

Paediatric Congenital Cardiac Services Consultation

Public Meeting 21 November 2012

Tullyglass Hotel, Ballymena

Panel members:

- Wendy Austin (Chair) (WA)
- Dr Miriam McCarthy, Public Health Agency (MMcC)
- Dean Sullivan, Health and Social Care Board (DS)
- Rosie Byrne, Belfast Health and Social Care Trust (RB)
- Clare Caulfield, Heartbeat NI (CC)

WA: We are going to start with the service model specification, which I reckon is “what’s needed” to use short hand. Looking at the standards that whoever provides this service will have to meet wherever it might happen to be – safety and quality, do you want them to be the best. Do you want to be able to measure the outcomes – the results, how your child comes out of whatever happens. How accessible those services are; engagement between the local team and other services whatever happens, as many of you are all too aware, sometimes what needs to be done can’t be done here and needs to be done somewhere else. You want to make sure that you are not like the departments in the BBC that don’t talk to each other. You want everyone to be singing to the same hymn sheet; and the arrangements for parents, as many of you know very well about how those can work better than others. So would anyone like to get the ball rolling on this?

P1: My name is [REDACTED]. I am slightly confused with regards to my own [REDACTED] who received open heart surgery [REDACTED]. [REDACTED] would be one of the babies who would not survive air travel. How many babies a year are like [REDACTED] who wouldn’t be able to survive air travel? Who would die if there was no service here in Belfast?

RB: Unfortunately Dr Casey isn’t able to be here tonight, he is understandably the expert on medical conditions but as a nursing background I will do my best to answer that. My understanding of septostomy procedure that it is often required fairly soon after birth within 24-48 hours after birth. It is mainly a stabilisation procedure. The element of air travel after that I can’t answer that because clinically I don’t know. But my understanding is that is not an open heart procedure, it is a stabilisation procedure. It is to stabilise the child to allow planned surgery.

P1: [REDACTED] to Belfast. There is no way [REDACTED] could have survived air travel. It is heart breaking to think that some parent will be told that if their [REDACTED] was born the year before, they would have received this operation.

MMcC: If I could make a comment – it is difficult for us to be considering individual cases, and obviously you have been through a lot of stress, and I hope ■ is doing well now. The issue of emergencies and ensuring that children get surgery when they need it and particularly if they need it quickly within hours and days is part of our consultation. We have had quite a lot of discussion in the working group about that particular aspect because we are very conscious that that immediacy has to be dealt with. If Frank were here he would say that there is about 3 and 8 babies born each year who will need a septostomy. Some within hours, some within days. But all of whom need it swiftly. It is not something you can wait for weeks and months for. For those 3-8 babies, it will vary from year to year, there does need to be measures in place so that they can access the care they need immediately, and that is the case in however services are provided. So that is reflected in one of our criterion – it is about the need for our services to manage emergencies and it is one of the things that we are saying in terms of access that everybody should have access in a timely manner, but for those in emergencies, the access has to be consistent with what would be expected for an emergency. Every case is different, so we don't want to get in to commenting on individual cases. We have said that we wish Frank were here, because we know that it is a real advantage to have him but he is covering for a colleague. I don't want to pretend to speak for him because I don't have that depth of knowledge, but we do know that every child is different; we do know that all children need to have access to emergency treatment and that is a key part. You have raised a really important issue. Many hours have been spent around the table and in the working group discussing just this issue.

WA: Is that one of the reasons why that is weighted in the way that it is? I don't want to move on to the next bit, but the whole weighting thing is quite complicated, but when you hear that it is quite important – the most important aspect of working out the criteria is the safety and sustainability of the service, followed by ensuring emergency and urgent procedures are undertaken within clinically indicated timescales, which I assume means when they are needed?

DS: Yes, and it is worth making the point without divulging all of the workings of the working group that that criterion has a lower weighting in the first draft of this, and it was very much the views of working group members, parents, parents representatives, clinicians, that brought the weighting up next to safe and sustainable, that is now the most important issue. Therefore without pre-empting what processes might look like next year, clearly it would be very difficult for any option that didn't ensure the delivery of effective services to children in an emergency situation. It is clear to us as a working group that it is a very important issue. We believe that both as a service specification where that issue is reflected and within the criteria where that is reflected with the second highest weighting that it is near to the top of the pile as one of the key issues to be addressed.

P1: Finally, it is a concern, thankfully it didn't happen to me and I didn't need a caesarean, but for mothers who cannot travel after birth not being able to go with

their son or daughter, I don't really know what is the right word, but to say that it is not ethical but it is a real concern for mothers and the whole bonding, and what if something happens to the baby – it sounds awful.

DS: In any service model, even currently that would be the case in some instances where children are required perhaps in Birmingham where care isn't delivered within Belfast. It is impossible to cover off the details of all the various combinations of events, but we talked about this with the audience in Enniskillen on Monday, whilst it is not formally part of this consultation, it is aligned to it. Because of the issues that were flagged up to me by the parents, and I should have mentioned as part of the working group, parents were also invited to come along to the working group as observers and we have had a very good turnout in that regard; one of the issues that was flagged up by parents were some of those things – not just the formal type of things, but some of the softer things that are very important to parents in terms of the practicalities, not what might happen in terms of sleeping arrangements, but even more fundamentally the issue that you were flagging up there. We have a workshop planned in the next few weeks with parents and if there are any parents within the room you would be very welcome to talk about some of those softer issues and what we might do to make the journey as comfortable as possible. That is not to say that there won't be certain circumstances such as the one you are describing where it would be impossible to meet all of the needs because clinical needs; but certainly if there were anything that is just in the administration of this as a board we can work with the Trust we will look at this.

WA: [REDACTED], you wanted to add something

CC: I will just reiterate for some of those who are in the audience who aren't the parent of a heart child, within the working group when we first started – I am only a parent, so a lot of this is really new to me. At the beginning of the working process, it was very stark and with the input of [REDACTED], myself and [REDACTED], we were able to give those softer views. E.g. that is all very well doing that for the child, but what happens if the parents don't go – we heard some awful horror stories of where the parents were en route to London and were rang on the tube on the way to Great Ormond Street to say that their child was dead. And that is how they were told – those things aren't good enough, that access retrieval are all being looked at in tandem with this process. Dr Casey gave a fantastic analogy one day in the working group when we were talking about this air ambulance taking the child to England for surgery. It is not as simple as putting the child in the air ambulance and taking them to England. This is process, and you could imagine for a critically ill child, [REDACTED]

[REDACTED]. [REDACTED]. [REDACTED] He says: you come out of the hospital; you put the child in the incubator, from the incubator in the hospital into the travel incubator; from the travel incubator into the ambulance – from the ambulance to the air field. From the airfield into the plane, which 9 times out of 10 isn't some Gucci air ambulance that you see in these

programmes on TV. It is a plane that has been hired that they have taken out the back seats, so the only people that can go in it is the doctor and the baby in the incubator, there is no room for the parents. They fly, so you need to take in the air pressure and I know there are varying conditions. You get to the other end, they land, you have to get the child from the aeroplane into the ambulance, from the ambulance into the next hospital, from that hospital out of the travel incubator and into the hospital. And then start thinking about surgery. So it is not as easy as this in a plane and go idea. The working group, and even me as a parent was very surprised at the starkness when Dr Casey said it that day in the working group. Hopefully it is all being taken on board, and we are assured that it is and another process that we can say is happening because it does need dealt with. When [REDACTED] I had to book my own flight, borrow money, because I had to give up work because [REDACTED] was so sick; I had to book my own flight, I had to find somewhere to stay – we stayed in hospital for a while until we found somewhere. We didn't realise there was a family unit where you could go in and bunk down in. My husband and I, we did shifts while we were there, days and nights. We didn't see each other so we were completely isolated and on our own. We were then told suddenly that [REDACTED] can go home tomorrow, after 3 weeks.... We thought I need to get the money... I need to book a flight... and it went on and it was just horrendous. Now, the care [REDACTED] got in Birmingham, [REDACTED] is [REDACTED] now, was absolutely fantastic, the whole process is terrible but we are assured that those will be looked at as well. But what we do need to do is, if something happens and we need to present our child to the A&E in the Royal, ensure that we have a cardiac surgeon to fix whatever problem is there. And we need you to be able to say what is going to happen.

P2: We are talking about the children going for surgery. There is also though another group – the young adult: children that had their operations [REDACTED] years ago. They are all coming in on this too. They have to be looked after as well as the smaller children. Children have to go to the Royal too for their treatment, teeth and all of these other things as well. What happens to them? Do they need to go to England or wherever to get this treatment

MMcC: It is important to say that the majority of treatments for children with congenital heart disease have is the cardiology treatment – and some of them will have it for life, others discharged after a number of years. Apart from the treatment with their general practitioner, that will primarily be through paediatric cardiologists at outpatient clinics, either in the children's hospital or in one of the outreach hospitals in NI. There are clinics done in most of the major hospitals. Also for a small number they will be admitted to Clark Clinic, also the paediatric wards if they have a more general problem. All of those services are an absolute platform for the service and will stay in NI as they are and will be developed in time as needs be. The associated things like dental treatment would still be local because I do recognise that dental treatment for children with heart issues can sometimes present another couple of

challenges. So, all of those aspects would still remain. The only thing in this consultation at this point is we are asking people for opinions on if they need a surgical operation or if they need an interventional catheterisation. Like an operative procedure but done through catheterisation rather than surgery. These are the only two things that we are saying that we are consulting on. The reason for that is they are done relatively rarely. The numbers are small for those two – the numbers for the medical treatment and outpatient hospital admissions are much greater and we need that service and we need the skills and expertise of Dr Casey and his colleagues in children's hospital who provide that. It is important to reassure people that that's a fundamental platform on which we have been providing service for many years and will continue to do so regardless of what comes out of the consultation.

P3: [REDACTED] To reiterate, the procedures that I would have had, and when I had to go to the Royal, and I still have to go to the Royal for teeth and various other procedures. I still attend paediatric doctors at my age. I still have my catheterisations with paediatric doctors, so what is going to happen to me? I understand that there are certain procedures that I have to go to the Royal for, like dental, and the reason why you go there is so that you have the surgical background just in case something happens. There are other procedures, and I am sure that hasn't changed.

DS: We sought within the document and working with clinicians and others within the working group to flag up a whole range of potential interdependencies within services. I don't know about dental, I think the practice has moved on, but the point is very well made. There are things that require the backup

P3: Even going down the line, I have a [REDACTED] child, and I used the services of the Royal just in case. My paediatric cardiologist had my best interests, and my unborn child. Then if it goes on that do you also take away the skill base? That skill base moves across to where the service will now be. Whether that be Birmingham or wherever. I am not sure if that is something that is being considered, but it is something that is in my mind. One other thing that is in my mind – air travel. That is great that we can get the child well enough to the plane. Is air travel reliable method of travel to get children to England?

DS: There is no evidence that it is not. It has been touched on already that a parallel process that the working group are fully informed of. They are aware of the process itself, and they will see in the coming weeks the outputs of that process. It is our understanding that it is a robust process. We are still looking at it both in terms of what the service will look like, the hours and availability of the service, the time to mobilise the service and so on, there are a range of issues that we are looking at.

P3: I may be naive in terms of how the whole process works, I have attended various meetings and I have listened to loads of people talking about their experiences... there was the ash cloud but if I am right, and I understand what is in the document

and some of the other things that have been drafted up, air travel is not deemed as a safe method of travel for children in England and they have to be within two hours of a centre by road travel. Why in NI would it be ok to deem air travel as safe but not safe for those in England? Why?

DS: I will go back to the point that was made earlier around that there were approx. 20 cases a year that need a service quickly.

P3: 1 every other week?

DS: I wasn't trying to say that it is... about 20 that need access to services quickly. And therefore what we sought to do within the service specification within the criteria for assessing different options; if an option required emergency surgery to be provided across the water, as I mentioned in terms of the weighting that would struggle to score as highly as an option where that surgery was available without air travel because by definition we are building in complexities within this journey that wouldn't be there for the land journey. I know this is a different process than if you have been involved in other consultation processes where normally people like us are giving a proposed answer or here are the 5 potential answers. This isn't like that – this is about you helping us make sure that the framework that we will apply, that will be applied by the working group – this isn't a darkened room exercise that people like Miriam and I go off... this is a process involving the individuals beside me and a range of other parent group representatives, clinicians and so on, where together we will reach a view, but we need your views... have we missed something on the ideal service model...on the criteria or weightings? If you have got all of that right, then it is a good faith application of all of that to come up with an answer; and I guess there will be compromise in any solution; but what is the best set of arrangements that we can have in place.

P3: I am aware of different families who have travelled across and I have attended quite a few of the meetings recently and listening to people's heartfelt stories about what has happened, the financial impact; the devastation that has caused the family; other children left at home. You have obviously talked about the financial aspects, and thankfully I haven't had to experience that but thinking back whenever I was a child, and I was still a patient and mum and dad were traveling up and down, thankfully dad was still able to work, mum was able to see me during the day, dad came up at night, and they were still able to care for my younger [REDACTED] at home as well. But taking that away, the financial...

CC: I think that is why it has been invaluable for the working group to be such a diverse group, because for the first several weeks every time we had a meeting, something else we hadn't thought of had come up. No matter what option is the preferred option, that we have to consider everything that we can to ensure that it is as seamless as possible for such a stressful time. And that is very supportive within the group.

Dr Casey was the biggest advocate within the working group for the continuity of care into adulthood. It was something I hadn't thought about, because I didn't have to but I should have done because [REDACTED] and [REDACTED] still is under the care of a paediatric cardiologist. [REDACTED] was a fluke that [REDACTED] is alive. [REDACTED] is still under that care. It has been taken into consideration. But coming back to your point about the flying – one of my biggest bug bearers is why does NI have to be the poor cousin? Why is it ok for everybody else in GB when we are all meant to be equal, but we have to pick up the scraps and do what fits in with someone else? We have to have a quality for our children and our families, because there are families that are splitting up over the pure stress over what is happening and if it is, half of the families have to go over. When I was over, if it wasn't for my parents I don't know what I would have done. We have to consider that. When you are thinking of this, and you are giving your feedback, do take into consideration the families that are left at home, and our children deserve the same as what the other children who travel by road get within the UK.

P3: Even to get your head down at home, for an hour to get a wash which probably seems very minor but...

DS: No, it doesn't at all

WA: Thank you for raising that – it is a hugely important point and one that has been raised in the consultation documents. Next please,

P4: [REDACTED] I had a couple of points. If access to emergency care is rated so highly, why is the option of taking all surgical cover away from Belfast even still being considered? Because in an emergency, how possibly are we going to transport surgeons from Dublin or Belfast over to here? If it is an emergency, what is the point in even still considering Birmingham? As well as that, I think there seems to be a feeling that because the cover that we have in Belfast isn't that perfect that we should just clear the board and start with nothing. That is a ridiculous predicament. I am sure nobody who takes any service in the NHS considers it to be perfect, but they still want it to be there. My wee [REDACTED] who doesn't like to watch TV for more than an hour at a time – [REDACTED] switches it off because there is nothing on, and I laugh at [REDACTED] because that is the same argument that is going on here.

Also, the wider impact. You say that Clark Clinic isn't part of the consultation, but if you take away surgical cover from Belfast, the skills that support Clark Clinic will wither and die. If surgery goes in January, Clark Clinic will be closed in ten years. All of our cardiac babies will all be born in wards, where instead of one nurse for two babies, it is one nurse for four or six. And each baby will have something different, and some of them will have things that are infectious, and nurses will be running in and out, using alcohol gel on their hands, and everybody will be hoping for the best. And you can say that it is not part of the consultation, but that is something that is going to happen, and I don't see why you are not considering that. Even the original

review document that kicked this all off, said that this was one of those things that needed to be considered, by closing certain centres you are starting to lose skills. That review document obviously has a lot of problems, but if that review document raised that as an issue, and this is a consultation on the issues thrown up by the issues in this document, why is nobody considering the future of Clark Clinic? How are we going to get new consultants when Dr Craig and Dr Casey retire? What consultants are going to come here and lose the skills that they took years to gain? It is probably a difficult enough job to try and persuade somebody to come to sunny Belfast instead of some cosmopolitan city somewhere else. Also, if you take away cardiac surgery from Belfast, it is bound to have an impact on the cardiac anaesthetist and cardiac surgeries in Northern Ireland.

As well as that, safe and sustainability, on the weighting, they are weighted together. I think they should be weighted separately, as there has never been an issue in Clark Clinic, with the cardiac services in Belfast being safe. The issue seems to be over sustainability. Sustainability I think it's totally separate. Ultimately that is the only decision; there are other ways to make surgery in Belfast sustainable. You could put more money into it. You take surgery from ROI which apparently is at the minute at capacity, so they would probably welcome the opportunity to get out from some of their jobs. You could encourage surgeons to go and take part in operations to get their skill levels up at other hospitals. There are other ways to think outside of the box and make it sustainable if you really want. I think the weighting for those 2 things should be separated because they are separate issues.

And, my last point. The review that this focus group is based on has been discredited. The hospitals that were due for closure are now being allowed to stay open. Or at least it has been suspended. If they had been closed, they would have had another two years anyway, we only have 6 months which finishes in January. Why are we having this review on a discredited document? Why are we having this review and making this decision on what to do? I have been to dozens of these meetings, and it is the same issues that come up every time. Just with different people every single time. And everybody keeps saying that we are not looking at that, this is what we are actually looking at. But this is what you are looking at. You are looking at baby's hearts stopping along the motorway trying to get to Belfast to get on a plane and that's it, job finished. There is nothing else you can do and that is what you are looking at. You can say that it is not about numbers, and there is always going to be some bad situation, well my wee [REDACTED] thinks that it is a bad situation not being able to watch Bill and Ten, but why when there are some bad situations, do you have to make everybody's situation more difficult and more stressful? I know that it has been stressed that it isn't to do with money, but on a wholly practical level I can't imagine that it is going to be cheaper to send all of these babies over to England, either by air ambulances, or us all going by commercial flights – and this is another point. Only emergencies are going by air ambulance. I will be taking my wee [REDACTED], who needs [REDACTED], over by easy

jet. Every time I go on a plane, I come back with a dose of the flu. ■■■ is going over to have ■■■ surgery, and ■■■ is going to go over. When ■■■ had the operation in Belfast, it got cancelled twice because ■■■ got bugs because ■■■. And that was with me barely taking ■■■ out of the house. I'd imagine the exact same thing happening even more times when I put ■■■ in a plane to take ■■■ to Birmingham. They would go to do it, and then see that ■■■ has the sniffles, and they can't do it. And we would go home, and wait for 3 weeks' time. I cannot imagine in a million years how that is going to be cheaper and more effective and a better use of resources, than having some surgical cover in Belfast.

WA: Thank you for that very comprehensive run through. Dean – one of the points that ■■■ made was the review of the review that is taking place across the water, the 10 to 7. And another point that was made on Monday night that the Health Committee has written to the Minister asking for this procedure to be halted until such times as the review of the review has taken place. What is the situation on that?

DS: It is an important issue to raise, and I will let Miriam talk through the detail on that. And I will pick up on some of the other issues that were raised.

MMcC: For those of you not familiar, just to say where they are in England. There were a set of standards called the safe and sustainable standards that were developed a few years ago, and supported by professional bodies and parent groups. Those standards looked at how they would be applied across GB and the team visited each paediatric cardiac centre and made an assessment on how closely they were in complying with the standards. There was then an additional piece of work brought forward by a group the joint committee in the primary care trusts in England, that looked at the application of the standards and specifically what would it mean for the ideal number of the centres for paediatric cardiac surgery that there ought to be in England. And the rationale for that was that the main thrust from all of the professional bodies is there should be larger centres but fewer of them. So instead of having 10 centres, doing whatever number of children per year, there would be 7 centres. Each centre would be larger, would do a greater number of activities. Each centre would have enough staff ensuring that there would be someone available every hour, of every day, every day of the year. They made a decision that it should be moved from 10 centres to a smaller number. There were a huge number of options about the possibilities and a wide range of issues. It was decided on the 4th July that there should be a move from 10 – 7 with 3 centres identified for closure in the future. And those 3 centres were the Brompton in London, because of there being already 2 paediatric cardiac centres in London as well as the Brompton; the Leicester centre and the centre in Leeds. And 2 or 3 of those 3 lodged a challenge against that decision, went to the Secretary of State for Health Jeremy Hunt said that he wanted that decision looked at. So it is the decision of should there be 10, should there be fewer than 10, and if so, which are the ones.

The reason why that decision has been reviewed is that those identified for closure brought a challenge again at the decision.

I think it is important to stress that it is not a review of the standards; it is a review of the decision around how many centres in England. In terms of our consultation, as you will have seen if you have looked at it in detail, it does not identify in our options where we are saying do you think it best to have surgery in Belfast, Belfast Dublin, Belfast Dublin or GB; we don't get into a level of detail where it is saying particular centres in GB would / could / should provide. We haven't got to that stage, and that stage would only be appropriate at the end of the consultation, and only then if this were in their outcomes. That is an English review and it is looking at the decision particularly around those 3 units that were identified as needing closed.

WA: Can I take another question out of what [REDACTED] had to say? If emergency cover is so important, and we have talked about the weighting for each of those aspect; why is removing surgical cover from Belfast being considered in any of the options?

MMcC: Firstly, the emergency cover is important and if we haven't reflected that correctly, tell us. For many years, we have known that we have had a very small vulnerable service, provided by really good, dedicated people but vulnerable because by virtue of its size, it is much smaller than anybody else across the UK. In days gone by, that was acceptable because there were lots of specialities where single handed doctors, working almost 365 days of the year provided that cover. That is no longer an acceptable practice, and it doesn't bring out the best because they are not getting sleep, they are not getting holidays, they are not getting family time. That is a pattern of working that has pretty much gone. The other thing is in years gone by, and I know we have a lot of successes in cardiac surgery now, but in years gone by we didn't have the same successes that we do have now. There has been a huge improvement in technologies, huge advances in what can be done for children nowadays. I had a very close member of staff that worked with me [REDACTED] whose [REDACTED] and I was living in the states at that time, and the reason that [REDACTED] died was because the family didn't have medial insurance to get surgery when [REDACTED] was little, and [REDACTED] condition got worse and worse. That would not happen in our country today. We have much better outcomes, much better survival, much better opportunities but because of that, patterns have changed and looking at our particular circumstances now, with doing a relatively smaller number it is very hard to sustain that, it means that we simply can't have somebody available 24 hours a day 7 days a week. And we did bring in Sir Ian Kennedy and his team to give us that professional assessment of services and they said we had a really dedicated team, really dedicated committed individuals, but the surgical aspect isn't sustainable, and can't be run in the longer term. And that is why that is in as an option, one option to consider among others. Services are struggling to keep the 24-7 skills and expertise there. It is one of the options, and we do invite your comments on this.

WA: It might be helpful before we move to the next page, do you think that these proposed standards, safety and quality – do you want it to be the best, well measured, have access to the services, have that clinical engagement between the teams here, and wherever something might need to be carried out. Because even at the moment, some children can't be dealt with here, they need to be sent elsewhere and you do want them all to be talking to each other; and the arrangements for parents, are you happy with those standards, or are there other areas jumping out at you that we should be considering as far as this specification is concerned or are there other areas which may come up in the next bit, which is about the "where" and the "how".

P5: My name is [REDACTED], my [REDACTED] is almost [REDACTED] now and [REDACTED] was one of the emergency cases when [REDACTED] was born. [REDACTED] Surgery will probably not be a future option for [REDACTED] unless it comes under emergency conditions but that aside, what sort of package or safety net will there be for children who have other special needs? [REDACTED], and [REDACTED] has a great rapport with the staff at Clark Clinic and [REDACTED] consultant Dr Casey – [REDACTED] and to go to another facility for [REDACTED] is hugely stressful because [REDACTED] has been managed palatably, the risk of infection is huge for [REDACTED]; even coming for outpatient appointments and things like that pose a risk for us as a family. What sort of a safety net is there for those children when it comes to implementing these changes?

WA: Thank you – this was raised by another person in Enniskillen when we were there on Monday, a child that had [REDACTED] as well and was worried about the similar area.

MMcC: As Rosie had said earlier, in our early meetings every time we had a discussion there was something new, and I have to say this was not something that we spent a huge amount of time talking about around the table, and I think it emphasises the value of having your feedback. I know that some children with cardiac problem only have a cardiac problem; other children have a range of problems each one bringing its own particular challenges but they need to be managed as children, not as conditions. We will take that on board and we will be pulling together a final document that reflects your input and I think that is something that is yet to be reflected. If you were sitting around the working group, that is something should be included that we have yet in the document, so thank you for that.

P6: I am [REDACTED] father and I want to bring 1 or 2 events in [REDACTED] young life to your attention. We lost [REDACTED] in front of our own eyes. If it hadn't have been for the doctors at Clark Clinic, [REDACTED] wouldn't be sitting here today. It was an emergency procedure carried out on [REDACTED], [REDACTED] was going for [REDACTED] first operation. The beepers went off, nurses ran from everywhere, it wasn't 1 or 2 nurses, it was a complete nursing staff,

a crash team came in, the doctors came in – they revived [REDACTED] and the first thing they said was to get this child to surgery. If that surgery facility wasn't there, [REDACTED] would have been dead. And one child dead is too many and you have to take that into consideration. The other thing is you want to move to England. You are sending children to England. There is absolutely no emotional support for the parents. [REDACTED] and I were over there by ourselves, [REDACTED] friend took a week off work to come and dedicate time to [REDACTED]. [REDACTED] flew over; we had left children behind us here. It was an absolute mess. The operation was fantastically successful but from the emotional and family side of it, it was a disaster. Are you going to make an allowance, with the facilities for families to get over or you just going to treat it just as a case, sort the child out and not take into consideration other people's emotional traumas? Your service specifications I think are pretty standard for any medical profession. There is nothing special about them. Safety and quality is required in any hospital, the monitoring comes as standard, access to services, again it is never off the news, clinical engagement – months and months of waiting lists, arrangements for parents – you don't make any. What are we going to do when [REDACTED] requires [REDACTED] next operation? If something happens to [REDACTED], and we need to get [REDACTED] to a doctor, we would be looking for the Royal. We wouldn't be phoning up Easyjet, because by the time we would get through to the people in Easyjet, I would have [REDACTED] up at the Royal, and [REDACTED] would be getting seen to. And you are going to take that service away? I have to say that I am going to fight you the whole way, every step of the way. Because you people haven't taken into consideration people's lives, and that's what it is all about here. And I nearly lost [REDACTED] and you are not taking that facility away from me as a daddy. Thank you for your time.

WA: Thank you – you made your point really strongly there. [REDACTED]:

P7: Two points about the service specification that you have laid out here. Apart from the real issue of someone needing immediate surgery, I am seeking clarification under the word safety that you are considering the safety aspect of the additional journey that would be above that of what happens at present. Whether that is a flight somewhere to England or a 2 hour journey in an ambulance, that is an additional safety issue; as opposed to the procedures once you get there. The other aspect which I think should be in the service specification is to meet future needs. I understand that over the last 10 years, or perhaps more, more and more babies are surviving that there is an increase in the on-going need of services even in terms of new procedures that these teenagers or older people will require in the future. The numbers that you are talking about at present may not be the numbers that are needed in the future.

DS: A couple of points that were made there, in reverse order. The second one is fair, in terms of there needs to be head room built into what our service specification and both in an ability to deliver more of the same or a broader range of services for patients as technology moves on. That is helpful and we will give consideration to that and we might build that into the service specification. The other issue you

mentioned isn't directly relevant for the service specification. The service specification is the model of the service that we are buying. The point that you are making is there are different ways of delivering that service specification and one of the options might be to buy the service across the water, and another might be to buy it from Belfast, Dublin or both. We have criteria and if you look at the implication of options that are set out in the paper they look at exactly that issue where they are picked up, and it was talked about at length within the working group about that flying across to England is not the same as being driven in an ambulance to Belfast or even to Dublin. There is something different there and we sought to capture that within the implications of the options that would require for some or all patients transport across the water, but if you feel that is not strongly enough captured we will certainly take that on board.

P7: It is the safety implication of an additional 2 hour journey by ambulance to Dublin or in the air flights. This is something that should be raised under safety considerations and not tucked away under somewhere else. This should be one of the overall factors that affect the success of the facilities you intend on commissioning.

WA: Moving on to the options for the future provision.

P8: I am a mother and my [REDACTED] old when [REDACTED] collapsed in [REDACTED] hospital. They resuscitated [REDACTED] back – I watched the doctor give [REDACTED] mouth to mouth and when we got [REDACTED] back they transferred [REDACTED] to Belfast, and I remember Dr [REDACTED] came in to us in the middle of the night and he told us that [REDACTED] had a very serious heart condition. [REDACTED]

[REDACTED] But I do remember the one thing he told me that night was not to worry, that they could fix this. In the middle of all of this turmoil I thought that they can fix this so it's ok. They told us that if [REDACTED] was strong enough to make it through the night, [REDACTED] could have open heart surgery. [REDACTED] that night, and on the [REDACTED] had open heart surgery in the Royal. And when I heard that they were trying to close this, I know that [REDACTED] struggled to make it out of [REDACTED] that night; [REDACTED] struggled to make it to Belfast; if I had of arrived in Belfast and Dr [REDACTED] said to me that once upon a time, we could have fixed that but tough luck mummy, [REDACTED] is on life support now... [REDACTED] is probably not going to make it. But I spent [REDACTED] in the Royal. We had very successful open heart surgery. [REDACTED] is now turning [REDACTED] and [REDACTED] is amazing, but I can't believe that you are going to take that service away. Nobody told me [REDACTED] had a heart condition and at [REDACTED] hospital that night when [REDACTED] collapsed, if I hadn't have had a fantastic young doctor who had done a bit of studying into heart conditions, they told me [REDACTED] was [REDACTED]. When we got to the Royal, Dr [REDACTED] told me that [REDACTED]. And that is how we lived, but Dr [REDACTED] promised me that if [REDACTED] could survive for another day, he would do surgery. I didn't have to worry – Dr [REDACTED]

assured me that he had done this before, and they could fix it if [REDACTED] could survive. You are talking about other children. I had a [REDACTED] year old at home. [REDACTED] went to bed that night, [REDACTED] woke up in the morning and [REDACTED] had no mummy, no daddy, no wee [REDACTED]. [REDACTED] had a house full of ones crying and nobody could explain to [REDACTED] where mummy and daddy went. And over those six weeks the Royal provided me with accommodation, I stayed in intensive care for quite a few nights, I stayed in Clark Clinic (I didn't know there was such a thing), they gave me somewhere to stay. I was able to sit in the ward until all hours of night with [REDACTED] anytime, and then we were able to bring my little [REDACTED] up, and [REDACTED] could understand – here's where mummy and daddy are, as much as it is a bad thing, we are all here. And we missed [REDACTED] birthday because we were stuck in the hospital, and things like that do have a big impact on people. I find it hard to believe how statistics can take over a child's life. I don't understand how money, how anything could be a factor. If I had of arrived at the Royal that night, and if I was told that [REDACTED] was not going to make it anywhere else and we had to take [REDACTED] home to let [REDACTED] die, there has to be something for those urgent cases.

There is another point that [REDACTED] had talked about there. Why cardiac surgery for NI? Down the line are we going to make other provisions for surgery e.g. renal?

P3: Is it going to set a precedent, and it will be acceptable and we will lose services like renal? I am not a medical expert but I know there are other services like this unit in the Royal, and specialist care that goes on that potentially, like cardiology can be provided somewhere else, then why not other services?

P8: We talk about numbers, I never thought it would happen to me. My whole experience was like something you would read in a magazine. This happens to other people, it will not happen to me. But every week when we went back for reviews, there were new children in the beds, there is never a time when you go into Clark Clinic and there are a couple of empty beds. The place is packed constantly. I suppose I was considered to be lucky because Dr [REDACTED] was there and he said that we would just do surgery there and then. The only other option would have been for us to travel maybe to Dublin if he couldn't fit it in surgery. You need to listen to the parents and look at all of the amazing children that are running about. They told me that [REDACTED] would have been a cot death if I had of put [REDACTED]. My [REDACTED] is running about at home, hopefully in bed now (!) but thanks to the amazing people in Belfast, I have a [REDACTED] who, because surgery was so excellent, shouldn't need any repair. [REDACTED] will go for [REDACTED] check-ups every year, but it is an amazing place and it will be so sad if someone takes it away from us.

WA: Thank you – I will pick up on a point that you made that was raised before. The thin end of the wedge – that is something that worries a lot of people.

DS: The same question was asked by the audience in Enniskillen on Monday. And we said then categorically not. That is not to say that health services are not

evolving with time, but there is no sense in which this is the case in any way – that is entirely incorrect.

MMcC: Just to build on that, our aim is to do what we can in NI and do it well. Inevitably we have been sending children away for years and will continue to do so. If children need epilepsy surgery they tend to go over to London or other centres; if they have very complex epilepsy, they tend to go over to London and other centres; if they need heart transplant they usually go to Newcastle or London; if they need bone marrow transplants they tend to go to other centres; and those things are just so specialised that it is important that children have access to the right tertiary centres – the real expertise. But we don't see this as the thin edge of the wedge, and I wouldn't want you thinking that is what's going on, because it absolutely isn't the case

CC: It comes back to within the Heartbeat Trust we believe that we shouldn't halt this process because there is a review going on in England. What we believe is, and I come back to the same shout I do every time, is we are not the poor cousins. Let's get our own bed in order and let the rest of the UK sort themselves out. Let's sort out our children, that's why we need your feedback on the review and then the minister will hopefully make the decision on that. For once, let us lead the way.

WA: [REDACTED]:

P9: I am [REDACTED], and my [REDACTED] has severe heart problems and I am in no doubt in my mind that [REDACTED] wouldn't be here without the care from Frank Casey, Dr [REDACTED] and the team up there. I think what [REDACTED] and Miriam just said about poor relations, and specialised care is all the more reason why we should be trying to fight to have specialist care in Belfast. Surely it is in all of your interest to have a top class local facility with continuous training of the staff instead of losing that? Every one of your options here, the last item is always to do with clinical linkages and option 4 – this option should ensure strong linkages into related services within Belfast for children with heart disease. The option should have either no impact, or else minimal impact on other specialist paediatric services. Surely it makes no sense to transfer the service across the water to England. I think Dublin in conjunction with Belfast, as someone said a while ago, if they have excess facility in Belfast, surely that is only a good thing if Dublin can avail of that? I sincerely hope that Clark Clinic will not disappear on us, because [REDACTED] when [REDACTED] was [REDACTED] old had a chest infection and we were able to take [REDACTED] straight up there – and they said if it had of been another hour, [REDACTED] wouldn't be with us. We live in [REDACTED] and we were up the road in 20 minutes. If I had to go to Dublin or anywhere else, [REDACTED] would not be here.

WA: [REDACTED], what about those options that we are looking at. There are some of them that I know many would have no truck with, but are there some that you do believe are good option.

P9: Clark Clinic is an invaluable support to all of us. I was on speaking to Frank Mitchell one morning and they said that there is only so many children have this, but as I read somewhere congenital heart disease is the most common birth defect in children, and there is nothing to say that if there are 100 this year, that there won't be 300 next year. Option number 1 is the preferred prime option for anybody here, with Dublin being considered with that. I don't know why they would even consider going to Birmingham. When [REDACTED] was born, we were able to spend 2 weeks sharing the load of staying up at night with [REDACTED] looking after them and supporting them. If we had of been in Birmingham that would have been impossible, and the financial hardship that that would have caused to [REDACTED] parents.

WA: [REDACTED] thanks very much indeed.

P10: I am [REDACTED] and we have one of the children who have had to travel to Birmingham on a number of times and has done very well under the care of Dr Casey and just to say, I don't know why it was different for us, but we didn't have to pay for the airfare or anything. They were paid for the 3 different surgeries [REDACTED] that was many years ago]. But my [REDACTED] is [REDACTED], but anyway. There is a great fear about Birmingham and it gets knocked all the time, but it is a very good hospital and they do give great care, and as [REDACTED] was saying about the bonding – you bond anyway. It is a nightmare, and I wouldn't like anybody who is in Clark Clinic who has to go across the water because it is a complete nightmare to be taken away from your [REDACTED] other children like the mummies were saying here – to be taken away from them across the water is horrendous. When you are there, as I was for [REDACTED], my husband couldn't stay because he had to come home to work and I was there, some of my sisters came over to visit, but many a night I was over there on my own with a wee baby in a land of strangers, with nurses and doctors, and [REDACTED] years on it is still a nightmare to me. [REDACTED] couldn't get [REDACTED] care in the Royal, [REDACTED] had to go, but to take that away from the parents here would be terrible, for things that could be done here. Why couldn't they try and improve this service – I know doctors need their practice and their hours for supervision, but could that not be looked at and money put into that in the Royal, instead of spending the money that it will cost to send people over there to Birmingham, or even to the south as it is definitely a lot more money, with flights paid, upkeep – and to get support as everyone doesn't have a family like I have with [REDACTED] who were able to help at home. I don't think people should be asked to go to Birmingham for surgeries that can be done here in the Royal.

WA: And your [REDACTED] old, is [REDACTED] ok now?

P10: Well, no. [REDACTED] has issues, but is still doing very well. [REDACTED] is one of the better cases, but I don't think you can replace the Royal. I know that is just Clark Clinic and not the surgical part of the Royal, but I have a [REDACTED] who has had experience of that. It is a great service and you should not be taking that away from the Royal, to send people across to England – for if the service is great over there, but to go through it... unless you have done it and experienced what we have experienced, lovely

people, lovely nurses, excellent doctors but without your family around you; and I couldn't come home on the nights when we went over, like ██████ said, there were no beds for us for 3 nights

CC: We were nearly a week; because surgery kept being put off, ██████ was fasting every single night for a week and back to the hotel every morning.

P10: As long as they are being looked after, I would go through everything – I would go to Africa if I had to. And that is the thing – you have to provide the best care. So why can't the money be put into keeping the doctors and the service there, and getting more doctors in there, if that's what they need. I know there is not that big a number of babies who need it, but look at a way of sharing with Dublin. Could they do some of the surgeries here that are the immediate surgeries from when babies are born, and some of more planned surgeries done in Dublin? You can't expect people to think. You will not teach us to suck eggs, people who have had a very ill baby, telling us that we are going to make it to Dublin. We have been there, and saw them passing out and all the rest. You are not going to convince us that a trip to Dublin is only 2 hours down the road with a good motorway.

WA: ██████ thanks very much for that.

P11: I'll be honest, I went to Birmingham, and surgery and everything else was fine, but I only went █ years ago, and yes the flights didn't cost me anything but financially it was a disaster as I am self-employed, but that is not really my point. My point is the only one of those options that can be considered has to include Belfast because you can't have neonates travelling. Point number 2, if you take away surgery and surgical cover from the Royal – my ██████ has **** heart condition, which if I had to choose a heart condition, that is the one I would choose. ██████ had an operation in Birmingham which took away the risk of dying at ██████ from suffocation and ██████ now has the chance of ██████, for the rest of his life, because that is what ██████ was repaired as. It is not a fix – it is a repair. The repair has to be checked – ██████ never has to go more than ██████ without having to see a cardiologist. I need that cardiologist that looks after the wee ██████ to be as skilled and as professional as possible. And I thank God every night for ██████, because that is what we have in ██████ and in Frank and everybody else. We won't have that in 2 years if they don't get the training. ██████ has to have another surgery, open heart surgery, probably in Birmingham just because ██████ has ██████ and I couldn't care less where that part of the surgery was but I need a cardiologist to tell me when ██████ can have that surgery that is totally skilled. If you don't have a surgeon, giving surgical supervision in Belfast, those cardiologists won't be skilled. My ██████ could just literally die because nobody picks it up in time because waiting lists get too long and this whole thing starts to spiral. ██████ will potentially have a very long life expectancy and will still stay under the Clark Clinic until ██████ is 102! If we have any of those options that don't include Belfast I will personally believe that you will be almost signing the death warrant on some children. And I

know that is blunt, and it is horrible, but it is how I think you have to look at it, because if you don't have the surgical supervision for children who have had surgery, need surgery, but also for the neonates who need things immediately, you can't choose any of those. I would go back to the point that every single one of those options that does not include surgery in Belfast, should just be taken away and they shouldn't be there in the first place.

WA: Thank you.

P12: [REDACTED] I have heard a lot here tonight of surgery and post-surgery but I haven't seen anything in the options to prepare parents. At this minute in time, [REDACTED] and I am personally looking at this moment in time, if we weren't able to avail of that support in Belfast, travelling to Dublin or Birmingham, even to go through the information and support that Dr Casey is giving us, would be unbelievable to comprehend. Not to have that professional there, who is preparing us for what is going to be lying ahead [REDACTED] [REDACTED] Due to this review, we don't know where or who is going to do that surgery. That is something you have to, as a board, take into account. There is already the surgery that has happened, the post-surgery and continual care, but it is the preparation for parents, and myself, that are in complete uncertainty as to where this surgery and the Trust is actually going to finish us up. There is a gentlemen over here, and when he said that option 1 was the only option, and he was going to fight you tooth and nail, I can assure you that as an [REDACTED] and as a parent, for somebody who is going to need services of Dr [REDACTED] I will be doing the damndest as well that I can.

WA: What about people who are looking at that sort of situation, who are now left having no idea what will be taking place in March or April of next year?

DS: The position is, as I hoped we mentioned during our introduction, the Minister will be taking a decision on this. Until a decision is made, to the contrary, the service continues as is, with the service provided within Belfast Trust. But I accept that the review has happened, that there is a consultation process on going so it will be reasonable for you to be concerned about the future arrangements but ultimately it will be the Minister's decision hopefully next year, as to where this will be undertaken in the future. All I would say that if the Minister's decision is that there would be some change to the current arrangements, that we would make every effort to ensure that any transition from the existing arrangements to something different is carefully planned and communicated and organised to minimise disruption and any distress for parents.

WA: There is a lady at the back, first

P13: I have [REDACTED] with congenital heart disease, [REDACTED] [REDACTED]. This will be [REDACTED] [REDACTED]. I was thinking if that was in England, flying back and forward waiting until the surgery is done. My [REDACTED] has already had a [REDACTED] and [REDACTED] will need more, and we are wondering where that was going to be. As a family, we have [REDACTED] children and we already feel as if we never leave the Royal. If it was in England, as a family for us, it would be 10 times worse. What happens there? You just can't comprehend, that if you have [REDACTED] children, in the one family and you are constantly running to the hospital, with that in England, what do you do? You have no family support. We already have parents taking off work to look after one child, when we are trying to care for another. It just wouldn't be possible for us as a family if that was in England. Or even Dublin.

WA: Thank you - a very stark and personal example.

P14: [REDACTED] – As you were saying, it is all about the Minister, his decision. But right now, he has my life and hundreds and thousands of other children in NI in his hand. Yes, it is all about our future life. We have a label that says we need special care. I would like that here – I don't want to have to go to England. When I was sick and I had to go over there, I didn't think much of it, because I got to go on a plane and got to go to another country and it was great. But now that I understand it more, I want to be home and near my friends and my family. Did you ever think about older children who understand?

MMc: You raise a very good point, and you are at an age now that you can look back and reflect on what it was like at [REDACTED], and what it is like now, as part of this we want to hear what people think and we are having these public meetings. But we are also having focus groups and we are having one particular focus group for young people between the ages of 14 and 18 so that they can tell us what they think about surgery and what it is like and where it should be and they can tell us what they think about the consultation document, and we will only be able to do that once. Time is limited, so there is only so much we can do so we are very keen to have that engagement with young people. If you want more details about that, very happy to provide that. Friends and colleagues, I think we are going to provide up to 12 places in that and hear from young people, because you raise a very important issue.

P14: If I am in hospital with the flu or something, the ride home from Belfast [REDACTED] [REDACTED] is really tiring for me – getting out of the hospital on a plane and then suffering the car journey home after heart surgery, that would be so tiring I think I would have to go back into hospital for special care for the process of healing again. It is fair to say that we do need cardiac surgery in NI and I always agree with my mum when she said this, why does NI always have to get the boot?

WA: Thank you [REDACTED]

P6: As [REDACTED] has said to you about a journey home from a place in England, when we were coming home, they were arranging for the Royal to be on standby in the case of an emergency. If the Royal is needed in the case of an emergency coming home from Birmingham hospital, what are you going to do – are you going to provide that cover? And if you are going to provide that cover, where are you going to get the specialist people from? Those people are all going to be made redundant. They are going to be moved on to England, Scotland, Wales, and Dublin. Where are you going to get the specialists from for anybody coming home and needing immediate help? Do you just send them back on another aeroplane – is that the plan? Is there even a plan for it?

MMcC: I think that is an issue that a similar situation applies when dealing with emergencies generally, whether the emergency happens when a baby is born, at some point or after surgery, the emergency need to be managed in a timely manner. That is all addressed in the part of the document that talks about the access and timeliness of that access, particular with the emergency situations. That may not have been spelt out just as explicitly, but we are looking at emergencies wherever and however they arise. Every child is different, and every emergency situation is different.

P6: You still need a heart specialist for a baby with heart issues. Therefore, you have to employ someone to do it.

CC: If I could just jump in there. Everything is very emotive, for all of us parents there is nothing more emotive than what we are talking about tonight. But we need to distinguish between we are looking for your views now and it is really, really important that these views are put on paper and given back. I know that it is being recorded tonight, but I can't reiterate enough the importance of putting your views on paper, and then that will be proof that this is what everybody feels and then we have a stronger case to make.

WA: And if I could say so, you have all put your views fantastically well tonight with total clarity and made your position 100% crystal clear.

P15: I am [REDACTED] and have [REDACTED] and I had [REDACTED] [REDACTED] and again when I was [REDACTED]. Thankfully I have been fine and haven't had to have more surgery, but the last couple of years have been quite an unsettling period. And I have been in and out of hospital. I would like to ask why we weren't considered in this document. The document finishes at the end of 18. We are an ever growing population of young adults who have gone through it. I still see [REDACTED] every 3 months, we are not in this document and actually I am part of one of the focus groups, but yet you had no focus groups directly for this group that it affects as well as teenagers and children.

WA: There is a growing number of people like you. It had never dawned on me that you all still needed to keep going to paediatric cardiologists. I can guarantee you that your views will be taken into account. Rosie, maybe you would like to add.

RB: The paediatric cardiology service is something that as a group and a Trust that we recognise, and I am really pleased to say that this year the Belfast Trust has appointed a new adult specialist for heart disease which is great. We also now have a paediatric and an adult liaison nurse – it is something that we recognise and I suppose it is something on reflection looking at the document when we have it in the paragraph on page 5 about continuing the service of cardiology moving forward, that is something that we may need to strengthen as it is something that we have heard a few times tonight and again on Monday. The grown up with congenital heart disease as a Trust, we recognise the importance of and are investing heavily in through time, and appointments and developing the service. Something that has improved and will continue to improve.

WA: It is nice to have so many elected representatives here.

P16: Declan O'Loan, a councillor in Ballymena. I am very glad that I came here tonight because I am hearing things particularly from people who have been involved in this service that I have never heard before. It is a very different consultation, than any other that I have seen. Normally you are asked what is the best solution, and why do you think it is the best solution. But we are not being asked that – is this the right way to solve the problem. Is this the right framework, the right mechanism and it is important to stay with that, this is what we are actually about. My instinct from what I am hearing, and from a quick reading of the document, is that it looks like a very sound framework for approaching the problem. If you set thing in the context if you want to provide any medical service, it would be great if you had that service within 10 minutes of your home, but even if all of the resource in the world was there, it is simply medically and clinically impossible to do that because it does depend on expertise, which involves specialists who are working on that all of their time. That is why, for all medical specialists, we do need centres of excellence, there is no other way of delivering it. That must be particularly true for something as complex as cardiology surgery. If there were, and we are told that the service as existing in Belfast is unsustainable, if it weren't unsustainable, we wouldn't even be having this discussion. It is quite natural that you try and put your services near where people live as possible. That is the first instinct that you would have. But there is a problem to be solved, and there is no getting away from that. It would be better if there weren't, but there is a problem to be solved. It doesn't concern me as it does concern some, when you look at all of these options when you include solutions in GB. In our walk of life, we come across optional appraisals all the time. You list any possible option that might be there; in this it says commissioned primarily, for some patients there is always going to be some cases where the places they are taken to might always be e.g. Great Ormond Street hospital, or Birmingham because at the end of the day it might not be possible to provide everything on this Island no matter

what way this goes. I am comfortable that when all of the information, in terms of the actual putting scores against these things, I don't think the political views come into it at all. I think that the views of anybody who isn't a clinician or is a family that hasn't been involved in this doesn't count for very much either. But all the clinician experience and all the experience of those who are family involved do have a major input to make into what will be the eventual outcome. If that framework is applied, then we can see that, and I feel more strongly since entering the room, if all of the service is taken from Belfast, if the figures produce that, I would be amazed because when you hear the actual evidence that was put in front of you, you would be very surprised if the mechanism when it is put into place actually produces that sort of outcome. I think if people provide more information, and when the evidence is being input into the framework then I think all of that will be very useful indeed. The final thing I wanted to say is I am a bit concerned about the emphasis put on that this will be the Minister's decision. At the end of the day and it is quite right that in a democracy, a political system has its weight, but the idea could be created that after all of this input, the Minister on a whim could decide something quite different. That would concern me, and all of us. And I am sure we could be reassured that the Minister is fully behind this evaluative process, and any decision that he makes will be based on the evidence and it will be a quality system that will be agreed upon for making the decision.

DS: We can be assured of that, and that was a very helpful summary of what it is we are trying to do. The description of this as a framework for a decision and effectively the nuts and bolts to plug the evidence is exactly what it is and it is the Minister signing off that framework in the first instance, and then in due course and through the working group – it is not going to be a separate process – once we are happy and the Minister is happy with the framework itself which is the out working of this consultation the working group through the board will give a recommendation to the Minister, so I didn't mean to give the impression that it would be made on a whim at all. It will be made on the basis of a recommendation from the board in due course which will come on the basis of the views of the working group and the process applied by the working group. But ultimately it will be the Minister's decision.

WA: We are coming towards the end of the evening, but a few more questions – Jim

P17: Jim Allister, I am conscious that I don't want to take much time, because this is an evening for families who are affected by this, and who have the most to say. One thing that does concern me, and I am not sure I agree with what Declan said at the beginning of his contribution, that this is about the best option. When I read this consultation, the thing that strikes me is that it doesn't mention the dreaded word cost. And yet I suspect, particularly when I see the foreword from John Compton, that is a lot of what this consultation is about, and it shouldn't be because as we heard from [REDACTED] and others, this should be about maintaining an essential service – not an optional service. Not something that is a luxury, something that is a matter, literally, of life and death. For so many people, as you have heard from the

testimonies, and even if it was for only 1 or 2, it is a vital service which must be maintained. Therefore I think that those things are far more important than the cost implications, and the cost savings which might result from reducing the facility. I think there is a message, a single message, out of this consultation, is that the only option worthy of consideration is the retention of surgical services in Belfast, because without them there are people who if that had been the situation in their time, wouldn't even be here tonight, and that is the sobering reality. That's the reality that we need to grasp hold of. And not lose it in all of the official speak that arises in discussing this. I recommend to this meeting that the only option that they are interested in seeing is retention of primary, surgical facilities in Belfast.

WA: I have skipped on to the next page, because that is where we are on the criteria. There are a few items on this that we have actually talked about through the evening, I think it was [REDACTED] who said that she believed safety and sustainability should be separate. Looking at the questions: Are the assessment criteria relevant for considering the most appropriate option for future service provision? Are the associated weightings appropriate? Are there other criteria which should be considered? There seems to be a number of people whose view is that safety and sustainability should be separate and have their own weightings. Your mention of the word cost – against no. 6 which is effective use of resources, which has the lowest weighting. Should the cost be in there?

DS: Going back to the point that Mr Allister made there. Without pre-empting the process, or the Minister's decision, or the framework for us to apply and make a recommendation, I can tell you now that in the day job that I have, the cheapest option by a stretch in the list of options, will be the maintenance of the service in Belfast – unequivocally. Any other option will cost more, and I know there has been a lot said in other forum around that this is a resource thing, a cost thing. It is categorically not a cost thing. The view within the room is that the cost should be a more important criterion in terms of the weighting it gets, then either tonight or after tonight, we would be very happy to hear that. But the view of the working group was that this was not a cost issue that this is fundamentally about the safety and sustainability of the service. The cost will be what the cost is, but it is very much at that end of the pecking order. But any sense in which this is driven by resources is absolutely misguided.

WA: I can safely say that there wasn't a drive in the room to have cost further up the list. [REDACTED]

P9: I just wanted to say that whenever I was informed about this meeting, I looked up this document on the internet and downloaded it and I thought that this was going to be a whole pile of stuff that we can't understand and I would just like to congratulate the panel on making it very clear for lay people like me to read through and understand. To finally say that through all of the discussions and options that you have given us, your final paragraph on page 30 is absolutely the best one. I will read it out to you:

“Therefore if Paediatric Cardiac Surgery were no longer performed in Belfast it would be extremely challenging to provide the skilled and experienced surgical input to effectively meet the needs of all adults with congenital heart disease.”

I can say no more than that, in my opinion that says it all.

WA: A final comment:

P18: I don't know if I am talking on behalf of everybody, but the weighting in criteria “Ensuring emergency and urgent procedures...” is only 30, but under European Law, the right to live which is effectively what that is saying, it should be a lot higher, and I know in the working group it went up a wee bit, but surely with safety, emergency procedures should be equal, sustainability should come under both of those.

WA: This has been enormously helpful and I have found the whole evening very informative. Thank you for sharing your stories from the heart. Thank you. Your views have been heard. Use the other methods for making sure your feelings are put across.