, around the long term sustainability of the service. [redacted], who I know has cared for a number of children of parents within the room, they don't make [redacted] anymore. As Frank will confirm, it was a model of a bygone era in terms of the way modern medicine works. That sort of model isn't the sort of model consultant surgeons work in these days. It is not a model that can provide 24 hour cover, one surgeon be on a one and one rota.

P28: The point I was making, was why did you call in a review that knew it couldn't pass, and then you wonder why we don't trust the motivations? If you knew it was going to fail, why even have the review in the first place, make the decision and then try and defend it?

MMcC: We have known, you are absolutely right, for years that it is a very small service and very vulnerable. And going back as far as 1998/99 when there was a national review, and [redacted]. We knew that Belfast was very vulnerable. Those issues remain, so that would have caused us a degree of concern. You ask a question of why did it happen more quickly than other places, which I think is an absolutely legitimate question and it would not have been our intention for it to happen so quickly, because we recognise the enormous amount of work done, within the Trust people were working a huge number of hours and it was over the Easter holiday I think so people gave up their time to prepare the material, but just shortly before there was a publication from CCAD that indicated that there had been a number of deaths within NI that put us on a line that said warning. When warning bells are rung, we all have to respond appropriately, and an appropriate action there was to say, is there something that we should be looking at because the advice from CCAD and the colleagues are that when that happens you should go in and take a look at services. That is good practice, it is normal practice that if you start seeing things that could potentially be a problem, don't wait until the problems actually happen. If there are warning signs, you go in and you look at a service, and that was exactly what was done. And that explains the short time, because safety has been mentioned a hundred times tonight. There is nothing more important than safety and

safety means that children live and do well. That was what drove us to do it quickly, because we wanted to ensure that we looked at the services as swiftly as possible. And what did Sir Ian Kennedy say – there are no immediate safety concerns. That provided us with a degree of assurance and that was important to the whole team in providing that care, but we couldn't have had that without inviting somebody in to do that. I am being perfectly candid and open with you, that's why it happened more quickly than anybody would have wanted, and you know we were very grateful to folks in the Trust for putting the wealth of work into working to produce material for that review group in a very, very short timescale. I know that was hard.

WC: We are over time.

FC: I do need to respond to the last question, and the answer to it. It is no secret to Miriam and Dean that the clinical team were extremely unhappy with the timescale that was given for the review team to come in, and the reason we were unhappy with that was the review process looked at a broad spectrum of the service which we didn't feel we had adequate time to reflect in the timescale that was left to us. Just in case there are any concerns in the issue that Miriam had raised about the CCAD surgical outcome figures, there was a separate review process which was in fact meant to deal with that process, not the safe and sustainable services review, where the Royal College of Surgeons came and visited the service in Belfast a little bit later than the previous review, and that review confirmed that the surgical service and the way that all of those cases had been handled was in a safe way. So there should be no ambiguity about that.

WC: We only have time for two final quick points.

P29: I only have one point that I would like to make. [redacted] and I would be deeply disappointed to see the excellent services in the Royal going out. I think we should be definitely building on our services and if we need to bring children from Dublin, we bring them from Dublin. If we need to bring them from the mainland, we bring them from the mainland. But we can't afford to lose the skills that the doctors and the surgeons have.

P30: Listening to everybody here tonight and I have the same concerns. The main issue goes back to Sir Ian Kennedy's report. Yes he found it safe, but found that it wasn't sustainable after six months. What happens after six months? He says in the next step that the default position would be to transfer all surgical services to England. That is why we as parents feel that this is a biased consultation and the consultation itself doesn't address these issues.

WC: The clock is beating us, but we are going to get a response to this and any other points that you wish to pick up on.

MMcC: Firstly, in terms of the consultation. We are open to all responses. There is no predetermined outcome and I can't emphasise that enough. If there are other options, or if you don't like any of the options presented, please tell us because there is no definitive option. It is not predetermined, and we would like to think that it is not biased. This kind of discussion and this input will help ensure that it is not a biased outcome in anyway.

WC: It is important to say that. At this stage, all you are doing is putting all the available options on paper. If someone in the room feels like there is an option that is not listed in this consultation, this is an opportunity to add that option to the consultation. No decision has been taken on any of the options. That is the next stage after the review and consideration. If you feel like something that you believe strongly should be an option, and it is not in there, have a look at the consultation and write it in. Then you will have an obligation, if it is a new option to consider it and bring it into the Minister's consideration.

Dean, what are you hearing from this group tonight?

DS: A lot of strongly held views. I know that the [redacted], and apologies if you think we haven't been answering, it is the joys of trying to respond to William's lead on this. There was a gentleman who asked if it was our own kids, what would we do? As the only non-clinician on this panel, I can probably speak fairly straightforwardly in that regard. [redacted] Unequivocally, what I would want for either of them is what I would want for anyone's kids in this room, which is that they have services that are as safe as possible. It is as straightforward as possible. If I thought for a moment that the safest service was in Birmingham or Bermuda, I would be in Bermuda.

[What if you needed an emergency?]

Sorry – I was asked for my view. The overriding requirement for me is that the service is safe, in any circumstance. The other issues that have been raised tonight in what we are hearing. I am not hearing, I don't think I've heard – I've heard some subtleties around the options – but in broad terms, my sense is that clearly there are strong views around about which might be the right option, but I am not hearing that we have missed any barn door option. Some subtleties around a greater emphasis on Belfast, options to make Belfast more sustainable either by bussing in surgeons or by bussing in extra kids to be cared for within Belfast, so I am hearing that. In terms of the criteria, I am hearing that, and it is a thing for us to reflect on as a working group, to me safety and sustainability are two sides of the same coin. There is no good at being safe four days a week and unsafe three days a week, or safe 360 days a year and not in the five, or safe in the daytime and not the night time. It has got to be safe and sustainable and resilient and all of those things. But I am hearing tonight that there is not necessarily a consistent view.

WC: And a number of people saying they would like the weightings in timescale and emergency to go up.

DS: That's right. I am hearing, as was the point that was made by parents, clinicians, and others on the working group, the crucial importance of what is a smaller proportion of the total number of patients, but as I made clear, we can't – it would be madness for us to have a cross the finger approach to commissioning care. Let's hope one of these doesn't happen because we don't know what to do in those circumstances. Clearly we have to be assured that there are effective arrangements to respond to the vast majority of different circumstances, all foreseeable circumstances. A once a year circumstance is not an unforeseeable thing for me. So we would have to be satisfied that we would have safe arrangements in place for that. That feeds into the criteria right? Well, I am not hearing that there are some criteria that we have missed. I am hearing that it is more the point that you are making William, around the weightings and perhaps a sense within the room that whilst we have weighting of 30 and it is the second highest criterion on the list, whether that should even be a little bit higher than it is at the moment.

WC: Can't it be 50?

DS: Theoretically it can be anything but I think that would be for discussion within the working group. Happy to take views.

WS: And if you believe that that emergency timescale weighting should be 50 not 30, you can write that in your response to the consultation. That could be a very clear response that you can make. That's the whole point of this exercise.

DS: I think that would be it. We have not picked up much around the service specification tonight in terms of whether it is appropriate or not, I will take from tonight's meeting that there is no barn door bits of an ideal service specification for the kids of NI that we have missed i.e. that what we are seeking to secure for the kids of NI is broadly the right sort of service.

WC: They like the kind of service that they have, they just don't want to lose it.

DS: It would be easy for me to just gloss over some of this. If you look closely at some of the service specification and if you look closely at the bit of the paper seeks to undertake a preliminary analysis of the options against the criteria which draws on the service specification. The doing things as we are doing now presents very practical difficulties in the service specification. Clearly [redacted], it doesn't meet what is said within the service specification in terms of 24/7 cover, the provision of a unit doing at least 400 procedures a year, a unit with four surgeons each of those surgeons doing a minimum of 100 each, but ideally 125 and so on. The service that we have now doesn't meet the ideal service specification. Maybe the view to be expressed after tonight is that the ideal service specification is

wrong, that it is not the right service specification for NI, which is what this process is about. So we are keen.

P31: What if the working group don't agree. I know that you have said you will cross that bridge when you come to it, but that question has been asked too. There should be a plan b for such a complex consultation. What if we can't agree in this, what happens?

WC: Dean has explained what will happen, they will put the disagreement to the Minister.

P32: Here's an idea, turn to the man beside you and listen to what he has to say, and the eminently talented and skilled surgeons. [redacted] Leave alone, if it's not broke, don't fix it.

WC: We are drawing the meeting to a close – Frank, some of your comments.

FC: I suppose the first thing that I want to say is to thank everybody who has come. On the working group I and Rosie try to represent what we see as important for the families, but the most powerful voice is actually parents who have been through the process and I think other people who are on the working group who are not clinicians would acknowledge that they have gained from the views that have been expressed. I feel that these public meetings and the ones held by the Children's Heartbeat Trust have been a great addition to the process in terms of truly reflecting the complexity of the problem. This is not just an issue a number of children who need operations each year. It is the whole implications of removing that service in emergency care and providing the full scale of services for children. I think that maybe sometimes you feel that your voices aren't being listened to, but I can assure you that we will reflect those views within the group, and I think everyone will have to listen to your views. It is a problem that in 2012, given the changing way in which medicine is delivered in which has to be dealt with in a different way than in the past. But that doesn't mean we can't find a solution that works for NI. The primary criterion here has to be safety. Sustainability is important but it can't be sustained at the expense of safety and therefore the final solution has to be trying to marry up both of those criteria.

WC: Rosie, what are you hearing? People need to know that their voices are being heard

RB: I agree with what Frank says and I have to say having been to all the consultation meetings, and as a member of the working group with my management hat on as a representative of the Trust, we hear recurring themes all the time, but every meeting we come to, we do hear another little nuance that we thought it was something else we need to be mindful of. So as a panel member on the working

group, I find these meetings invaluable to remind me when I come back to the next meeting of the working group or when sending in comments.

WC: What is the sound of this audience?

RB: I think probably the safety element for the audience seems to be somewhat easier in their minds to split from the sustainability and as a working group we haven't had a debate about safety separated from sustainability which is something I will bring back. But it is the personal experiences that remind us of everything that we need to include as members of the working group that inform any decision that is made, and that will be included.

WC: One more comment.

P33. Miriam, you had said and I think it has come out from a lot of the responses from the floor tonight, there is nothing more important than safety. That being the case, and it is what I have taken from the meeting tonight, could the panel confirm that of the six options outlined, the three which do not include Belfast, are actually unsafe because a child in an emergency situation could potentially die for want of treatment.

MMcC: I think what the panel will need to do in taking stock of all the input following the consultation is for each option consider what the balance is. What is the balance of risk of maintaining something?

[That doesn't answer the question.]

Well it is more complex. This is not a safe / unsafe and the term unsafe is not particularly helpful. We will need to balance the risk. We will assure you that as a working group that nobody wants to put something in place that puts children at more risk than the current. We want the next step forward to be better for children in NI. Therefore, we are as conscious as you are around the emergency issues and the safety and [redacted] I know what it feels like to be wondering around worrying about your child and not knowing what is going on. I can't imagine what that would be like to do that for weeks or months for people who have little ones in hospital. But I know that as a parent, we all want the best for our kids. The task of the working group, and there will be no easy task following the end of the consultation, is to ensure that we balance the benefits and risks of every option and every way forward after the framework has been agreed by the Minister. We will, I can only speak for what I have seen around the working group, we will all take that role very seriously and we will do our absolute best to ensure the outcome is the best outcome.

P33: That's not answering my question.

WC: Let's put the question again. In order to be an option on that list, have you had to take the decision that is passes the safe test?

MMcC: All of those options are potentially deliverable. But all of those options, as explained in our document in the implications, some of those options pose problems. The paragraph that Dean read earlier, if everything was to go to England, there are inherent problems with that. If everything was to stay in Belfast, there are inherent problems with that. There is no option that is absolutely not a chance, and no option that is the only good way forward.

WC: But are they all safe options, all of them?

[Inaudible]

MMcC: They are all potentially deliverable. What is a safe service? A safe service is one as described. If we are describing a safe service a safe service is one that will deliver reliable care every time to every child and with a good outcome. The measures that need to be put in place to deliver that are what we consider to be included in this service specification. We need to sign up to a specification that represents safety. In any service, things can go wrong and in this particular service, where children are undergoing heart surgery, it is complex and no service will deliver 100% perfection at every time, so we do need to recognise that. But all of those are potentially deliverable options. They all have good things to them, they all have drawback. And the best way forward will be to find the model that delivers the very best while we minimise risk.

WC: To summarise that, they are all deliverable, workable safe options.

MMcC: Potentially deliverable once we look at…

[Do you believe they are all safe options?]

WC: By the definition of safety that is applied in the specification they have to be safe, to be options to deliver that safe specification.

MMcC: It is late in the evening to be getting back into the discussion, safe and sustainable – there are no….

[I'll answer for you – they are not safe.]

We cannot separate safe and sustainable. Safety is having the best outcome for your child undergoing a procedure, but sustainability is being able to do that every day because you have got the right people around you to be sure you can deliver it every day. It is not just on a Monday when we tend to do our surgeries, every single day. That is the issue, you can provide the safety on a particular procedure on a particular group, and being able to do it every day and in unpredictable surroundings is the bit that we need to get.

WC: That's where we have got to leave it. I feel that we have had a consultation.